ZIMBABWEAN WOMEN AND HIV CARE ACCESS:

ANALYSIS OF UK IMMIGRATION AND HEALTH POLICIES

Hana Rohan

Department of Public Health and Policy
London School of Hygiene and Tropical Medicine

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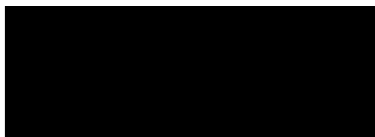at the University of London

May 2010

Statement of originality

I, Hana Sophia Rohan, confirm that the work presented in this thesis is my own.

Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed: ██████████████   Date: 30 June 2010

Abstract

Background: NHS Regulations were amended in 2004, restricting access to secondary healthcare for refused asylum applicants. In recent years there have been substantial numbers of unsuccessful asylum applications from Zimbabwean nationals. HIV-positive Zimbabweans with insecure immigration status in the UK occupy a precarious medico-legal position, especially since HAART is not available to most in Zimbabwe. There has been little research on these policies or their effects on the lives of Zimbabwean HIV-positive women in the UK.

Objectives: This thesis examines the development and implementation of UK policy relating to access to HIV-related services by Zimbabwean HIV-positive women with insecure immigration status, and explores how these policies influence women's healthcare.

Methods: Three separate strategies were used for data collection. Policy analysis scrutinised 35 publicly available documents and additional material obtained through Freedom of Information (FOI) requests. Data for policy analysis were also collected through semi-structured interviews with 24 HIV/immigration key informants. Further qualitative data were collected through semi-structured interviews with 13 Zimbabwean HIV-positive women with insecure immigration status. These different approaches allowed for data 'triangulation'.

Results: Policy restricting access to healthcare for migrants is situated within three immigration control strategies of deterrence, internal control, and 'enforced discomfort'. Implementation of the policy has been limited by staff who interpret it to suit their own agendas. Access to HIV-care for Zimbabwean women seems to bear little relation to these policies, but their access to other health services and their wellbeing was influenced by a number of other socio-structural barriers associated with their immigration status.

Conclusions: These results offer new evidence and theoretical models on the politics of immigration policy, the role of street-level bureaucrats as mediators of the gap between policy and practice, and on access to healthcare for migrants. There is a disjuncture between policy on entitlement and clinical practice, which may reflect a conflict between clinicians' duty of care and UK policy. Zimbabwean women's HIV- and migrant-status places them in a periphery, reducing the resources available to them that could mitigate some of the barriers they face.

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List of Acronyms

AIDS	Acquired Immuno-deficiency Syndrome
AIT	Asylum and Immigration Tribunal
ARC	Application Registration Card
ART	Anti Retroviral Therapy
ARVs	Anti Retrovirals
BA	Borders Agency
BHIVA	British HIV Association
BMA	British Medical Association
BME	Black and Minority Ethnic
CMO	Chief Medical Officer
CRE	Commission for Racial Equality
DfID	Department for International Development
DH	Department of Health
ECHR	European Convention on Human Rights
FOI	Freedom of Information
FOIA	Freedom of Information Act
GP	General Practitioner
GUM	Genito-Urinary Medicine
HAART	Highly Active Anti Retroviral Therapy
HIV	Human Immunodeficiency Virus
HO	Home Office
IND	Immigration and Nationality Directorate
IOM	International Organisation for Migration
JCHR	Joint Committee on Human Rights
LA	Local Authority
MDC	Movement for Democratic Change
NASS	National Asylum Support Service
NGO	Non-governmental Organisation
NHS	National Health Service
OVM	Overseas Visitors' Manager
PCT	Primary Care Trust
PLWHIV	People Living with HIV
PPO	Paying Patients' Officer
SGBV	Sexual and Gender-Based Violence
SLB	Street-level Bureaucrat
STI	Sexually Transmitted Infection
TB	Tuberculosis
UK	United Kingdom
UN	United Nations
UNHCR	United Nations High Commissioner for Refugees

Dedication

For Z and Tát. Děkuji.

Acknowledgements

Introduction

This thesis is about the overlap between immigration and health policies, and the effect of that overlap on migrants with healthcare needs. It takes an approach that can be likened to widening the aperture of a camera. It begins by providing the reader with a broad overview of migration, HIV, and relevant policies. As the aperture increases in size, its depth of field increases, and objects in the foreground become clearer against those in the background. Similarly, as the reader moves through the thesis, the 'depth of field' of the results presented is shortened, while growing increasingly sharp. A 'narrow aperture' is used to examine UK immigration policy formulation as it relates to healthcare access. The thesis then focuses down into the microcosm of clinic-level implementation of policy, and leads into the final three results chapters. These examine Zimbabwean women's experiences of life and health in the UK against the broader immigration policy background. Conversely, the healthcare experiences of HIV-positive Zimbabwean women with insecure immigration status can also be viewed as a case study through which to examine the way in which UK health and immigration policies are implemented, and the relationship between health service access and the 'high politics' of immigration.

Thesis Aim and Structure

Aim

The aim of this thesis is to examine UK immigration and health policies and their effects on access to HIV services for Zimbabwean HIV-positive women with insecure immigration status.

Objectives

The objectives of this thesis are:

1. To describe the history of UK immigration and health policies for insecure immigrants under the Labour government (1997-2009), with special focus on HIV;

2. To document the development of policies that may restrict access to healthcare for individuals with insecure immigration status;

3. To explore the experiences of Zimbabwean women as affected by these policies, and of those professionals required to implement them;

4. To describe the obstacles and facilitators to access to HIV services for Zimbabwean women with insecure immigration status in the UK;

5. To discuss the effects of current immigration and health policies on women's wellbeing, and their implications for future UK immigration and health policy-making.

Chapter 1 provides an overview of the literature on Zimbabwean migration to the UK, the HIV epidemic among the UK Zimbabwean diaspora, and recent UK policy approaches to immigration and healthcare provision for migrants.

Chapter 2 explores existing theories of policy formulation, implementation, and healthcare access to identify those which are likely to be appropriate for understanding UK policy on access to healthcare for insecure immigrants. This chapter identifies key theoretical concepts to inform the research on policy formulation and implementation, and individuals' experiences of access to healthcare. These form the basis for building new theories about policy development, implementation, and the healthcare access experiences of HIV-positive migrants. It outlines two models – the first, the 'triangular' model of context, content and processes, provides a simplified account of the policy process. It also provides insights into the way in which important components of the policy formulation and implementation processes are mediated by power. The second (*The Contextual Model of Access to Health Services for Populations with Insecure Immigration Status*) uses the existing theoretical literature on behavioural approaches to healthcare access to explore how individual, social and structural factors might interact to affect healthcare access. The latter model is strongly informed by Andersen's behavioural model of access to health [2], but unlike previous models, this views the healthcare access process as fundamentally non-linear, and takes account of individuals' subjective experiences and perceptions.

Chapter 3 sets out the research questions informing both the policy analysis and healthcare access components of the research, as well as the design and methods employed in each of these.

The results of the policy analysis, which took data both from document analyses and key informant interviews, are presented in Chapters 4 and 5. Chapter 4 explores the motivations and approaches of the UK Government in developing policies that may restrict access to healthcare for individuals with insecure immigration status (the NHS (Charges to Overseas Visitors) Regulations 2004, or 'Charging Regulations'). In addition, the role of non-governmental actors and processes on the development of policy are examined. Chapter 5 examines the implementation of the Charging Regulations, with a particular focus on the strategies of those actors required to implement them within a clinical or hospital setting.

The findings from the qualitative research undertaken with Zimbabwean HIV-positive women with insecure immigration status are reported separately in Chapters 6, 7, and 8. Chapter 6 introduces the reader to the sample of women interviewed for this research, and provides an overview of their migration, HIV diagnosis, and UK immigration system experiences. Chapter 7 discusses the ways in which women's healthcare access was affected by the Charging Regulations, and their reactions to the interplay between their immigration status and healthcare access. Chapter 8 explores other (non-policy related) obstacles and facilitators affecting women's access to healthcare. Taken together, these three chapters provide a case study of the obstacles and facilitators that can affect access to healthcare for individuals with insecure immigration status.

Chapter 9 discusses the five empirical chapters in order to develop theoretical insights about how UK immigration and health policies are formulated, implemented, and enacted through Zimbabwean HIV-positive women's experiences. It also identifies the key implications for policy, practice and further research.

1. Chapter 1 – Background: Migration, HIV, and UK Policy Responses

Introduction

This thesis examines the formulation and implementation of UK policies that relate to access to healthcare for asylum-applicants and unauthorised migrants (or individuals with 'insecure immigration status). It also examines access to healthcare services for HIV-positive Zimbabwean women living in the UK. This first chapter presents an overview of global migration as it pertains to the Zimbabwean diaspora and the HIV epidemic in the UK. It examines migration flows internationally before turning to the UK specifically and what is known about Zimbabwean migrants in a UK context. It then provides an overview of UK HIV epidemic data, with a particular focus on Zimbabwean and other African migrant populations. It also examines key behavioural features and other barriers to care that contribute to the epidemic among this population. Finally, a brief and recent history of UK immigration policy provides a detailed overview of the heart of this thesis: policies on access to healthcare for individuals with insecure immigration status.

The first intention of this thesis is to synthesise the existing literature on migration, migration-health and HIV in the UK, and UK immigration policy. There is a significant body of literature both on the HIV-related experiences of African migrants in the UK, and on the development of immigration policies under New Labour. However, there is little evidence linking policy to migrant health needs. Further, although Zimbabweans contribute a substantial number to the UK's migrant population and HIV epidemic, there is scant research documenting their experiences of life or healthcare access in the UK.

1.1 International Migration to the UK

Total international migration to the UK has increased substantially since 2000, but asylum applications over the same period have decreased [3], reflecting changing patterns of conflict, as well as the impact of UK immigration policies. Notably, asylum applications from Zimbabweans grew considerably in the mid-2000s [4]. There is a substantial Zimbabwean diaspora in the UK, about whom few data exist, but for whom decisions about settling in the UK may often remain dependent on changing political circumstances in Zimbabwe [5].

1.1.1 Refugee Law and Definitions

Both the International Organisation for Migration (IOM) and the United Nations High Commission for Refugees (UNHCR) place migrants into two broad categories: voluntary and forced [6, 7]. Voluntary migration is characterised by a response to the inequalities in labour supply and business demand in different parts of the world. Forced migration is driven by conflict, political repression, human rights abuses [7], environmental change or natural disasters and sometimes, economic development [8]. However, the distinction between these two groups is not always clear cut. As Castles et al point out:

"Voluntary migrants may feel compelled to seek new homes because of pressing problems at home; forced migrants may choose a particular refuge because of family and community ties or economic opportunities"[8].

Distinguishing between different types of migrant is not easy, particularly since migrants may occupy both these categories over the course of their migration. For example, voluntary migrants may find that their personal circumstances or the situation in their home country has changed since emigrating, making them into forced migrants [8]. Furthermore, there is usually a voluntary component even where there is a politically compelling motive for leaving [9]. This migration-asylum nexus creates considerable policy challenges, not least the difficulty in assessing the validity of asylum applications [8]. For these reasons, the data presented here should be interpreted with caution, given the capacity for misclassification and changes in the definitions of migrants. However, as Martin (2001) observes, interpreting migration data is "more than an exercise in semantics" (p. 1), as different migrant categories create different obligations for nation-states. One-hundred and forty-seven countries are signatories to either the 1951 Convention relating to the Status of Refugees [hereafter: '1951 Convention'] or its 1967 Protocol[1]. [10] They are thus obligated to protect refugees as defined in the 1951

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[1] The original Convention was limited to the protection of European refugees in the aftermath of World War II, and the 1967 Protocol expanded the scope of the Convention as it became clear that forced displacement was a global problem [10].

Convention[2]. States that are not signatories to the Convention or its 1967 Protocol are still bound to the principle of *non-refoulement*, which prevents individuals from being returned to countries where they face persecution[3]. Other instruments of international law such as the European Convention on Human Rights (ECHR) and the Convention Relating to the Status of Stateless Persons (1954) also contain provisions which may be relevant to the treatment of refugees and migrants [11].

States face challenges in developing and maintaining an efficient asylum determination procedure, as a result of these blurred definitions [7]. In addition, developing procedures (such as visa restrictions or carrier sanctions) that make it hard for a potential asylum-applicant to enter a country can often have repercussions for those who are genuinely in need of international protection [8].

1.1.2 Global Migration and Refugee Movement Overview

In 2005, the United Nations (UN) estimated that there were approximately 191 million international migrants[4] globally, with 60% of the world's migrants living in more developed regions. Europe has the largest number of international migrants, with 64 million; second to this is Asia, with 53 million [12]. These figures represent a substantial growth in the global migrant population – in 1960, the total number of migrants (76 million) was less than half the current figure, and represented a smaller percentage of the world's total population[5] [6]. International migrants come from and go to all parts of the world; few countries are unaffected by migration. Many countries are net 'sending countries', others 'receiving countries', and others still are 'transit countries', through which migrants travel to reach other destinations [7].

Definitive migration statistics for Europe are hard to ascertain. Many European countries use nationality rather than country of birth for their economic/social statistics. As a result it can be hard to differentiate between those who are foreign-born (and therefore international migrants in the definition mentioned previously), and those who are locally-born non-citizens [6]. Indeed, the picture is further complicated by the fact that many of those in the UK who are

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[2] A refugee is defined by the 1951 Convention as "a person who, owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country."

[3] This is the overriding principle of the 1951 Convention. There is no 'right to asylum' as such, but the principle of *non-refoulement* guarantees protection from repatriation into countries where individuals may face persecution (Hovy 2001). This principle is a peremptory norm of international law [10].

[4] Defined as people who are living outside of the country in which they were born [12].

[5] 2.6% in 1960, compared with 2.9% in 2000 [6].

foreign-born (and therefore migrants, according to the above definition) may become citizens through naturalisation, predominantly through residence or marriage to a UK citizen[6]. In addition, migration to Europe is complex: no country or region of origin dominates, and nor does any single type of population movement (i.e. economic migration, students, family reunification, authorised/unauthorised, asylum seeking). Furthermore, migration by type and origin varies substantially between different receiving countries [14]. Population movement sometimes reflects historical and colonial ties, but also emanates from, and contributes to, processes of globalisation [15, 16]. While migration has traditionally been within regions, with migrants typically moving from one developing country to another [7], migration from the global South to North is rapidly increasing[7].

Detailed data on asylum-applicants and refugees in Europe are readily available, primarily because refugees are well-defined in international law (namely in the 1951 Convention). Signatory states are obliged to collect statistics on the numbers and conditions of asylum-applicants and refugees in their own territories [17]. The United Nations High Commissioner for Refugees (UNHCR) estimates that in 2005, the total number of refugees and asylum-applicants globally was approximately 10 million[8], with around 2.3 million of these residing in Europe (for more detail on forced migration trends, see Appendix 1).

a   ***Women and Forced Migration***

According to UNHCR, forty-seven percent of the world's refugees and asylum-applicants are women. However this may be an underestimate because UNHCR is only able to collect age/sex specific data in those countries where it is operationally active. Consequently, accurate demographic data on forced migrants in developed countries, where individual states have responsibility for data collection, can be difficult to ascertain [19]. For example, in the UK it is hard to estimate the true number of asylum-seeking women because women who entered the UK in the company of a male relative were, until recently, registered as their dependents, and not as independent claimants [20].

Moreover, some women with insecure immigration status may be in a human rights 'black hole' that would affect refugee definitions and therefore data collection. The 1951 Refugee Convention does not include gender as a recognised basis for persecution, and there is no

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[6] 1,197,640 individuals were granted UK citizenship 1997-2007 [13].
[7] The number of migrants in the developed world more than doubled in the period between 1980 and 2000, growing from 48 million to 110 million, while the number of migrants in the developing world increased much more slowly in the same period: from 52 million to 65 million [16].
[8] However, these data do not include the 6.6 million individuals who were thought to be internally displaced at this time [18].

specific provision for *refugee* women in the Convention on the Elimination of All Forms of Discrimination against Women. In 2005, fewer women than men were granted asylum in the UK. The lack of recognition of sexual and gender-based violence (SGBV) as a form of persecution in the international legislation that protects refugees has caused speculation that some applications for asylum in the UK from women fail because many cannot satisfy the standards of proof required. Rape and torture, when perpetrated against women, are often described as 'individual acts of indiscipline' rather than persecution [21].

1.1.3   Refugees, asylum-applicants and undocumented migrants in the UK

The UK experienced its first formal influx of refugees in the decades before the First World War, when 120,000 Jews were received, and this led to the first formalisation of asylum policy. In the interwar period, refugees from Europe did settle in the UK, although their numbers were still relatively small. Towards the end of the Second World War about 200,000 East Europeans who had sought asylum from the Nazi occupations of their own countries requested leave to remain, rather than be repatriated to countries that were now part of the Soviet bloc [22][9].

Since the 1970s, the largest numbers of refugees have come under special 'quota' programmes, with noteworthy groups coming from Chile and Vietnam, and more recently Bosnians and Kosovans in the 1990s [23]. In addition to these quota programmes, asylum-seekers can identify themselves at port of entry, or 'in-country'. Their claims are passed on the relevant agency[10] at the Home Office (HO).

Figure 1 Total International Migration (data from the IPS) and Asylum Applications to the UK 1997-2007 (data from the Home Office RDS), data from IPS and Home Office RDS

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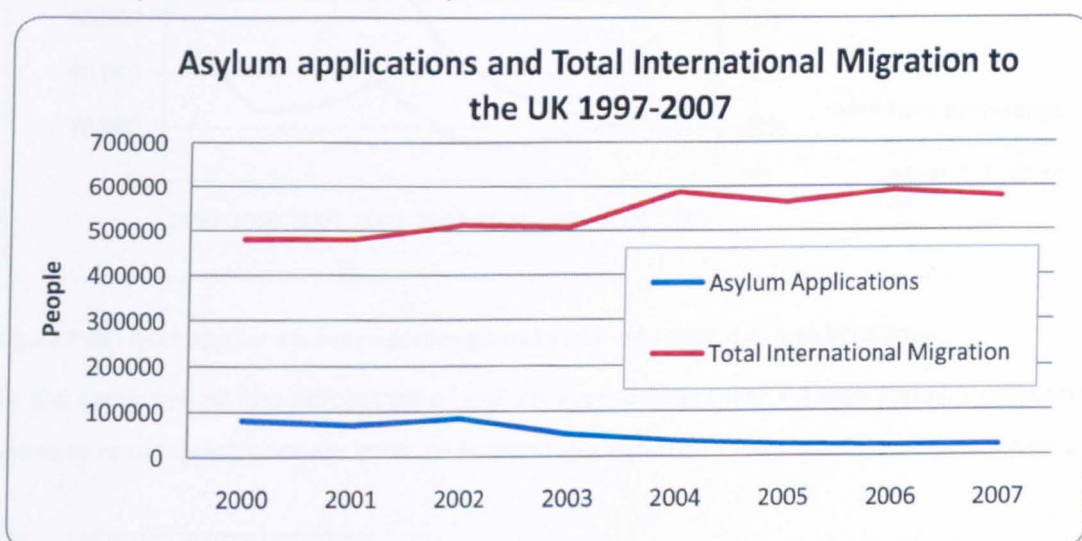
[9] However, the anti-Soviet stance of this group may have contributed to the motivation to allow settlement, since few Jews were 'enrolled' (around 3000), despite the holocaust and awareness of conditions in the concentration camps [22].

[10] Recently, and variously: the Immigration and Nationality Directorate, the Borders and Immigration Agency, and now the Borders Agency.

Immigration rights for Commonwealth subjects have been slowly eroded through a succession of legislation starting with the Commonwealth Immigrants Act 1962. This has meant that primary settlement from the Commonwealth is now limited to family reunification and refugees or asylum-applicants [24]. An increase in asylum applications in the same period as much of this legislation was introduced led many to the "false logical leap" that many asylum-applicants were in fact economic migrants trying to exploit loopholes in immigration controls [25]. This argument failed to take account of the global increase in refugees since 1975 as a result of civil wars, ethnic conflict, and regional violence, and the fact that asylum applications did not occur in a generalised way from all developing countries, but rather reflected political disturbances from specific locations[11] [22].

Total international migration to the UK has increased from below 500,000 migrants entering the UK annually in 2000, to nearly 600,000 by 2007 (see Figure 1). In contrast, the number of asylum-applicants has decreased over this period, and therefore asylum applications constitute a shrinking proportion of total UK immigration statistics. This may reflect the end of some of the refugee-producing conflicts of the 1990s and early 2000s.
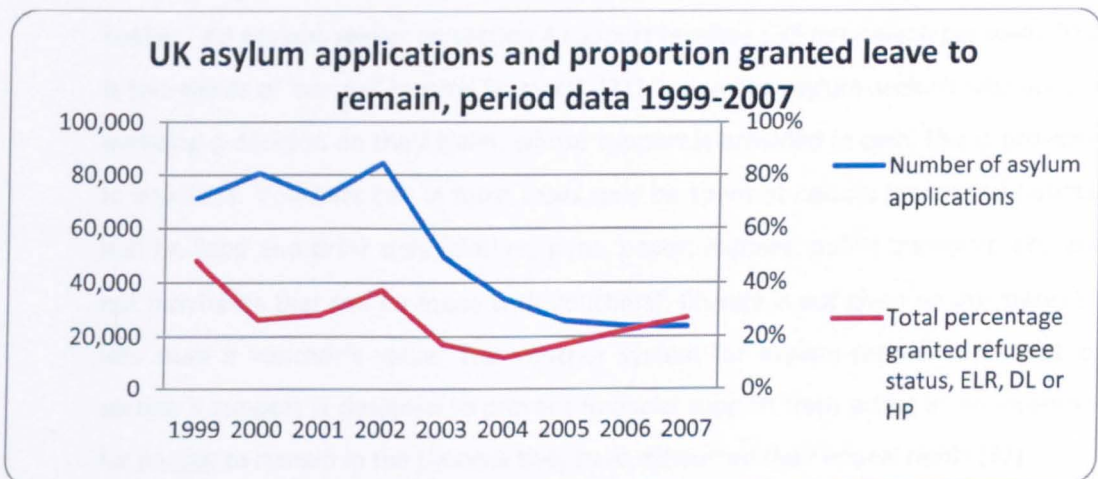
Figure 2 UK asylum applications and proportion granted a stay, 1999-2007, data from (ICAR 2009)

In the same period, the percentage of asylum-applicants granted refugee status, exceptional leave to remain, discretionary leave, or humanitarian protection has also fallen[12] (see Figure 2).

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[11] For example, applications from Serbia & Montenegro surged to a high of 11,465 in 1999 when the Balkan conflict was at its peak, but tailed off towards the mid-1990s. Similarly, applications from Iraqi nationals peaked at 14,570 in 2002, as it became clear that an American invasion was imminent, and were substantially reduced by 2004 [26].

[12] The main countries of origin for asylum-applicants to the UK in 2007 were Afghanistan (11%), Iran (9%), China (9%), Iraq (8%), Eritrea (8%) Zimbabwe (8%), Somalia (7%), Pakistan (4%), and Sri Lanka (4%).

There are some problems with UK data on asylum-applicants and refugees, not least the fact that the most extensive data that are publicly available are produced by the Home Office (HO) [28]. These data are usually only available in period, rather than cohort format, making it difficult to relate refusal or leave to remain data for a given year to the year of original asylum application. However, these deficiencies are minimal in comparison to the difficulties faced in trying to determine the size of the unauthorised population in the UK, largely because of the hidden nature of unauthorised migration [29]. For the purposes of this thesis, unauthorised migrants are:

- Those who entered the UK without detection or under false documentation (wittingly or unwittingly),
- Visa overstayers,
- Refused asylum-applicants, including those who have not complied with removal directions and those in receipt of Section 4 support[13]. Section 4 support can be provided to an asylum-seeker whose asylum application has failed, but who satisfies one or more of five conditions (one of which is medical inability to travel) as to why they are temporarily unable to return home. Section 4 (of the Immigration and Asylum Act 1999) enables the Home Office to support an otherwise destitute failed asylum-seeker. An asylum-seeker on section 4 support receives £35 per person per week (this is two-thirds of 'normal' Income Support), [31], but unlike asylum-seekers who are still awaiting a decision on their claim, whose support is provided in cash, this is provided in vouchers. Vouchers can in most cases only be spent at certain prescribed outlets, and on food and drink only (clothes, pens, paper, nappies, public transport, etc; are not purchases that can be made with vouchers). Change is not given on purchases of less than a voucher's value. The voucher system for asylum-seekers in receipt of section 4 support is designed to prevent financial support from acting as an incentive for people to remain in the UK once they have exhausted their appeal rights [32].

This thesis uses the term 'unauthorised' rather than 'illegal' since most offences related to determination of immigration status are administrative rather than criminal in nature, although there are increasing parallels between asylum law and criminal law [33]. The use of the term 'illegal immigrant' may also have implications for the human rights of those labelled

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In 2007, over two-thirds of applicants were from these countries, and although absolute numbers of applicants have fluctuated, most of these countries have featured consistently in the top ten sending countries since 2002, implying protracted refugee-producing situations [27].

[13] This is also the Home Office classification of unauthorised or 'illegal' migrants [30].

in this way or undermine an application for asylum [34]. Recent attempts to estimate the size of the unauthorised population in the UK have placed the total at the end of 2007 at 618,000[14] (range 417,000-863,000) [35].

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[14] However, this figure includes children born in the UK to unauthorised couples, and therefore does not use exactly the same definition of 'unauthorised migrant' as that outlined above.

1.2 Zimbabwean Migration to the UK

Migration from Zimbabwe can be characterised into three distinct waves [36]. The first wave followed Independence in 1980, when 50,000-60,000 whites left Zimbabwe [37] in the period 1980-84. In the 1980s, a further (black) exodus from Zimbabwe occurred in response to conflict in Matabeleland [38]. The third wave began in the early 1990s, and followed the introduction of an IMF-sponsored Economic Structural Adjustment Programme. This contributed to significant deprivation for many black Zimbabweans who chose to respond by emigrating to improve their living and working conditions [36]. This has been the context for current ongoing emigration as substantial out-migration of skilled workers contributed to economic decline and was accompanied by violence and political repression by the Zimbabwean Government, Zanu-PF [38]. It exploited populist nationalism to try and shore up support against challenges from a new political opposition, the Movement for Democratic Change (MDC). Relations with the UK have become particularly tense, as the Zimbabwean Government portrayed the opposition as agents of British colonialism and have used this to justify increasingly violent tactics [39]. Zimbabwe is still in crisis, with unemployment estimated at 94% [40] and inflation running at 2,200,000% by the end of 2008 [41]. The deterioration of human rights in Zimbabwe is also thought to be reflected in the increasing numbers of Zimbabweans seeking asylum [38].

It is thought that the largest population of Zimbabweans outside Zimbabwe is in the UK, with estimates in 2005 placing the total migrant population at between 176,400 and 1.1 million[15] [43].

The United Kingdom, as the former colonial power, has long cultural and political ties with Zimbabwe [37]. It is not possible to know exactly how many Zimbabweans with insecure immigration status are currently residing in the UK, but HO data used in Figure 3 illustrate that between 1998 and 2007, there were 21,000 asylum applications to the UK from Zimbabwean nationals. In the same period, 4,246 Zimbabweans were granted refugee status or some other leave to remain[16] [17]. In 2007, more than 56% of Zimbabwean applications were from women, and 75% of applications from Zimbabwean nationals were refused [26].

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[15] It is hard to quantify the exact total number of Zimbabwean émigrés globally since the 1990s, since many acquired citizenship in the countries to which they migrated, and many others are thought to be undocumented. However, research conducted among documented Zimbabweans in South Africa and the UK estimated that a total of 535,609 Zimbabweans had migrated since 1990, with the largest numbers living in the UK (36.8%), Botswana, (34.5%), the USA (6.9%), and South Africa (4.6%)[15] [42].

[16] This figure excludes dependants and includes those given humanitarian protection, discretionary leave, or exceptional leave. 3,951 out of the 4,246 Zimbabweans given leave to remain 1998-2007 had been given refugee status.

Zimbabwean asylum applicants to the UK 1998-2007
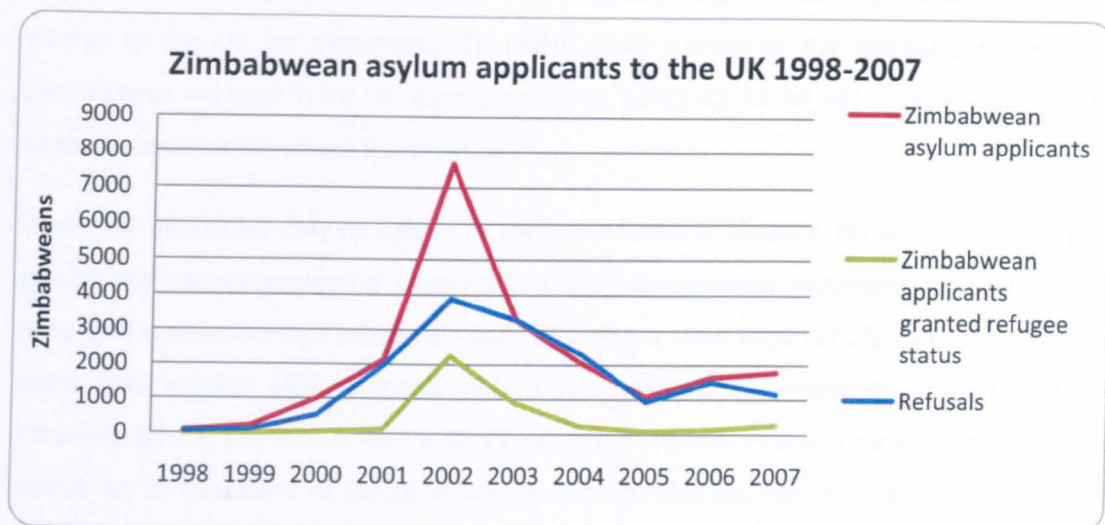
Figure 3 Zimbabwean asylum-applicants, grants of refugee status and refusals 1998-2007, (data taken from Home Office, 2008)

Asylum-applicants, by definition, experience some degree of insecurity and anxiety [44] about their legal status and where they might reside in the future. Zimbabweans in particular, have recently been subject to much uncertainty about their legal status: forced returns to Zimbabwe for failed asylum-applicants were halted in 2002 (at the height of Robert Mugabe's land reform policies) to ensure that no one was sent back to face intimidation or torture. However since then, numerous Asylum and Immigration Tribunal hearings have overturned or reinforced this decision (see Appendix 2 for more detail).

At time of writing (June 2009), the HO had recently issued an Operational Guidance Note commenting on the changing political situation in Zimbabwe, following the election in March 2008 and the power-sharing deal signed between Zanu-PF and the MDC in September 2008. The note indicated that these developments meant that the November 2008 Asylum and Immigration Tribunal (AIT) ruling that a person unable to demonstrate loyalty to Zanu-PF, no longer stood [45]. Therefore Zimbabweans currently awaiting a determination on their case, or whose cases were refused some time ago face considerable uncertainty regarding their future in the UK. The back and forth on suspension of removals has left many Zimbabweans in a "protracted situation of insecurity" [39].

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[17] It is worth noting that Home Office asylum statistics are not cohort data: those granted refugee status in this period may have initially applied for asylum in an earlier period, and therefore it is not possible to say that, for example, 'roughly a quarter of Zimbabwean applicants between 1998 and 2007 were granted leave to remain'.

There is very little published research on the specific experiences of Zimbabwean migrant women in the UK (or elsewhere). Therefore I will summarise the literature available on Zimbabwean migrants in the UK more generally [5, 36-40, 42, 43, 46, 47], and provide detail on women's experiences where it is available.

Women in Zimbabwe may be subject to particular forms of violence. Numerous human rights groups and non-governmental organisations have documented systematic rape and sexual torture of women during Zimbabwe's political violence since 2000 [48]. Since few women are overt MDC activists [43], women's asylum applications often reflect the most recent AIT determination – i.e. that a failure to demonstrate explicit loyalty towards Zanu-PF would suffice for ill treatment at the Government's hands. This has had implications for refusals, since HO determination procedures have tended to conclude that although such testimonies are credible they do not identify the asylum-applicant as a 1951 Convention-defined refugee.

The protracted insecurity and constant awareness of, if not contact with, the immigration authorities described above has implications for the narratives of Zimbabwean women who participate in research in the UK. As Ranger points out, their voices are rarely their own spontaneous utterances, but instead reflect something between the measured advice of lawyers and the 'street wisdom' of other Zimbabwean migrants [43]. Nevertheless, the existence of testimony, both in court and in research, demonstrates an agency on the part of those who testify that would otherwise be overrun by narratives of victimhood [43].

Research carried out among Zimbabwean migrants in the UK found that 94% of women held a tertiary-level educational qualification[18]. The majority of Zimbabweans who have migrated to the UK are of working-age, with most studies finding that over three-quarters of their sample are aged 25-39 [5, 46]. Perhaps because of this, there is a strong focus in the literature on access to employment, and the associated imperative that many Zimbabweans feel to send remittances to extended family networks in Zimbabwe, especially when they have left children behind [5, 35, 36, 39, 46]. Bloch (2006) found that substantial remittances were being contributed by most of the respondents in her research with Zimbabweans in the UK, including those who were formally unemployed or otherwise not earning. She expressed concerns about the impact of this on their everyday lives. In this context, the informal economy provides opportunities for Zimbabweans structurally excluded from getting a job [39]. The growth of

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[18] This proportion is higher than those educated past A-level in the UK native population, but is also substantially higher than in Zimbabwe itself. In Zimbabwe, 3.9% of the population are enrolled in tertiary education (although this low figure may represent the declining economic context in that country), and higher than among Zimbabwean migrant women in South Africa (52%).

service sector and care jobs in Europe more generally may have contributed to a feminisation of Zimbabwean migration and potentially 'emancipated' diasporic Zimbabwean women who may have had fewer employment opportunities in Zimbabwe[19] [47].

According to the majority of respondents in Bloch's (2008) research with Zimbabweans in the UK, improved conditions in Zimbabwe were necessary criteria for return migration. Although over three-quarters of respondents said that they hoped to go back to Zimbabwe, improvements in the political, economic and security situations in Zimbabwe were a prerequisite. Among those who did *not* wish to return, factors such as job security and access to education for their children were given as reasons to stay in the UK, rather than an explicit preference to stay in the UK *per se*. This implies that political and economic stability also drove this group's motivations [5]. Skilled individuals were thus trapped within the UK, feeling unable to return home, but were blocked from being able to use their skills or experience [39].

A common theme in the literature on the Zimbabwean diaspora in the UK is authors' emphasis on the liminal nature of migration status for Zimbabweans in the UK[20]. Bloch points out that "immigration status is fluid and people can move in and out of categories when necessary or expedient" [5]. In her study, of the 500 respondents, 24 per cent had at some point been a refugee or asylum-seeker, while at the time of the survey 18 per cent had refugee, asylum or a humanitarian status. Others had been through the asylum system and had become citizens, obtained Indefinite Leave to Remain or become undocumented migrants when their asylum claim was rejected. McGregor notes that individuals' trajectories lead them in and out of the different categories often used to discuss migration [39], and in Bloch's research 90% of respondents had extremely complex reasons for migrating, making it hard to classify them either as forced or voluntary migrants [5].

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[19] This feminisation of labour adds another gendered component to the migration experience, in its effects on men's gender identity. Zimbabwean migrants undertaking 'de-skilling' or otherwise unpleasant jobs make 'transnational calculations', weighing up the conditions they experience working in the UK against the conditions in Zimbabwe and the opportunities available to support family there [39].

[20] Liminality refers to a threshold or transitional state – for example, the changing situation in Zimbabwe means that some migrants who originally came to work or study might enter the asylum system once their visas have expired.

1.3 African Migrants and HIV

This section provides a brief overview of the literature about the relationship between migration and health, before describing dominant features of the HIV epidemic in the UK as it relates to sub-Saharan African migrants. Key behavioural features of the epidemic among Africans in the UK are late diagnosis and stigma, which are themselves interrelated. These barriers to timely and effective HIV care access are discussed below, followed by a brief examination of other cultural and structural barriers to healthcare access that have been identified in the literature for this population.

1.3.1 Migration, Health and Gender

Migration, gender and health are linked in many ways. The health needs of migrants may vary according to differently gendered migration experiences, and the ways that migrants access healthcare can often be gender-dependent [49, 50]. The impact of migration on an individual's health is a subject for which there is a significant body of research [49, 51-59]. Findings on the health impact of migration have been varied, both in terms of infectious and non-infectious diseases. The experiences of voluntary as opposed to forced migrants, or political as opposed to economic migrants may differ substantially[21] [60, 61].

For individuals with insecure immigration status, many of their health problems are often mirrored in other deprived or vulnerable groups. For example, infectious diseases such as HIV that are often associated with insecure immigrants in popular discourse [62] are also prevalent among other migrant groups. On the other hand, some studies have suggested that most asylum-applicants are relatively fit and well on arrival in the UK, and that their health deteriorates over 2-3 years in the UK [63, 64]. This decline in health may be a result of, among other things, poor access to services, poor living conditions, difficulty expressing health needs, and other problems (legal issues, housing etc) taking precedence over individuals' concerns for their own health [64]. However, other research has suggested that duration of residence in the host country can have the converse impact on health, with recently arrived migrants having poorer health outcomes than those who have integrated more fully [65]. Psychological problems in particular are often compounded by poverty and isolation [66], although traumatic migration experiences have also been identified by some refugee groups as a cause of their illness [56]. Asylum-applicants may have a higher prevalence of infectious disease or illness than other migrants [57], and may have experienced torture or other trauma that could have an array of psychological, musculoskeletal or sexual health consequences [67].

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[21] However, it may be better to view these four migratory 'states' as a matrix: migration that is strongly political and involuntary represents refugee flows [60].

For women who may pass through a refugee camp, the absence of appropriate reproductive health services both there and during the migration process means that family planning information and availability may have been compromised [49]. Given women's greater vulnerability to sexual violence during migration, unwanted pregnancies and other complications are also commonplace among asylum-seeking women [49]. The failure of much of the literature on refugee health to differentiate refugees and asylum-applicants by gender, neglects the increasing feminisation of migration. Moreover, migration can have an important impact on gender roles, and this can, in turn, have an impact on the health of women with insecure immigration status [68]. Common risk factors affecting migrant women's health in particular include: an increased incidence of sexual and gender-based violence (which can promote the spread of STIs and increase the likelihood of maternal morbidity) [55]; isolation[22]; and altered gender roles in the host country (which can have psychological sequelae) [66]. However, studies have shown that women may have better contact with services and medication use (compliance) than their male counterparts [69]. This may be because of their role in pregnancy and child-rearing, although research has shown that this assumption is not always true [70].

1.3.2   The HIV Epidemic in the UK

By the end of 2007, 73,300 adults aged 15 to 59 were estimated to be living with HIV in the UK [71]. The prevalence of diagnosed HIV infection in England in 2007 was estimated to be 3.7%

Figure 4 Applications for asylum by Zimbabwean nationals by age and sex, 2005, data from IND 2005
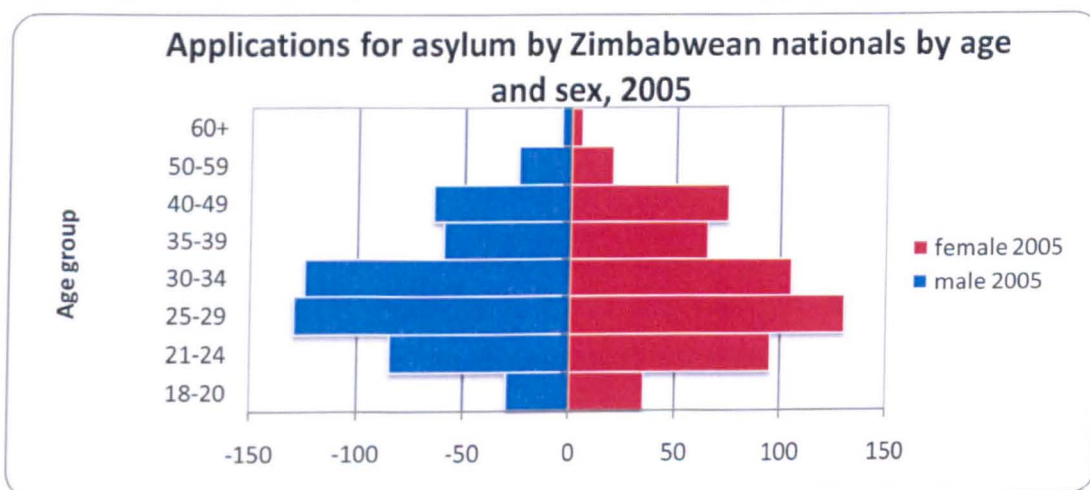
among black Africans, correlating to 40 times the estimated prevalence of diagnosed HIV infection in white heterosexuals (0.09%) [72]. In 2003, Africans represented 28% of those diagnosed with HIV in the UK, but only 0.4% of the UK population [73]. In 2004, over 90% of

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[22] Husbands and wives are often separated in asylum seeking, and this may be one factor contributing to experiences of isolation [68].

heterosexually acquired HIV infections diagnosed in the UK were probably acquired in high prevalence countries of origin, with 38% acquired in Zimbabwe alone [74]. HIV prevalence in the UK among African-born women is higher than among men[23]. By comparison, HIV prevalence (in 2004) in the UK population overall was 0.16%, and 0.5% in London [74].

Declining prevalence trends in Zimbabwe have been accompanied by reductions in some risky sexual behaviours among young people, giving rise to the suggestion that prevention messages are having an effect[24]. However a substantial drop in prevalence in Zimbabwe (from over 30% in 2000, to less than 20% by 2006) suggests that extremely high AIDS-related mortality must be a component of this trend. Worldwide, HIV prevalence growth does seem to be slowing, incidence has reduced, and mortality is decreasing, probably as a result of improvements to Anti-retroviral (ART) roll-out [75]. All of this notwithstanding, the overall meaning of global epidemic data has altered fairly insubstantially: despite a 16% reduction in the prevalence estimate, 33.2 million individuals are still thought to be infected worldwide.

Despite recent declines in HIV prevalence in Zimbabwe, in 2006 prevalence was still nearly 20% [75-77], and some surveys have shown HIV prevalence in Zimbabwe to be twice as high (among 15-29 year-olds) for women as for men [76]. Of the 17,551 HIV-positive black and minority ethnic (BME) individuals for whom country of origin information were available, 43% were born in Zimbabwe [78]. As Figure 4 shows, there was a substantial number of asylum applications from Zimbabwean women aged 21-29 in 2005, and as such the UK saw an increase in a population highly at-risk for HIV.

a   ***Africans, HIV and Health Behaviour in the UK***

Two key behavioural features of the HIV epidemic amongst Africans in the UK are late diagnosis of HIV, and high levels of stigma.

Late Diagnosis of HIV

Late diagnosis of HIV is defined either as having an AIDS defining illness at diagnosis or a CD4 count of $<200/\mu m^3$. In 2007 over 30% of those newly diagnosed HIV-positive were diagnosed late [71]. For the individual, late diagnosis means a need for emergency treatment, complex therapy, an inflated risk of developing an AIDS defining illness within three months (29%

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[23] 4.3% versus 3.3% in London, 8.2% versus 6% elsewhere – 58% of the black and minority ethnic (BME) individuals seen for care in 2004 were women and girls, and the vast majority of BME individuals seen for care in 2004 were of black African ethnicity.

[24] Recent revisions to the methodology used to estimate HIV/AIDS prevalence globally have modified previous estimates slightly downwards. However, while most of the revisions came about as a result of better estimates of the epidemic in certain countries (e.g. India), a real decrease in prevalence in Zimbabwe (and Kenya) has also contributed [75].

compared to only 3.8% of those not diagnosed late) [78], an increased mortality risk, and reduced effectiveness of ART [79]. Late diagnosis also has implications for public health as it reduces the opportunities for prevention of onward transmission [78]. ART reduces viral load and thus infectivity [80], and an individual who does not know their HIV status may miss out on opportunities for behavioural prevention of transmission [81]. Individuals who are unaware of their HIV status are up to three times more likely to pass on the virus than those who are aware of it. In 2007 it is estimated that heterosexual men and women accounted for 80% of late diagnoses [71].

It is estimated that 40% of black Africans in the UK have ever been tested for HIV, compared with only 13% of the general population, suggesting relatively high awareness of HIV among black Africans [82, 83]. However, there is a large body of research to indicate that in the UK, African-born populations are more likely to test late, compared to white non-African populations [84-86]. Twice as many late diagnoses occur among black Africans who were infected in Africa than among those infected in the UK [87]. The Health Protection Agency [72] estimated that in 2006, among black Africans living with HIV in the UK, 36% of men and 23% of women had not been diagnosed with HIV and were thus unaware of their infection.

Given the risks associated with late diagnosis, promotion of HIV testing among sub-Saharan African communities in the UK has been one of the main preventive interventions for migrants [88]. However, Chinouya and Reynolds [89] found that despite Health Service awareness of the high rates of late presentation among African migrants, most marketing of HIV prevention strategies was focused on those who were already accessing services, thus missing those most at risk. Migrants may also have limited access to culturally appropriate or reliable sources of information [70].

Research suggests that one factor contributing to late diagnosis among black Africans in the UK may be low self-perceived risk for HIV[25]. One study found that Africans were, relative to their white or Caribbean counterparts, more likely to test only because of the onset of symptoms or antenatal care rather than because of perceived risk [86]. Fenton et al [91] found that among African men, having an HIV test was independently associated both with a previous STI diagnosis and self-perceived risk. However, for women, the only factor independently associated with having an HIV test was a previous STI diagnosis. Perhaps because of this reduced perception of risk, African-born women test for HIV less often than their male

[25] Other authors have suggested that Africans may test late as much because of a low perceived benefit to testing for HIV, as because of low perceived risk, since the availability of ART in migrants' home countries may influence the extent to which migrant Africans believe accessing care is of use [90].

counterparts[26] [91]. Indeed, research with HIV-positive women in Zimbabwe also found that the majority of women only found out that they were HIV-positive after their partners had become sick or died, or during or after pregnancy [92].

In addition to low-self-perceived risk, late diagnosis may also be related to health-seeking behaviour and service provision. In many African settings healthcare is only sought out when there is a specific need, and in this context, the philosophies of health promotion and preventive messages are not well established in African communities [83]. This pattern may continue when individuals are in the UK. A survey of 435 HIV-positive Africans in the UK found that while the majority had been diagnosed in Genito-Urinary Medicine (GUM) clinics, 38% had been diagnosed as hospital in-patients, and 5% at their general practitioner (GP) [93]. Indeed, another study found that many Africans identify GPs as an important source of information, yet few attend their surgeries. This highlights the importance of improving access to primary care, and access to HIV prevention information in primary care settings [70]. However, this finding is contradicted by another study which found that GPs were widely used by HIV-positive black Africans [94]. Strained relationships with healthcare providers are also a factor which leads many Africans in the UK to present late [95, 96]. Concerns over confidentiality have also been identified as barriers to testing [94, 95], especially given the high degree of stigma attached to HIV in African communities and beliefs that an HIV diagnosis would lead to social exclusion [62].

HIV Stigma

HIV stigma can affect contact with health and support services, leaving individuals isolated and with reduced healthcare access [96-98]. Stigma was classically defined by Goffman as "an attribute that is deeply discrediting"[99, p.13], and that reduces the stigmatised individual from a "whole and usual person to a tainted, discounted one" [99, p.12]. In this sense, individuals who do not match social expectations of normality can be blamed by others for their own misfortune, and often aware of the potential for this, may try to conceal their condition from those around them [62]. Scambler views this tendency to ascribe deviance to 'anomalous' individuals as emerging from humans' need for a symbolic framework to order social reality to stabilise their relations with others [100], and in this sense, social construction is a central component of stigma. Stigmatised medical conditions tend to be those that are associated with negative attributes, and that can induce strong emotional responses "such as fear and revulsion" [101]. The perception of HIV as a disease transmitted as a result of morally

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[26] Fenton et al (2002) suggest that antenatal testing provides a good opportunity to redress this, but only if women can be encouraged to maintain contact with services [91].

and socially reprehensible behaviour like promiscuity and injecting drug use [102] can elicit such a response, and helps to construct a stereotype of the HIV-positive individual as an aberrant Other. If discrimination is viewed as unfair treatment as a result of dislike of the Other, then stigma can be seen as an enabling phenomenon. This definition necessitates an examination of the idea that the stigma process relies on the use of social, political, and economic power that enables the (preceding) stigma to have (structurally) discriminating consequences [103]. Parker & Aggleton [104] emphasise "the cultural production of difference in the service of power", and point out that stigma plays a central role in reproducing relations of dominance, power and control, and therefore in social exclusion [105]. Given that the HIV/AIDS epidemic in the UK is spreading fastest among heterosexual black Africans and that the majority of those being seen for care are women and girls – social groups that are typically deprived of power – it becomes more important to consider the stigma experiences of these disadvantaged groups [102].

For the HIV-positive individual, pejorative societal responses build a devalued identity through the process of stigmatisation, as events are interpreted in the light of their HIV status, its accompanying stereotypes, and societal expectations [101]. This internalisation of societal stigmas contributes to what Scambler [100] defines as 'felt stigma' where the individual experiences the shame associated with being HIV-positive. The individual fears encountering discriminatory episodes as a result of their own social or cultural reprehensibility, or 'enacted stigma'. In this way, HIV status can take on a psychological 'master status', subsuming the identity of the person living with HIV beneath a social label constructed in part by the social and biomedical markers associated with an HIV diagnosis [96].

HIV STIGMA WITHIN AFRICAN MIGRANT COMMUNITIES

HIV is greatly stigmatised within African communities [90], both in its own terms, and in its association with other stigmatising conditions such as mental health issues or tuberculosis [106]. The association of HIV with sexual transmission has been identified as contributing to HIV associated stigma, since it carries implications about morality and personal character [83]. These shameful behaviour associations can mean that individuals are seen to carry personal blame for having contracted HIV [107]. Given that felt stigma is shaped both by individual perceptions of HIV, and the dominant attitudes in one's community, the experience of stigma is intrinsically tied to the responses of society and community, as well as the individual [107]. Burns & Imrie's [83] research with key informants in the African HIV community in the UK identified that Africans are perceived often to be fearful of testing for HIV as the process itself is seen to imply an admission of guilt. This was compounded by the fear of death that was

associated with an HIV diagnosis in migrants' home countries where the disease had different clinical outcomes. The perception of HIV as a terminal illness and the associated stigma can act as powerful barriers to forming new relations within ethnic minority or migrant communities, thus compounding the isolation that HIV-positive migrants may experience [108].

Women may be especially stigmatised by an HIV diagnosis [106] as the symbolism associated with sexual transmission can have particular ramifications for perceptions of female morality and shame [109]. It can also have implications for stigma avoidance strategies, such as stigma transference (blame) and 'passing' (the avoidance of disclosure). The portrayal of the HIV-positive body as polluted compounds an implication of failure in women's traditional role as carers and moral guardians when they become infected with HIV [110]. This can transform HIV infection into a peculiarly gendered transgression, where a greater stigma is assigned to HIV-infected women than to HIV-infected men [102]. Felt stigma, or the fear of encountering discriminatory treatment, can result in the avoidance of disclosure, and most of the women in Anderson & Doyal's [111] study believed the chances of discrimination against them from within their own community to be very high. Enacted stigma or discriminatory treatment as a result of the stigma associated with HIV infection can take on a specifically gendered focus. Research conducted with HIV-positive African women in London found that about a third had experienced explicit HIV-related stigma such as rejection by their husbands, eviction from home, marking or special washing of kitchen utensils and refusal to allow contact with children [111, 112]. Erwin & Peters [95] also report anecdotal evidence of women being beaten by their husbands and evicted from their houses following disclosure of their HIV status.

HIV STIGMA OUTSIDE AFRICAN MIGRANT COMMUNITIES

The perception of HIV as a disease of the Other is magnified by the increasing association of HIV with risk categories in the form of groups of individuals who are anyway outsiders (such as African migrants). If the association of tuberculosis and mental health conditions with HIV infection boosts stigma, then the association of marginalised groups with the HIV epidemic has a similar effect. By portraying disease (and migrants) as a threat to a robust and healthy society, health concerns are inverted such that the receiving population is seen to be under threat. In this way, health too becomes an instrument of social control, and Othering enables the location of disease to take place far away from the general population [113]. If HIV is viewed in terms of its threat to others and the economic costs of service provision [101], then the hostility that the lay public feel towards immigrants [90] may be exacerbated by a perception of migrants as simultaneously threatening health and consuming NHS resources. This perception is reflected in the popular press on a regular basis, which propagates

discriminatory and stigmatising attitudes towards HIV-positive migrants [90]. Policies that restrict access to ART for certain classes of migrant use state power to (structurally) discriminate against an entire group, and facilitate a stigmatised view of HIV-positive migrants. Yang [103] observes that the stigma process is dependent on the use of social, economic and political power to ensure that the preceding stigma has discriminatory outcomes, and that power is often lodged in the apparatus of the state. In this way, HIV-positive migrants may bear a double stigma, since both migrant status and HIV status become bi-directional stigmatising attributes, and facilitate mechanisms of social exclusion.

CONSEQUENCES OF HIV STIGMA

The fear of stigmatising encounters can mean individuals adopt stigma prevention strategies, such as avoiding disclosure to manage their identities and prevent becoming 'discredited' [99]. Avoiding disclosure or 'passing' [99] helps to perpetuate the illusion of normality, but simultaneously compounds the individual's isolation [62]. Black African HIV patients have been shown to be significantly more likely to avoid disclosure to family or friends than their white counterparts [94]. For many black African migrants who have shared or communal living arrangements, disclosure can represent 'painful changes' to the domestic arrangements of living with others, as rejection is perceived to be a likely outcome if their condition becomes known [96]. The desire to avoid disclosing can affect HIV service uptake, especially where concerns about confidentiality in the clinical setting lead to fears that news of an HIV-positive diagnosis will reach family members back home [83]. Similarly concerns about being recognised by someone from their own community can affect access to health information, and clinic visits may be kept as short as possible [95]. Perceptions of discrimination from healthcare providers, including fears of being experimented upon or treated less well than Caucasian patients was also shown in Erwin and Peters' [95] study to influence service uptake among migrant African populations. Initiating and maintaining ART can be affected by communal living arrangements when patients have concerns about the risk that they carry of involuntary disclosure through their 'stigma symbolism'. The visible signs associated with HIV treatment transform HIV identity from 'discreditable' (when the person may pass as uninfected) to 'discredited' [96].

The management of identity in this way and avoidance of disclosure of HIV status can have a particularly isolating effect when it entails a failure to connect with peer support organisations, as well as clinic services. According to Flowers et al [96], many HIV-positive people feel that the disclosure implicit in accessing social or community support groups militates against their seeking out support. Other research with African HIV-positive migrants also found that the

primary manifestation of stigma was in isolating individuals from communities [106], and stigma is likely to be the main barrier to migrants' participation in HIV-specific peer support [114]. Research with HIV-positive African migrants in Europe found that African women had much less access to support networks than European women [115]. Isolation is not without its own health sequelae: Doyal and Anderson identified rejection and isolation as having a profound impact on mental health for HIV-positive African women in London. This was exacerbated when it was mapped onto the hostility towards migrants that some respondents perceived in wider society [112]. In addition, stigma and social exclusion can themselves affect health and wellbeing [110, 116]. Given increased survival times, quality of life has become an important measure of treatment success in HIV patients. The presence of social support has been identified as one of the most important factors that help to explain differences in quality of life following a diagnosis of HIV [116]. However, for vulnerable migrants with limited access to care, peer support can be crucial to the initiation and maintenance of life-saving ART [111].

b   Barriers to HIV Care Access

The difficulty migrants and individuals with insecure immigration status have in accessing health services has been well-documented [69]. Racial discrimination, cultural difference, and needs that compete with healthcare needs can affect HIV care access [66, 117, 118].

Racial discrimination in society or on the part of service providers can be an important obstacle to access [66]. Even where there is no overt discrimination, research suggests that ethnic minority patients experience a lower quality of consultation with service providers than their white counterparts. Factors that may contribute to this inequality include the clinician's response not only to the patient's health issues, but also his or her own prejudices, language problems [119], lack of knowledge or training about the specific issues that may face insecure immigrants [120], and limited time for consultations [90]. Perceptions of discriminatory treatment at the hands of service providers can have implications for the trust between patient and clinician[27], as they may affect patients' willingness to seek care [123]. Mistrust and fears of discrimination may be particularly present in migrant African populations: Erwin and Peters [95] found that some HIV patients believe that they receive inferior or deliberately detrimental care as a result of their ethnicity. Others have noted that the origin of HIV is seen by some to be a synthetic virus designed to eradicate black people. A lack of trust in mainstream medicine may mean patients turn to traditional healers in preference to biomedicine [90].

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[27] Some authors have argued that trust in doctor-patient relations needs to be conceptually revisited in an era where a consumer model in medical care puts patients in a position of greater vulnerability [121, 122].

Cultural differences between the treatment needs of migrant Africans and white patients may also militate against successful healthcare access. Different ways of viewing illness and the expected role of service providers may have an effect on willingness to seek out care[28] [118]. Language barriers are an obvious example of cultural difference that can influence health encounters [119], and employing interpreters can be costly or impractical [124, 125], especially where interpreters are not medically trained [126]. Using family or friends to interpret raises problems when sensitive issues need to be discussed [66]. Disseminating health information can be difficult where there are language barriers and limited appropriate information about service availability [127]. Research has shown that the need for HIV information is much greater among migrant Africans than white British patients, with 91% of African respondents in one study reporting a desire for more information on HIV treatments [93]. Since a lack of knowledge of what services are available has been identified as a barrier in itself for HIV-positive migrants, better provision of culturally appropriate information could improve access to HIV services [90].

HIV-positive migrants with multiple other concerns may not prioritise seeking out HIV care over other pressing issues, and worries over day-to-day survival can take precedence [117]. Health is often only a priority when patients are unwell [83]; even if there is a perception of HIV risk, accessing HIV services is unlikely to be a primary concern when patients are also dealing with housing, immigration, finance or childcare [90]. Confusion over entitlements to access healthcare services can exacerbate obstacles that already exist [128]. The next section discusses policy on access to healthcare for insecure immigrants in more detail.

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[28] Research from France, for example, suggests that cultural differences point to a need for culturally sensitive service provision in the medical and psychiatric care of HIV-positive women [115].

1.4 Policy Background

This final section of the background chapter discusses immigration policy under the Labour Government in the period 1997 to the present, in the context of global migration trends and the political philosophy of the Labour Party. The social construction of asylum-applicants has both been affected by, and had an effect on immigration policy development. For this reason, a short précis of some of the literature on policy and media representations of migrants is offered. Policy changes and proposals that aimed to achieve access restrictions are discussed in detail. Finally, the specifics of policy on HIV care access for individuals with insecure immigration status are outlined.

Changes to immigration policy in the UK prior to 1997 divide into four distinct periods. Between 1709 and 1905, the dominant preoccupation was with demographics and protecting the population from external threats. Following this, the first half of the twentieth century formalised the restrictionism that had grown out of the desire to protect the population from aggressive outsiders in the development of the 1905 Aliens Act. Indeed, this Act was the first immigration control legislation in Britain, and firmly embedded the notion of migrants as a resource burden into policy discourses. It permitted refusal of permission to enter the country for those deemed 'undesirable' in being a 'burden on public funds' [129]. Between 1948 and 1976 there was an increased focus on migration from the new Commonwealth, which was thought to pose a risk to 'race relations'. 1976-1997 saw an increase in asylum applications as the collapse of the Soviet Union and conflicts elsewhere led to an increase in asylum flows to the UK. Policy attempted to extend UK borders beyond the physical borders of the country in an attempt to contain these new migrations [130].

1.4.1 Overview of Immigration Policy under New Labour

In 1997, when New Labour came to office, asylum applications had grown to over 32,000 from approximately 4,000 per year in 1988. There was a severe backlog in the asylum system at that time, with "50,000 cases awaiting decision and over 20,000 queuing for an appeal hearing" [131]. The Government initiated a review of migration, and while this was in progress, asylum applications increased to 68,000 by 1998, with the backlog also increasing to a peak of over 100,000 [132]. Migration more generally had also increased[29]. Trends in asylum application have also varied considerably in terms of the origin of applicants, with the numbers of

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[29] Arrivals at UK ports grew from 50 million in 1990, to nearly 90 million by 2000 [133].

applications from individuals of sub-Saharan origin rapidly outstripping those from Europeans[30] [26].

The administrative pressures on the asylum system contributed to a restrictionist approach that lent itself to an 'efficiency drive' in the development of immigration policy [130]. This focus on efficiency in public services [134] was accompanied by another on race relations that followed on from the immigration policies of the previous Conservative Government. These focuses were tied in policy terms to the increase in asylum applications [132] through the conviction that social cohesion was dependent on limiting the amount and type of migration to the UK. This policy approach was first seen in the 1999 Immigration and Asylum Act, which was borne out of the White Paper *Fairer, faster and firmer: A modern approach to immigration and asylum* [131]. While the White Paper emphasised Labour's commitment to the principles of human rights, the central tenet of the 1999 Act was restriction. It introduced restrictions on right of appeal, the establishment of a parallel system of welfare support for asylum-applicants (with concomitant restrictions on their eligibility to social security benefits), the introduction of dispersal for government-supported asylum-applicants[31], growing surveillance of asylum-applicants [130], and an increase in the use of detention [136]. In addition, the 2000 Race Relations (Amendment) Act, that requires public authorities to promote racial equality, specifically exempted immigrants and asylum-applicants from the remit of the Act [132].

The second immigration White Paper was published by New Labour in 2002: *Secure borders, safe haven: Integration with diversity in modern Britain* [133]. This document marked a second phase of policy in which Labour took a pro-active approach to immigration policy, rather than reacting to the system it had inherited [130]. The White Paper emphasised the concept of 'managed migration' in which migration was seen as a source of economic enrichment, and in this sense deviated from decades of immigration policy that focused exclusively on immigration control [137]. This new approach, in which migration was opened up for economic benefit, took place within a continued dialogue on maintaining social cohesion. This stance represented an inherently contradictory position as it required the further exclusion of asylum-applicants in order to be able to continue with an inclusionary approach to economic

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[30] The numbers of applicants from Europe and sub-Saharan Africa were approximately equal in 1997 (9-10,000 applicants each). By 2002 applications from individuals of sub-Saharan origin had climbed to a peak of more than 29,000, while in the same year applications from Europeans numbered little over 13,000 [26].

[31] Dispersal entails relocating asylum-applicants to various parts of the UK in order to relieve pressure on London and the South-East. It is a no-choice scheme unless the applicant opts to receive subsistence-only (i.e. no support towards housing costs) support [135].

migration[32] [138]. The legislation passed in this period, Labour's second term, followed the ideas set out in *Secure Borders*, upholding economic migration but with an emphasis on control of asylum and measures to deal with unauthorised migration [130], and built on the restrictive measures initiated in Labour's first term. For example, Section 55 of the 2002 Nationality, Immigration and Asylum Act enabled the Secretary of State and Local Authorities to refuse to support asylum-applicants if the former was not satisfied that "the claim was made as soon as reasonably practicable after the person's arrival in the UK" [139]. It had an explicitly deterrent intention [140] that made many asylum-applicants effectively destitute [141].

The 2005 five-year plan on immigration and asylum (*Controlling our borders: Making migration work for Britain*), released prior to the general election that heralded Labour's third term, emphasised again the economic benefits of migration. It set out increased use of restrictive and surveillance measures against asylum-applicants, including detention and electronic tagging. *Controlling our borders* also established the 'tipping-point' target, which aimed to ensure that the monthly rate of removals of asylum-applicants exceeded the number of 'unfounded' applications [142]. It was therefore an extension of the strategies of reduction of numbers, and increased control over asylum-applicants [130]. The use of surveillance technologies as a component of restrictive control strategies was enabled by an increasingly securitised discourse on migration in general and asylum in particular [138, 143]. This discourse had grown out of the attacks on the Twin Towers in September 2001, and was substantially exacerbated in the UK by the July 2005 attacks in London [144].

a   Constructions of Asylum

Asylum-applicants and other irregular or undocumented migrants have increasingly been criminalised – indeed, immigration law is unique in its focus on the person as illegal, rather than the deed [145]. They have also been deemed potential terrorists, helping with a reduced government focus on their human rights [138]. Kathrani argues that in the UK, there is a growing visible parallel between asylum law and criminal law. He points out that the components defining criminal law (public protection, culpability, *mens rea*, and deterrence) have all become common features of asylum law, and that this further criminalises asylum-applicants [33]. The binary language often employed to discuss asylum-applicants and other migrants ('legal/illegal', 'good/evil') may help to reduce ambiguity around these constructions. Together with the language of threat and invasion (with asylum-applicants described as

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[32] With incitement to racial hatred having been made illegal under British law in 2007, the UK's British National Party has increasingly turned to asylum-applicants as the 'racialized other' in its propaganda, facilitating the exclusion of this group [137].

'swamping the UK' or as 'tidal waves'), this criminalisation has underpinned the representation of asylum-applicants and others as deviant and therefore deserving of social exclusion [146]. The sustained use of metaphors of flooding, invasion, and fraud in UK press coverage of immigration and asylum issues constitutes a particularly acute form of 'moral panic' [147]. It has contributed to the binary construction of individuals with insecure immigration status as either victim or villain. The 'genuine' refugee and the 'bogus' asylum-applicant [147] are at opposite ends of a spectrum composed of a 'spectacular cast' of victims of trafficking, 'bogus' asylum-applicants (economic migrants in disguise), terrorists and 'illegal' immigrants [148].This discourse allows the 'bad' migrant to be sacrificed for the 'good' in policy terms, with the disciplinary components of immigration control legitimised for a particular group [148, 149].

b   Asylum-applicants and Social Exclusion

The Labour Party's philosophy on poverty and social exclusion provides an insight into some aspects of immigration policy. It also enables an examination of specific restrictions established in this period, such as the removal of the right to work for asylum-applicants, and restrictions on access to healthcare services. Asylum-applicants are viewed as a socially excluded group [150, 151], and the definition below has informed much of the broader literature on social exclusion:

"The novel characteristic of les exclus was not that they were poor (although most were), but that they were disconnected from mainstream society in ways that went beyond poverty - for example non-participation in politics, poor health and geographical isolation." [152, p.4]

The above definition of social exclusion provides for a broad characterisation of the phenomenon that encompasses much more than poverty in the sense of a limited household income, and instead bears a close relationship to Sen's notion of capability deprivation[33] [153]. The European Commission joint report on social inclusion defined social *exclusion* as "circumstances where people are prevented from participating fully in economic, social and civil life" [154]. Indeed, when the new Labour government established its Social Exclusion Unit in 1997, it was charged with a correspondingly broad remit [155]. However, it became increasingly clear that at the heart of New Labour's 1997 shift from a focus on 'equality' to 'equality of opportunity' and from poverty reduction to combating social exclusion was *improved access to the labour market* [130]. Indeed, in her 1997 speech on social exclusion, the then Social Security Minister, Harriet Harman, said, "We are reforming the welfare state

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[33] Capabilities enable people to have the capacity to live lives that they value, and these capacities depend on access to goods including health, education, income, security and political participation [152].

around the work ethic... promoting employability, adaptability and inclusion". With this statement she demonstrated the centrality of access to employment to Labour's approach to tackling social exclusion [156]. Another central component of the New Labour philosophy is the notion that 'rights entail responsibilities', and this can be tied to the emphasis on access to the labour market in its emphasis against the notion of unconditional entitlement [152]. These ideas have also been linked to immigration policy through New Labour's thinking on citizenship, which has also emphasised the concepts of sharing "rights and responsibilities" or "benefits and obligations" [131, 133, 142, 144, 157].

Social Exclusion and Access to the Labour Market

In July 2002, asylum-applicants were excluded from the labour market (in order to prevent 'economic migrants in disguise' from applying for asylum). As Somerville notes, where the logic is that paid work will reduce exclusion and poverty, the converse must also be true – that restricting access to work "ensures poverty and exclusion" [130, p.168]. In this paradigm, the social exclusion of asylum-applicants relies on their portrayal as fundamentally 'undeserving' of equality of opportunity and establishes new boundaries of exclusion [151]. Removing the right to work has also been criticised on the grounds that the cost to the taxpayer is greater when welfare support must be provided and that integration is likely to be impeded [130]. With the need for welfare support for asylum-applicants comes an increased likelihood that they will be represented as a burden or drain on the public purse, further undermining efforts at inclusion and integration [151]. Others have noted that excluding asylum-applicants from race relations legislation is also likely to have contributed to their experiences of exclusion [132]. And the proliferation of policy messages that draw a distinct line between the way that citizens and migrants can expect to be treated influences the public discourse on asylum, and defines the normative limits on asylum and race relations [158].

Similarly, HIV patients also experience limited employment opportunities, with recent research by Ibrahim *et al* showing that 46.6% of patients in a large survey were employed on a full or part-time basis [159], compared with 73% of the working age population in the UK as a whole [160]. Ibrahim *et al's* research also showed that unemployment rates among African heterosexual HIV patients were much higher than those among their white homosexual counterparts. This difference remained even when insecure immigration status was controlled for[34]. HIV positivity, immigration status, and black African ethnicity then, would each seem to

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[34] In the adjusted analysis, almost 99% of white homosexual men had UK residency, compared to around half the African heterosexual respondents, although the proportion employed did increase in the latter analysis.

independently affect employment opportunities[35]. This also suggests that asylum-applicants and refugees experience a highly racialised form of social exclusion, with "problems of discrimination, dislocation and powerlessness" that are often shared with other BME groups [161]. These findings echo other research that has found that despite higher levels of educational achievement among Africans in the UK than among the population as a whole, unemployment rates are more than twice as high [162]. In London, despite being well qualified, less than 20% of HIV-positive black Africans are employed [163].

Studies have shown that there is a complex, but bi-directional relationship between social exclusion and health – poor health is one factor that can contribute to social exclusion; and social exclusion can itself affect health, particularly through access to healthcare [154, 164]. Other London-based research with HIV-positive African women found that this low employment rate was felt acutely by respondents, who saw their lives as most likely to be improved by being in a position to work or study, in order to regain a sense of purpose, come off benefits, and improve their families' circumstances [111]. The concept of social exclusion is widely seen to be the complex interaction of multiple variables, including poor health, poverty, restricted spatial mobility, and cultural marginalisation [161]. It is therefore worth noting that although access to the labour market was a central component of New Labour's approach to social inclusion, the government did also see access to certain public services – namely education and healthcare – as crucial to social inclusion [152]. UK refugee integration policy emphasises social inclusion [130]. However, up to 450, 000 asylum-applicants may have been waiting for a determination on their case for up to a decade [165]. Restricting access to key components of successful inclusion for this population (e.g. the NHS) has been seen as liable to undermine other aspects of integration policy[36] [137].

1.4.2   Policies on Healthcare Access for Insecure Immigrants

Universal access is the first core principle of the NHS: "the NHS will provide a universal service for all based on clinical need, not ability to pay" [167]. Many different Government policies relate to, or have some impact on either facilitating or obstructing access to health services for asylum-applicants and refused asylum-applicants. In this context, successful access may be dependent on a variety of factors, some of which may not seem to be explicitly related to

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[35] Unsurprisingly, unemployed respondents in the sample overall were significantly more likely than the employed to say they did not have enough money to cover their basic needs, but a significantly greater proportion of African respondents said this even when unemployment was controlled for. Ibrahim *et al*'s data on employment rates among HIV-positive Africans show that being African in itself affected employment rates, even when the analysis controlled for insecure residency [159].

[36] The seemingly deliberate social exclusion of asylum-applicants then perhaps makes more sense if viewed through the prism of denial of social rights; if citizenship encompasses social (as well as civil and political) rights, then social exclusion is an inevitable component of withholding citizenship [166]

health (such as entitlement to welfare benefits [168, 169], integration into society [170, 171], or level of social capital [115, 172, 173]). These can themselves be affected by myriad other policy areas, including immigration and nationality legislation, national assistance policies, or the level of Government financial assistance available to peer support groups. While this thesis takes this broader policy context into account, the main focus is on the 2004 NHS (Charges to Overseas Visitors) Regulations (Amended) since the stated aim of amending these was to restrict access to certain groups of migrants.

a   *The NHS (Charges to Overseas Visitors) Regulations*

In 2003, a consultation was opened by the Department of Health (DH) which proposed to close certain 'loopholes' in the existing legislation on charging overseas visitors for hospital (secondary) care [174]. In April 2004, those proposals became law in the NHS (Charges to Overseas Visitors) Regulations 2004 (Amended).

The 2004 amendment to the NHS (Charges to Overseas Visitors) Regulations 1989 (hereafter 'Charging Regulations') inserted the word 'lawfully' into the following sentence of regulation 4(1)b:

"No charge shall be made in respect of any services forming part of the health service provided for an overseas visitor who has resided **lawfully** in the United Kingdom for a period of not less than one year immediately preceding the time when the services are provided" [175, my emphasis].

Section 121 of the National Health Service Act 1977 gives authority to the Secretary of State to make regulations to charge those who are not ordinarily resident[37] ('overseas visitors') for any NHS services that they receive in the UK, and has so far only been used to charge for hospital services. The Secretary of State has no power to charge someone who is ordinarily resident [175]. The Charging Regulations lay down a number of categories of person or specific conditions that are exempt from charging. Following the 2004 amendment, those relevant to this research[38] include:

People who are in the UK and are:

- Refugees or asylum-applicants

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[37] 'Ordinary residence' is a legal term with substantial bearing on the judiciary's involvement with the policy process in this case, and is discussed in more detail below on page 85.
[38] Other exempt individuals include full-time students and those engaged in legal employment [175], but are not directly relevant to this thesis.

- Detained under the Mental Health Act or receiving treatment for mental health conditions as part of a court probation order.
- Care provided in the following settings/for specific conditions:
- Care provided in an accident and emergency setting unless and until the patient is accepted as an in-patient at the hospital.
- Care provided at walk-in centres similar to accident and emergency departments
- Provision of family planning services, treatment for sexually transmitted infections, and treatment for diseases listed in Schedule 1 (conditions of public health concern such as measles, tuberculosis and smallpox) of the Charging Regulations are also exempt from charging.

In the case of HIV, only diagnosis and post-test counselling are to be provided free of charge to patients who are otherwise chargeable. Treatment for HIV is not exempt from charging [175].

Refused asylum-applicants and others deemed not to be ordinarily resident are therefore considered chargeable for any secondary care that they require outside the exempt locations/conditions stated above.

Whilst the on-paper legislative change was relatively minor, many advocates have expressed concerns that these policy changes have had serious negative consequences for access to NHS services for insecure immigrants [176-178]. One of the key exemption categories in the 1989 Regulations was based on length of stay in the UK. This required a person to have resided in the UK for twelve months or more in order to be exempt from charges for any treatment they might require. In practice, this often meant that NHS Trusts (organisations providing services on behalf of the NHS in England and Wales) provided care to those who needed it, regardless of residency status [179]. The addition of the word 'lawfully' to the residency requirement for charge-free treatment in the 2004 Charging Regulations was seen by some to have had a major effect. It was observed that many insecure immigrants began to be turned away from secondary care services or asked to pay bills that few of them could afford [177]. The effect of this policy on the health of insecure immigrants is hard to quantify, but it is unlikely to have been constructive. In the context of HIV positivity, denying treatment may also have public health implications [179, 180].

Accompanying these Regulations is Department of Health guidance (*Implementing the overseas visitors hospital charging regulations - Guidance for NHS Trust hospitals in England;* hereafter 'the Guidance') advising trusts on how to implement the Charging Regulations. Although this is non-statutory, it is this document to which most NHS managers would turn

when they feel that the Charging Regulations are engaged; it defines in more detail than the Charging Regulations who is and who is not entitled to charge-free healthcare; and it has been subject to legal challenge in the form of judicial review. It thus constituted a central aspect of the legislative backdrop for the implementation of the 2004 amendment. It emphasised a legal obligation on the part of all NHS Trusts to establish the residency status of all patients receiving NHS hospital services, and that one of the consequences for an absence of ordinary residence status was an obligation to charge the patient [181]. The Guidance stated that a refused asylum-applicant (i.e. someone who has exhausted all their rights of appeal) would fit this category [181]. The Guidance did not provide clear advice to Trusts on what to do in situations where the patient was not able to pay, although as mentioned above, there are certain circumstances where patients would be exempt from charging. These include 'emergency and immediately necessary' treatment, although Trusts have sometimes been obliged to try and recoup costs even for these categories of treatment [182]. In circumstances where many refused asylum-seekers are destitute or near destitute [31, 140, 169, 183], these funds are unlikely to be recouped.

However, the story of this policy is far from over. In April 2008, a High Court judge ruled that refused asylum-applicants did qualify as 'ordinarily resident', and therefore the Guidance was unlawful [184]. Anyone who had ever applied for asylum, regardless of the stage they had reached in the appeals process, was entitled to free hospital treatment[39]. Between April 2008 and March 2009, refused asylum-applicants were entitled to access secondary healthcare without charge. However, the DH appealed this decision, and in April 2009, refused asylum-applicants were no longer deemed to be in possession of ordinary residence. Nevertheless, the Court of Appeal did also conclude that the Guidance did not make it clear enough that hospitals must consider providing treatment where a patient cannot return home and cannot pay for the treatment in advance [185].

b   Consultation on Charging for Primary Care
Entitlement to primary care services is also in flux [186]. In 2004, the same year that the secondary care charging legislation was amended to exclude refused asylum-applicants, a consultation was opened to examine restricting access to healthcare into the primary sector as well [186] (hereafter the 'primary care proposals'). At present, it is up to the individual discretion of the GP to decide whom to treat, but the consultation considered removing GPs' current discretion in order to bring charging regulations in the primary care sector further 'into

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[39] As long as they had been granted 'temporary admission' by an Immigration Officer when they entered the country.

line' with those in the secondary care services. Current NHS guidelines encourage charging in primary care [187] and "illegally stigmatise applications from refused asylum-applicants" [188].

The responses to the 2004 consultation have still not been published. Nor has the DH been transparent about the reasons for that delay. The DH and the HO are now said to be engaged in a joint review of the Charging Regulations, but the publication date of that review has been pushed back, month on month, for nearly two years (at time of writing – June 2009)[40].

While the DH has not enacted legislation preventing GPs from treating refused asylum-applicants and other categories of insecure immigrant, the publication of the consultation in 2004 caused much confusion among some primary care practitioners. Moreover, there is anecdotal evidence from many health and refugee organisations that insecure immigrants are often turned away from primary care because of a misunderstanding over the obligations placed on GPs in the 2004 Regulations and the subsequent primary care consultation. The Royal College of General Practitioners has opposed the proposals on the basis that they conflict with GPs' duty of care [189], and several clinicians and advocates have voiced their opposition in medical journals such as the British Medical Journal and the Lancet [120, 188, 190-197].

c   Policies restricting access to care – focus on HIV/AIDS

Should a refused asylum-applicant or unauthorised migrant be diagnosed HIV-positive, the Guidance states that they should be charged for any treatment that they subsequently require. It is unlikely that a destitute or near-destitute person would be able to pay for ART [198]. The risk of treatment denial for those unable to pay has raised concerns among HIV prevention organisations [178, 199-203]. The public health effect of withholding ART has not been quantified, however at least one study (in Taiwan) has shown a 53% reduction in onward transmission of HIV where ARV provision is free [204]. In addition, some HIV organisations have concerns that there is little incentive to test for HIV at all where treatment may effectively not be available [205], which would have implications for late diagnosis, and consequently individual, and public health.

The Charging Regulations may also have an effect on individuals who are legally entitled to healthcare. As mentioned above, the exemptions laid out in the Regulations include (non-refused) asylum-applicants, and as such, hospital treatment should be available to them without charge. However, anecdotally there have been cases of non-refused asylum-applicants

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[40] The review was announced in the Home Office strategy paper *Enforcing the rules - A strategy to ensure and enforce compliance with our immigration laws,* published in March 2007 [157].

being denied hospital care to which they were entitled [178]. Additionally, rumours about health or immigration policies may lead many asylum-seekers to doubt their rights to HIV services. Likewise, there is anecdotal evidence to suggest that within certain minority communities (e.g. African-born individuals living in London) similar rumours have spread, undermining longstanding campaigns to encourage regular testing in these populations [201].

A number of policy documents imply that the reduction of new cases of HIV through improved health promotion and access to sexual health services is a priority for the DH. Several health and HIV charities have expressed the view that it is hard to see how these aims and objectives are to be successfully achieved in an environment where hospital Trusts are legally obliged to charge those who are not eligible for free NHS care [206].

By outlining literature on Zimbabwean migration to the UK, data on the HIV epidemic in the UK, and policies affecting access to healthcare for insecure immigrants, this chapter has contextualised the results chapters that follow. There are potential public health problems associated with restricting access to care for a population that significantly contributes to the UK's HIV epidemic. However, there has been no empirical research on the formulation or implementation of these policies, or on access to health and HIV services for Zimbabweans who are affected by these policies. This thesis responds to that information gap to develop theoretical insights into UK health and immigration policy formulation, implementation, and to offer implications for policy and practice.

2. Chapter 2 – Theoretical Concepts for Exploring Policy Formulation and Access to Healthcare for Individuals with Insecure Immigration Status

2.1 Introduction

The purpose of this chapter is to outline the key theoretical concepts that informed the methods for the policy analysis and qualitative research with Zimbabwean women (outlined in Chapter 3), the analysis of these data (presented in Chapters 4-8), and new theoretical insights regarding the relationships between immigration policy formulation and access to healthcare for individuals with insecure immigration status (Chapter 9).

These theoretical concepts are grounded in the literature described in the previous chapter and offer a specific framework for examining: a) immigration and health policy formulation and implementation, and b) access to healthcare for individuals with insecure immigration status.

The first set of theories presented in this chapter provides an overview of conceptual frameworks used for understanding different stages of the policy formulation and implementation processes, and shows how they can be used in parallel for *analysis* of health and immigration policies. First, Walt's 'Health Policy Triangle' [207, p.113] is presented alongside Leichter's accounting framework [208], before showing how Kingdon's Multiple Streams [209] approach to understanding agenda-setting can be applied within Walt's framework.

The main aim of the second model described in this chapter was to define and distinguish key concepts relating to healthcare access and to propose how these concepts are linked. The second aim of this model was to establish a structure that could be operationalised for qualitative research. It offers concepts and relationships between concepts that were applied to topic guide development (both for the research with Zimbabwean women and, to some extent, key informants).

The models described below form the foundation for the methods and frame and inform the findings of this thesis.

2.2 Theoretical Framework for Policy Analysis

The theoretical framework used for policy analysis in this thesis is informed by multiple theoretical approaches. The data analysis itself was structured by Walt's 'Health Policy Triangle' [207, p.113] and is presented alongside Leichter's accounting framework [208], which provided additional detail. Kingdon's Multiple Streams [209] approach can be applied within Walt's framework, and provides a useful tool for understanding agenda-setting in this highly political policy area.

Models such as the 'Stages Heuristic' have viewed the policy process as linear, divided into separate stages of: agenda-setting; policy-formulation; implementation; and evaluation [210]. Thus the Stages Heuristic separates formulation and implementation from one another in the policy process [211, 212]. However, policy itself is, according to Easton, a network of both formal decisions *and* actions that allocate values, where values are the full range of rewards and sanctions that those "in a position of authority are able to distribute" [213, p.113]. In this view, linear models of the policy process that neglect the interaction of one stage with the others assume a rationality in policy-making that oversimplifies the complexity of policy processes.

Kingdon's 'Multiple Streams' approach to the agenda-setting process provides an overview of the policy process that is fundamentally political and concomitantly irrational [214]. For Kingdon, policy is made through three independent streams: the 'problem stream', the 'politics stream', and the 'policy stream', and policy is only likely to be taken seriously by those in authority when all three streams come together at the same time, creating a brief 'policy window' [215]. This 'coming together', or 'coupling' can be facilitated by a 'policy entrepreneur', who is able to manipulate difficult preferences and 'unclear technologies' [216], although entrepreneurs are not a necessary precondition for the emergence of a policy window. The *problem stream* refers to conditions being defined *as problems*, and the perception that they require government action [213, 217]; the *politics stream* encompasses the flow of political events, including the national mood, administrative change, and advocacy [216, 218]; and the *policy stream* refers to the availability of a possible solution or solutions, where a range of options is explored and narrowed down through a consideration of their technical feasibility and value acceptability [216-218]. This is a systemic approach that views a decision as the outcome of the 'push and pull of several factors' [216].

The 'health policy triangle' [207] highlights the importance of taking into account the content of policy, the processes of policy-making, and the context in which policy-making takes place, as well as emphasising the central role of actors and their power in the policy process (see

Figure 5). Walt acknowledges that the framework provides a simplified account of a highly complex process, but it nevertheless provides a useful structure through which to examine the development of the policies under scrutiny in this thesis, since it emphasises the role of politics in the policy process [217]. Moreover, Sabatier emphasises the need to find some way of simplifying the "staggering complexity" of policy processes, if only to enable analysis and understanding [212, p.4].
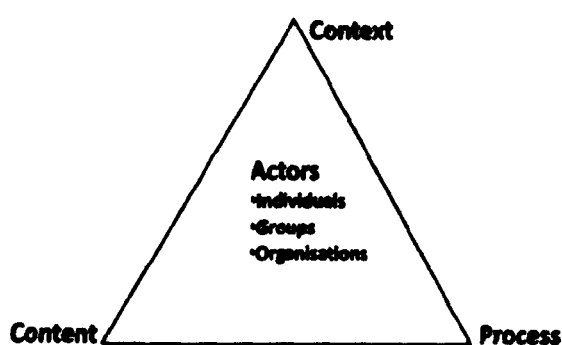
Figure 5 Walt's Policy Analysis Triangle

This framework is grounded in a political economy perspective [219], and though apparently simplistic, emphasises the need to analyse interactions between the four elements of the model: Actors are influenced by the contexts in which they operate; the process of policy-making is affected by actors, their values, and their position in power structures; and context is affected by many factors [217]. Walt's model (Figure 5) provided a framework for the analysis of key informant data in this thesis, and because the emphasis on actors and processes was appropriate both for analysis of formulation and implementation of policy. Lipsky observed that since individuals' direct experiences of government (and therefore of policy) is via those implementing them at the 'frontline' (in his terms, 'street-level bureaucrats'), their actions *are* the policies that they are charged with implementing [220]. Given Easton's emphasis on the importance of *actions* as policy as well as formal decisions, it is appropriate to use one analytic framework that can draw together formal decisions (or formulation) and actions (or implementation).

However, literature on immigration and health policy in the UK implies that context has been particularly important in shaping decision-making and agenda-setting, and so Leichter's 'Accounting Framework' [208] was also used to provide further analytic detail, within the 'context' component of the Policy Analysis Triangle. Leichter organises the factors influencing policy into four domains: situational factors; structural factors; cultural factors; and environmental, or 'external structural' factors [208, 215]. Situational factors are transient or

impermanent conditions or events that have an impact on policy, such as wars or other violent events that bring sudden change: 9/11 and the London bombings in July 2005 can be viewed as such events. Structural factors are relatively intransient elements of society and polity, such as a nation's economic base or political institutions: the legal system in the UK is such a feature, as is its market economy. Cultural factors are the value commitments of groups or society as a whole, and this encompasses both political and general cultural values: perceptions of migrants by the British public can be seen as value driven and cultural. External structural factors are the events and structures that exist outside the boundaries of a given political system, but influence decisions within those boundaries, such as international agreements: the UK's commitments to international development can be seen as emanating from these external structural factors.

The *politics stream* in Kingdon's Multiple Streams approach is affected by the many factors that can contribute to a government's political success or failure, including reshuffles, elections, polls and individual ministers' decisions. Since these are all capable of changing the direction of the national mood [214], it is possible to see how the Multiple Streams approach can be tied to Walt's 'triangular' model, and thus Leichter's accounting framework, through their emphasis on the importance of context for policy development. None of these theoretical approaches views the policy process as linear or rational, and it is this view, of the policy process, as political and irrational, that is adopted in this thesis.

Law & Policy

Immigration
Legislation (Asylum & Immigration Act 2004)
Country-specific asylum policy
Immigration rules (Immigration Act 1971)
Asylum Policy Instructions (APIs)
Consultation Documents

Health
NHS (Charges To Overseas Visitors)
Regulations
Sexual Health Strategy
NHS Frameworks
DoH Policy and Guidance

Consultation Documents
Public Health

Personal Characteristics

Demographics
Age
Gender
Marital Status
Parity
Personal Characteristics
Education
Acculturation
Language
Family size
Religion

Resources

Personal/Family Resources
Immigration Status
Access to public benefits
Income: NASS - cash/vouchers,
none, informal-sector work
Stability of residence
(e.g. dispersal)
Accommodation status (NASS
housed/homeless/friends houses)
Social networks
Stigma

Food availabilty
Competing health/other needs
Self-help skills
Ability to negotiate system
Transportation
Information resources
Community Resources
Residence
Region/Borough
Health services resources
Social services resources
Charitable/NGO services

Access & Use

Health status
Perceived health
Evaluated health
Satisfaction with care
General satisfaction
Interpersonal aspects
Cultural competence
Coordination between
services
Continuity of care
Administrative hassle

Individual's Perceptions & Knowledge

Own Identity
Stigma
Services
Rights
Health Beliefs
Values concerning health/illness
Attitudes towards health services
Knowledge about disease

Service Providers' Knowledge & Attitudes

Knowledge of Policy
Cultural Competence

Health Behaviour

Personal health practices
Self-care
Compliance
Disclosure
Use of health services
Outpatient care/walk-in clinics
Inpatient care
Alternative healthcare

Figure 6 The Contextual Model of Access to Health Services for Populations with Insecure Immigration Status

2.3 The Contextual Model of Access to Health Services for Populations with Insecure Immigration Status

The 'Contextual Model of Access to Health Services for Populations with Insecure Immigration Status' (hereafter the 'Contextual Model'), shown in Figure 6, illustrates the multi-level pathways that affect access and use of health services for populations with insecure immigration status. The research aims and instruments took into account the variables (obstacles and facilitators) identified in the Contextual Model that can either mediate or impede access to services. This model was designed to explore how individual, social and structural factors might interact, and to construct what is a very complex set of relationships. It has been strongly informed by the literature on migration, asylum seeking, health-seeking behaviours, and access to health (see Chapter 1).

The model depicted in Figure 1 was adapted from Andersen's behavioural model of access to health [2], which has previously been modified for use with specific populations. Most saliently, for the purposes of this research, the model has been adapted both for work with vulnerable populations [221], and to test differences in ART access for different groups [222]. The processes operating on Zimbabwean women's lives in the UK, and their access to services are not thought to be linear, and the Contextual Model reflects this better than other behavioural models. In addition, Andersen's behavioural models do not take into account individuals' subjective experiences and perceptions, which, in the Contextual Model, are seen as an important mediator in the pathways to access and use.

'Access' is a concept that is fundamental to this model. The term 'access' as a concept, is meant to include successful utilisation of services, and not mere arrival at the clinic door. In fact, access can be described as "the freedom to use", and should include the "social possibility of use", and the individual's ability to "give direction to one's will to use health services" [223]. In addition, health services should be culturally, as well as medically, appropriate. Therefore, in this thesis, 'use' is viewed as a component of access: linking "access and use" brings together many aspects of both user- and provider-side components of access.

Dominant features of the Contextual Model are the *law and policy* and *resources* dimensions. Variables comprising the *law and policy* dimension include: NHS (Charges to Overseas Visitors) Regulations, immigration policies determining level and type of support (e.g. the Asylum and Immigration Act 2004), and country-specific asylum policy (such as the temporary halt on deportation of Zimbabweans). Much of the literature reviewed above (see Chapter 1) emphasised the obstacles that these policies created for insecure immigrants with healthcare needs, and as such, these features are hypothesised to be the major determinant(s) to access for a population with insecure immigration status. The model considers individual members of

this vulnerable population in the context of a society in which healthcare is in principle available, but not always accessible because of laws and policies (i.e., immigration and health legislation and policy).

Resources

The variables in the *resources* dimension include: income, accommodation, and self-help skills. These are seen to mediate all subsequent components of the model, following Andersen's concept of individual and community resources as enabling or impeding use of health services [2]. As such, they hold sway over all (non-statutory) structural and cultural obstacles and facilitators of access. *Resources* are both individual material and psychological resources (such as self-help skills), and community resources (e.g. social networks).

Resources is the most important component from a policy perspective, because relative to other components in the model, they are highly mutable (unlike, e.g. personal characteristics), and very sensitive to policy change. For example, the community support resources available to HIV-positive individuals are dependent on funding determined by health policy. Moreover, *Resources* are influenced by *Personal Characteristics* and *Law and Policy* and both mediate and are mediated by *Individuals' Perceptions and Knowledge.* For example, having competing health or other needs may affect an individual's values concerning health and illness. Literature suggests that HIV-positive migrants are unlikely to prioritise their health when, for example, housing is also a concern [90]. In this example, *Resources* affect *Perceptions and Knowledge.* Conversely, knowledge about one's entitlements may influence access to public benefits in facilitating an individual gaining financial support. In this example, *Perceptions and Knowledge* led to *Resources.*

Law and Policy

Key to this model is the component representing *Law and Policy*, and it is given greater weight than other components because the relevant population is one which experiences continuous uncertainty about legal status [151, 224]. It highlights the weight given to laws and policies as research variables. In many ways *Law and Policy* can be seen to operate on all components in the model, albeit indirectly. However, *Law and Policy* does have a direct relationship with three components: the model's outcome – *Access and Use, Resources,* and to some extent, *Service Providers' Knowledge and Attitudes* (insofar as, for example, alterations to policy can change a service providers' obligations, work environment etc; in the health sector, service providers may be more directly affected on a daily basis by policy change than laypersons).

Personal Characteristics

Personal Characteristics are relatively static demographic or background characteristics that are unaffected by changes in UK policy change, but do influence access to care, through their impact on *Resources*. For example, an individual's education might influence the extent of their self-help skills; their religion might influence the social networks of which they are a part.

Individuals' Perceptions and Knowledge

Individuals' *Perceptions and Knowledge* are a central component of the framework. They include concepts such as identity and health beliefs, as well as value-systems. It is an important component because it has a strong influence on *Health Behaviour* and a bi-directional relationship with the *Resources* component of the model. The model's feedback loop is mediated by *Perceptions and Knowledge*, since for **access** to have longevity, an individual must be motivated to seek out healthcare. *Perceptions and Knowledge* are affected by *Resources*, but also affect them – some of the *Resources* are personal resources, or can be affected by changes in perception. If, for example, a woman fears stigmatisation, this could affect whether and how she accesses *Resources* by making her fearful of being identified at, e.g. an HIV peer support group. In addition, *Perceptions and Knowledge* act on *Health Behaviour*, i.e. living in a community where HIV-positivity is highly stigmatised (or perceiving one's own HIV-positivity as alienating) is very likely to have an effect on health behaviour [96, 111, 117], and ultimately, on access to and use of services.

Health Behaviour

Health Behaviour is directly influenced by Individuals' *Perceptions and Knowledge*, which can itself, as explained above, be altered by other components in the framework. *Health Behaviour* leads directly to *Access and Use* of health services, and includes personal health practices and use of health services.

Service Providers' Knowledge and Attitudes

Finally, *Service Providers' Knowledge and Attitudes* can act as a facilitator of, or obstacle to, successful access. Physically accessing healthcare is insufficient for successful utilisation, e.g. cultural competence on the part of a service provider can make an important difference in terms of successful use of health services. As mentioned above, service providers' attitudes are likely to be directly influenced by policy in a way that patients' may not be.

Operationalising the Model

The following example offers an illustration of one of the possible pathways (within the framework) mediating access to care. An HIV-positive asylum-seeking woman (*Personal Characteristics*) is living in National Asylum Support Service (NASS) Accommodation, and only

has access to a shared fridge (*Resources*). Even if she has managed to access a clinic and is receiving ART, she has nowhere private to keep her medicines that require refrigeration. She may not want to disclose her status (*Perceptions and Knowledge*), and is therefore unable to remain compliant (*Health Behaviour*). Her use of services has been mediated by a chain of related factors and not directly by policy (as would be the case if she were not entitled to access HIV services). What this example also illustrates is that the framework does not describe a finite process: the fictional woman in the above example has accessed services, and used them, but other issues have impeded her continued compliance. As a result, a feedback loop leading from *Access and Use*, back into the bulk of the framework (via *Individual's Perceptions and Knowledge*), completes the model.

Unlike most other models of healthcare access this framework takes secular change, experience, and the feedback loops that exist in almost any access system into account and it allows the factors that affect health service access to be explored in the context of a wider political and cultural context. It is worth noting that the classic behavioural model has usually been used to describe access to health quantitatively, and to examine empirically the best predictors of service use. This model served as a framework for qualitative, case-oriented research to explore iteratively HIV-care obstacles and facilitators, and informed the development of the research tools used in this study.

3. Research Questions and Methods

3.1 Introduction

This chapter describes the methods used for the two components of research in this thesis: the policy analysis and the qualitative research with HIV-positive Zimbabwean women. Two methodological approaches were adopted for the policy analysis: unstructured interviews with key informants; and document analysis. The methods used in the qualitative research with Zimbabwean women were based on semi-structured interviews. A qualitative approach was selected to achieve an in-depth understanding of the formulation of a particular set of policies, and the perspectives and experiences of individuals affected by those policies. Qualitative research can offer policy analysis a "theory of social action grounded on the experiences of those likely to be affected by... policy" [Walker, in 225, p.174].

These three strategies for data collection (document analysis, unstructured interviews with key informants, and semi-structured interviews with Zimbabwean women) allowed for data 'triangulation', where using more than one method for data collection, and diverse sources of data, improves validity by making it possible to offset the weaknesses of one method alone. Green & Thorogood point out that the use of triangulation to improve validity in qualitative research need not imply improved accuracy from a positivist perspective, but rather improved *understanding* of a particular phenomenon [226]. Moreover, this research also relied on theoretical triangulation, where multiple conceptual approaches are adopted in order that a range of theories and models inform data analysis.

3.2 Epistemological Position

Blaikie has critically reviewed a wide range of "paradigmatic disputes" [227, p.1] within the philosophy of science and considered their relevance for the social sciences. He suggests that key questions have emerged that force social scientists to consider what kind of science *social science* is, whether the methods of the natural sciences can be used for the social sciences and whether knowledge of 'reality' can be obtained. Like other authors [226, 228], he questions the applicability of methods emerging from the positivist natural sciences to social sciences. Positivism proposes that there is an objective (natural and social) reality 'out there', and that there are 'right' and 'wrong' explanations for phenomena [226]; perspectives such as interpretivism or social constructionism question the assumption that objective reality can be independently established [227], and point out the unpredictability and complexity of human behaviour as phenomena that cannot be explored using methods derived from the natural sciences.

This study is informed by a critical realist epistemological perspective which asserts that there are social and natural phenomena that exist as structures or relations behind the surface of social reality, and that these can be studied using methods that share principles with the natural sciences. However, the qualitative difference in subject matter between the natural and social sciences (for example, human structures and relations change more readily than those in the 'natural' world) means that exact procedures for enquiry will differ [227]. Critical realism acknowledges the interpretative view that our understanding of social reality is limited, but posits that it *can* be understood through the social sciences [228]. Therefore, the role of social science is to explore and explain observable phenomena, but also to acknowledge the difference between the *empirical*, the *actual* and the *real* 'social worlds' [229]. According to this perspective, the empirical domain relates to observable experience, the actual domain relates to experiences and events whether or not they are observed, and the real domain consists of experiences, events, and the deep underlying mechanisms which produce these events.

This thesis uses empirical data to generate theoretical insights and build 'models' of structures and mechanisms which, if they did exist in the 'actual' and 'real' domains and operated in the theorised way, would account for the phenomena being examined. Critical realism is *critical* because acknowledging underlying mechanisms offers the possibility of changing the status quo [228]. Furthermore, because the social sciences have a subject-subject relationship with their subject matter (i.e. their subjects have agency) [227], theoretical insights emerge from 'lay' interpretations of actual and real events while social scientific concepts also inform and reproduce these interpretations of the 'real' world (Giddens' 'double hermeneutic [230]), and

thus social scientists must also be *critically* reflexive of themselves as components in the research process.

3.3 Policy Analysis Methods

3.3.1 Aims and research questions

The policy analysis research aimed to describe the history of and changes within UK immigration and health policies for insecure immigrants under the Labour government (1997-2009), with special focus on HIV; to document why and how policies that may restrict access to healthcare for individuals with insecure immigration status had been developed; to explore the experiences of those professionals required to implement them; and to discuss implications for future UK immigration and health policy-making. The research questions informing data collection were:

- *Why and how were policies developed that might restrict access to healthcare for individuals with insecure immigration status?*

- *What are the experiences of clinicians and managers required to implement the Charging Regulations?*

3.3.2 Sampling

a   Recruitment of Key Informants

It has been noted that where access to the motivations for policy formulation are not thought to be overtly available in policy documents, or aspects of implementation phenomena have not been officially documented, 'elite interviewing' is an appropriate method for accessing these data [226]. For this study, key informants were initially identified through the UK literature (advocacy and oppositional) on access to health services for insecure immigrant populations. Where organisations, rather than particular individuals were mentioned, I contacted the organisation's policy officer. These individuals were approached (usually by email) to ascertain whether they were interested in taking part in the study. Subsequent actors were identified using snowball sampling[41]. Thus, at the conclusion of each interview, actors were asked to identify other actors in the field whom they considered influential/engaged with the research topic. In order to avoid biasing the research by only interviewing those actors who were 'networked' with one another in a domain thought to be highly partisan, theoretical sampling was also used in parallel. When participants were asked to identify other actors, it was emphasised that they should consider recommending individuals or organisations with whom they had disagreed, or that they knew to hold divergent opinions, as well as actors with whom they had good working relationships. These individuals were subsequently contacted and approached for participation in the research.

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[41] Snowball sampling entails identifying a small group of individuals who are relevant to the research topic, and then using them to establish subsequent contacts with other relevant participants [231].

b   Identification of Documents

This research was able to sample the total 'universe' of publicly available Government policy documents pertaining to immigration and health policy-making in the period 1997-2009, as well as drawing on relevant documents that focused solely on either immigration or health for context. Documents included were: all 'health and immigration' policy consultation documents; consultation summaries and responses; all primary immigration legislation and accompanying white papers in the period; parliamentary reports and hearings on healthcare access, human rights or immigration, and government responses, where available; transcripts from Strasbourg and UK court cases, as they pertained to the confluence of immigration and health; and DH and HO policy directives, where available (for a full list, Appendix 3).

I also attempted to gain internal government documents relating to the policy process for the 2004 amendment by making a Freedom of Information (FOI) request under the Freedom of Information Act (FOIA) 2000. This has been partially successful, and is ongoing. For more detail, see Appendices 4-8.

3.3.3   Data Collection

I conducted unstructured interviews with 24 key informants during 2007-2009. Although a loose topic guide (see Appendix 10.9 for breakdown of key informants and Appendix 10.10 for the topic guide) was prepared to act as an *aide memoire* and facilitate some consistency between interviews [231], it was not appropriate to use a semi-structured approach since different key informants had substantially different areas of expertise or interest. Further, unstructured interviews are a more appropriate tool when the aim is to elicit respondents' views and priorities [232]. The topic guides were covered in a flexible way in order to allow individuals' views, experiences, beliefs and accounts of their actions to emerge in their own words and so as not to lose part of 'their story' [226]. The unstructured approach also enabled respondents' values to emerge from their accounts [231], a feature considered important as a result of the theoretical approach to this research (see Section 3.2). The loose topic guide was based on the literature and theoretical frameworks described in Chapters 1 and 2. I pilot-tested the topic guide on two clinicians before conducting the research, and found that it had initially assumed a particular level of knowledge about policy on entitlements to care; since I was interested in respondents' knowledge of policy (following the theoretical frameworks), as well as perceptions and attitudes, I amended the topic guide so that this assumption did not remain.

3.3.4   Interviews

Interviews took between 30 minutes and 1.5 hours. Interviews were carried out at the respondents' place of work or another convenient location such as a café, according to their

personal preference. I carried out all interviews myself. Prior to initiating the main focus of the interview, I obtained informed consent from participants. I then asked a series of introductory questions relating to the participant's work and professional history as it related to the subject matter for the interview, including the remit of their organisation and client group, and how much direct or indirect experience they had of the Charging Regulations. I then introduced key topics from the topic guide. Participants responded in their own words and I intervened to clarify what was said if necessary, or to prompt if I wished the respondent to pursue a particular theme.

The interviews were recorded with permission using an Olympus DS-50 digital recorder, and interviews were transcribed as soon as possible following the interview to facilitate an iterative approach to the research. Where rapid transcription was not possible, I was able to rely on field notes to guide further topic guide development and theoretical sampling. The interviews were transcribed verbatim. All information related to the individual's identity was removed from transcriptions to preserve anonymity.

3.3.5 Data Analysis

In keeping with a critical realist epistemology, the data were analysed using an interpretative approach to studying the meaning of phenomena [226]. In this approach, the researcher draws on the concepts and meanings used by 'social actors' in the analysis of the data, and to build theory. This hermeneutic approach was applied to documents, as well as to interview transcripts, since it allows an "understanding in context" to emerge [228, p.395], and because policy documents, like interview transcripts, also cannot be viewed as depictions of reality. All data were transcribed in full, read and re-read. Data collection and analysis was an iterative process [228].

The policy documents and transcripts from the key informant interviews were coded using NVivo (Version 8) to a loose framework informed by Walt's Policy Analysis Triangle [207] (i.e. context, processes, actors) and within the 'context' component of this structure, Leichter's Accounting Framework [208] was used for further elaboration and detail.

However, beyond this loose structure, data collected early in the research were coded openly and the approach borrowed from the constant comparative method insofar as the data were initially 'fractured' cross-sectionally into categories (rather than line-by-line codes, since the data for policy analysis were being used to understand a specific set of processes and phenomena rather than individuals' 'lived experiences'). These categories were compared across transcripts, and to facilitate theory-building, 'memos' were also used to record initial hypotheses and any relationships between the themes emerging from transcripts and

documentary data sources [233] (see Figure 7 for an example of the themes that emerged from coding).
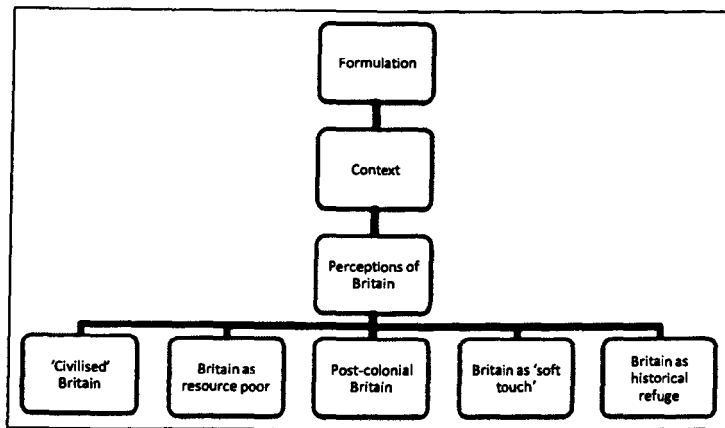
Figure 7 Example tree node hierarchy - policy analysis

Topic guides for later interviews were guided by the themes that emerged in earlier analyses, and these also informed the theoretical sampling by helping to identify gaps in the emerging thematic framework and achieve thematic saturation [226]. Subsequent analysis interrogated the categories and fractured data for their underlying meaning and relationships between categories, and can be likened to Strauss & Corbin's 'axial coding' [234]. Finally, all transcripts were checked to ensure that all the early categories were now incorporated under the themes that had emerged. As a result, the theories and concepts developed were inductive and grounded in the data [231].

3.4 Methods for Qualitative Research with Zimbabwean HIV-positive Women

3.4.1 Aims and research questions

The qualitative research aimed to: explore the experiences of Zimbabwean women as affected by these current immigration and health policies (i.e. the Charging Regulations); describe the obstacles and facilitators to access to HIV services for Zimbabwean women with insecure immigration status in the UK; and to discuss the effects of these policies on women's health. The research questions informing data collection were:

- *How are Zimbabwean HIV-positive women's healthcare access experiences affected by policies designed to restrict healthcare access for insecure immigrants?*

- *What are the effects of current immigration and health policies on Zimbabwean HIV-positive women's health and wellbeing?*

- *What are the other obstacles and facilitators to access to HIV care for Zimbabwean women with insecure immigration status?*

3.4.2 Sampling

HIV-positive Zimbabwean women with insecure immigration status were sampled opportunistically and theoretically and were identified through a Zimbabwean women's community organisation based in Isleworth, West London.

Inclusion criteria were that: participants should be documented to have been HIV-positive for at least six months; to have been born and spent the greater part of their lives in Zimbabwe; to have an *insecure* immigration status (i.e. are asylum-applicants or unauthorised migrants) and have not been given refugee status; to be willing to take part in the study; to be able to give informed consent to participate; to be over 18 years of age; and to be English-speaking. A staff member at the organisation acted as a gatekeeper for recruitment and identified women who met the inclusion criteria. Although sampling was largely opportunistic given the difficulty with identifying individuals from this 'hard-to-find' population [235], some theoretical sampling was possible and the community gatekeeper helped to identify potential respondents that 'fitted' particular theoretical sampling criteria[42].

The aim was also to recruit women through a GUM clinic in East London in order to be able to compare the experiences of those who were definitely receiving HIV care with those who

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[42] For example, early coding revealed that the data did not represent the experiences of individuals who had lived in the UK 'illegally'. As a result of identifying this gap in the data, a woman was recruited who was living in the UK 'illegally' in order to compare her experiences with those who had made an asylum claim. Women identified by the gatekeeper were first contacted by her, and she informed them of the study. If they expressed an interest in participating, they contacted me on a mobile phone that was reserved for this purpose, and we arranged to meet.

might not be. A relationship was established with the clinic and research protocols and ethics approval were developed, but recruitment in this context was not fruitful (for a detailed discussion of this, see Chapter 9).

All participants were provided with a study information sheet prior to recruitment, and were formally consented to participate only if they were happy with the details of the research. The voluntary nature of participation was strongly emphasised.

3.4.3   Data collection

Data were collected from 13 HIV-positive Zimbabwean women with insecure immigration status during 2007-2008 through in-depth semi-structured interviews. The semi-structured approach was used in this component of the research in order to facilitate consistency between interviews [231] and cross-case comparison. However, topic guides (see Appendix 11) employed open-ended questions to produce in-depth and valid responses, and prompts and probes were used if necessary to encourage respondents to expand on what they had said and to seek clarification. Topic guides were initially informed by the Contextual Model (see Section 2.3), and reflected the structure and components of that model. For example, women were asked questions relating to their healthcare access experiences, their perceptions and knowledge (of, e.g. policy or the mechanisms of HIV), and the resources available to them. The topic guides were approached flexibly and the order of questions was determined by the priorities of the respondent. In this way, individuals' experiences, beliefs and accounts of their actions emerged in their own words and preserved 'their story' [226]. There was no opportunity to pilot the questionnaire because of the limited and hard-to-find nature of respondents, but given the iterative approach to data collection and research tools, any problems identified with the topic guide were quickly corrected.

3.4.4   Interviews

In-depth interviews took between 45 minutes and 2 hours. Interviews were carried out either at the Zimbabwean women's community organisation in West London (in a private office), or in a Central London location (in a room at a sexual health clinic), according to the respondent's preference. I carried out all interviews myself. Prior to initiating the interview, I established that participants had read and were happy with the study information sheet, before obtaining their consent to participate in the study. Prior to initiating the main focus of the interview, I asked a series of introductory questions to establish some basic demographic and background data as well as ensure that the interview began with relatively 'neutral' material [231]. This helped to build rapport and facilitated a more spontaneous interview [226]. I then introduced key topics from the topic guide. Participants responded in their own words and I intervened to

clarify what was said if necessary, or to prompt if I wished the respondent to pursue a particular theme.

Interviews were recorded and transcribed as reported for key informants, above.

3.4.5 Data Analysis

Like the key informant and document data, data from the in-depth interviews with Zimbabwean women were analysed using an interpretative approach to studying the meaning of phenomena [226]. This approach focuses on the social construction of meaning, with a view to understanding the interpretations people make of their beliefs and actions [236] and the implicit meaning in individuals' accounts.

Data were again coded using NVivo 8, and were 'fractured' across transcripts. However, because the research questions for this study component were more concerned with individual experiences and less with professional perceptions of external forces on the policy process, the coding strategy did not rely on any initial framework, but rather began with line-by-line coding in order to capture nuances in the data and in respondents' accounts of their experiences, as well as to avoid making assumptions about processes [234]. Three transcripts were coded at this level of detail in order to identify initial patterns and to enable the development of more focused codes through constant comparison of data with data, both within and across transcripts. This process entails emphasising the most common codes and those that are seen as most revealing about the data and grouping topics into larger conceptual categories with the aim of achieving full representation of the range of participants' views [234]. Subsequent transcripts were coded using these more focused codes.

These focused codes informed subsequent data collection (through sampling and the research tool) and analysis, and were developed into categories through which relationships between phenomena could be explored. Although a formal axial coding strategy according to Strauss & Corbin's scheme [233] was not used, I did develop subcategories of categories and explore the relationships between them. Constant comparison also meant checking and re-checking these more theoretical categories against the early open codes I had developed to ensure that these emergent theories were grounded in the data and therefore in women's accounts of their experiences. Again, the process concluded by checking all transcripts 'vertically' and ensuring that all data were accounted for, and that all the open codes derived from 'fracturing' the data were now incorporated into emergent themes, and that both data and thematic saturation had been achieved [231].

3.5   Ethics

All Zimbabwean women and key informants who participated were provided with study information sheets, in order that they could give fully informed consent before taking part (see Appendices 12 and 13 for Study Information Sheet and Consent Forms). The voluntary nature of participation was repeatedly emphasised, and participants were made aware that they could terminate the interview at any point and for any reason.

Participants were given the opportunity to decline being recorded by digital Dictaphone, without the interview being terminated. No one declined recording. If a participant had declined to be recorded, detailed notes would have been taken instead. All the data collected were anonymised. Key informants are referred to by a general label for their role/job (e.g. 'HIV clinician 1'; 'Civil Servant 3'). Data have been stored securely, and only the principle researcher had access to the locked filing cabinet/computer in which audio files, transcripts, and consent forms were stored. In addition, some of the data presented have been edited/redacted, in order to preserve anonymity/confidentiality (e.g. by removing names or other identifying characteristics).

Risk of harm to participants' physical health as a result of a medical intervention was not a concern for this study, as participants were not subject to any health interventions. However, Zimbabwean women might be construed as a vulnerable population, and it was possible that participants could experience psychological trauma on discussing certain personal issues. During the interview process I was observant to any upset caused, and was prepared to pause/reschedule/terminate the interview, as necessary. Emotional support for women who needed it following the interview was available through the community organisation used for their recruitment.

This study gained approval from the LSHTM ethics committee, and the NHS (East London and the City) Research Ethics Committee.

1998
- July - *Fairer, Faster and Firmer* is published

1999
- November - *Immigration and Asylum Act 1999* receives royal assent

2001
- September - the Twin Towers are attacked

2002
- **January - Zimbabwe deportations halted in response to Operation Murambatsvina**
- February - *Secure Borders, Safe Haven* is published
- November - *Nationality, Immigration and Asylum Act 2002* receives royal assent

2003
- July - *'Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: A Consultation'* is published
- December - *'Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: A Consultation'* Consultation outcome published

2004
- April - Secondary care amendment made to NHS (Charges to Overseas Visitors) Regulations 1989
- April - *Implementing the Overseas Visitors Hospital Charging Regulations – Guidance for NHS Trust Hospitals in England* is published
- May 1st - A8 Accession
- May - *'Proposals to Exclude Overseas Visitors from Eligibility to Free NHS Primary Medical Services'* is published
- July - *Asylum and Immigration Act 2004* receives royal assent
- **November - Zimbabwe deportations resume following increase in applications**

2005
- February - *Controlling our borders: Making migration work for Britain* is published
- May - *Case of N* heard in the House of Lords
- July - London bombings
- **October - Zimbabwe deportations halted following AIT ruling in Case of AA**

2006
- March - *Immigration, Asylum and Nationality Act* receives royal assent
- **August - Zimbabwe deportations allowed following AIT review of Case of AA**
- September - John Reid makes *'I stand with the public'* speech to Labour Party Conference

2007
- March - *Enforcing the Rules* is published March 2007 Zimbabwe deportations halted as Case of AA re-heard
- **May - Zimbabwe deportations - AA's test case dropped by AIT in favour of 'HS' test case**
- October - *UK Borders Act 2007* receives royal assent
- **November - Zimbabwe deportations allowed as Home Office wins in Case of HS**

2008
- April - Justice Mittings rules that the NHS Guidance *'Implementing the Overseas Visitors Charging Regulations'* is unlawful
- **June - Zimbabwe deportations HS appeals against earlier loss at AIT**
- May - N's case heard in the Strasbourg courts
- May - *Criminal Justice and Immigration Act 2008* receives royal assent
- **October - Zimbabwe deportations - UKBA undertakes not to resume returns until case HS resolved**
- **October - Zimbabwe deportations - AIT significantly broadens scope of previous rulings that Zimbabwe is not safe for returned asylum applicants**

2009
- March - Mittings judgment overturned at Court of Appeal

Figure 8 Policy and Immigration-related events timeline

4. Chapter 4 - Policy formulation – access to healthcare for individuals with insecure immigration status in the UK

Figure 9 - The Main Determinants of Health
Source: [1]

4.1 Introduction

This chapter explores the motivations and approaches of the UK Government in developing policies that may restrict access to healthcare for individuals with insecure immigration status. In addition, it attempts to illustrate the role of non-governmental actors and processes in the development of policy. Data for this chapter are derived from both document analysis and from qualitative interviews designed to ascertain the perspectives of key informants on why and how these policies were formulated. Sectors represented by the qualitative interviews are: Home Office and Department of Health civil servants; Conservative and Labour Ministers; Clinicians; Non-clinical hospital staff; HIV and Migration non-governmental organisations (NGOs); Lawyers, academics and the media; and 'resource-protection' oriented thinktanks. Their interpretation of policy can be viewed as broadly split between being resource-protective and humanitarian.

The chapter utilises Walt's 'policy triangle' of actors, context, and power [207] as a framework for analysis. Thus the first section examines the motivations for policy within Leichtner's 'accounting scheme', which suggests examining decisions within a **context** encompassing situational, structural, cultural and external structural categories [208]. The second section discusses the **processes** associated with immigration and health policy-making through an examination of the actors (and their influence) involved in the policy process, before considering the ways in which the specific policies attended to here fit within broader immigration strategies.

4.1.1 Defining policy

Policy is itself a contested term, and it is therefore defined here as:

"A series of more or less related activities and their intended and unintended consequences, for those concerned" [215].

This definition therefore encompasses both the broad strategies and the minutiae of policy as it is enacted in primary and secondary legislation.

Specifically, this research examines:

- the Charging Regulations; and
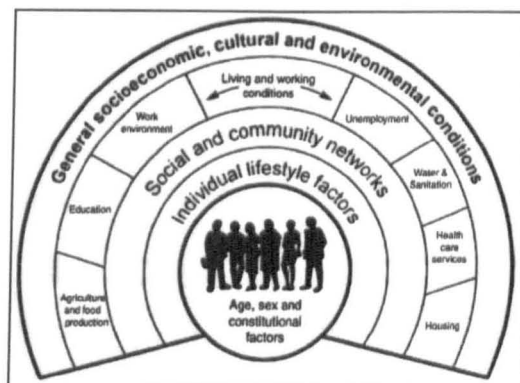
- the primary care proposals.

It is my contention that these policy changes were constructed within a broader immigration policy agenda, and with that in mind I will discuss other aspects of immigration law and policy as they relate to the specific focus of this research (access to healthcare).

Furthermore, since access to healthcare has been defined, for the purpose of this thesis, as the successful use of services, as well as mere arrival at the clinic doors (see p. 53), other aspects of engagement with the immigration system (including its deliberate avoidance e.g. unauthorised immigration) are considered to have a bearing on access to healthcare for this group as distal social determinants of health (see Figure 9). It is in this sense that both the 'intended' and 'unintended' consequences of policy activities are pertinent to access to healthcare for insecure immigrants.

In this thesis, the state is defined (following Walt, 1994) as the institutions of which it is comprised, and the functions that those institutions perform. In the UK context therefore, the relevant institutions are parliament, ministries/departments of state (including local authorities), courts of law, law enforcement agencies, and the armed forces. Their functions include providing services, raising revenue, and making and keeping law and order.

4.1.2 Contested Aims

The 2004 amendment inserted the word 'lawfully' into the 1989 Charging Regulations, making charge-free healthcare conditional upon proof of residence. Inconsistent accounts provided by government departments as well as disagreement between government departments and third sector actors mean that the intended aim of the 2004 amendment has been disputed. Therefore a brief exploration of different actors' perspectives of the intended outcome of this change to policy will precede an analysis of the motivation for the change.

Documents published by the Government have provided differing accounts of the initial aim of the legislative change. The original DH Consultation document stated that the amendment aimed to close legal 'loopholes', and deny access to NHS services for those not entitled:

> *This amendment will close a loophole in the Regulations which has caused significant difficulties for the NHS. It will help to ensure that only those who are genuinely entitled to free NHS treatment will receive it... more important it will ensure that money provided by UK tax payers for the NHS is not diverted to healthcare for those who are not resident in the UK.*
>
> *Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: A consultation* [174]

The argument that the amendment was designed to clarify the original intentions of the Charging Regulations and prevent use of NHS resources by those not entitled to them was

repeated in a number of key documents and by a DH civil servant interviewed for this research. This line of reasoning was commonly framed within a resource-protection approach to policy-making.

However, other government documents have implied that resource-protection was not necessarily a key aim of the 2004 amendment. The House of Commons Health Committee expressed concerns that the 2004 amendment could have implications for public health, and for the costs associated with the onward transmission of HIV. In response, the Secretary of State for health stated that preventing the use of the NHS by those not entitled was an important principle in itself, irrespective of the financial implications:

> *The key issue is that the Government must fulfil its responsibility to preserve the NHS for those who are entitled to use it free of charge by reducing the opportunities for abuse to a minimum, irrespective of the actual cost of that abuse.*
>
> **Government response to the Health Select Committee's Third Report of Session 2004– 2005 on New Developments in Sexual Health and HIV/AIDS Policy [237]**

There also seems to have been a lack of clarity regarding which groups were being targeted by the amendment. The original 2003 consultation emphasised refused asylum-applicants as a key population for whom access to healthcare needed to be restricted:

> *In summary, the proposals that will require changes to the Regulations aim to stop the following abuses:*
>
> o *free hospital care for failed asylum seekers (i.e. those whose applications and any subsequent appeals have been finally rejected) and others with no legal right to be in the country.*
>
> **Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: A consultation [174, emphasis added]**

However subsequent evidence suggests that the Department of Health has since attempted to distance itself from deliberately targeting refused asylum-applicants in the Charging Regulations. A letter sent to one key informant by the Chief Medical Officer (CMO), Liam Donaldson, indicated that refused asylum-applicants were not a target of policies designed to restrict access to healthcare:

> *I would like to reassure you that at no point does* Enforcing the Rules *propose to restrict access to healthcare to refused asylum seekers.*
>
> **Letter sent to key informant GP and Migrant Advocate – dated March 2008**

The key informant who was sent this letter saw the CMO's comment above as a "failed memory" that neglected to recognise the deliberate inclusion of refused asylum-applicants in earlier policies.

This lack of clarity in official statements and actions regarding the intentions behind the 2004 amendment may have contributed to key informants' assessments of the intention behind the 2004 changes, since very few reported that they perceived the 'closing down of loopholes' or resource-protection as the primary aim of the legislative changes. A number of respondents (representing the media, migration and HIV NGOs, and non-clinical hospital staff) felt that the 2004 amendment was part of a larger programme of a chimera of stringency; that the amendments allowed the Government to bolster itself against critical reports in the mainstream press, without having to take real action:

> *The last thing they want to be seeing is sort of headlines saying, "And Now We've Got to Pay to Give All Asylum Seekers State-of-the-Art Cancer Treatment" or something. But if they can just quietly make a policy change which means that you're not going to get those sorts of negative headlines, they don't need to then stand up and actually use it in a very PR driven way because you can see how that's going to react against them.*

Home Affairs Editor, National Broadsheet, Key Informant Interview, April 2008

Other key informants expressed that the amendments were part of a concrete immigration strategy (rather than simply being designed to give the illusion of restriction), but that they contributed towards an approach that allowed the Government to shift its immigration focus from border control, to a strategy of internal control. However, this move towards internal controls was not perceived as entirely dissimilar to the media-focused intention described above, in that it was seen as part of a politically defensive strategy by the Government. In this key informant's view, it enabled action to be taken on immigration whilst simultaneously allowing the Government to protect itself against policy failure:

> *It's a way of acting on immigration without actually having to do very much because ...well, you can change the regulations but ... implementation sort of moves away from the Government at that point ... if it fails it's the Department of Health that's failed or it's whoever. So it's arms length, and it's much easier to change the regulations for the Department of Health on NHS access than it is to, for instance, change the way that we manage the borders at airports.*

Migrant Health NGO Coordinator, Key Informant Interview, February 2008

Many key informants, across the sectors represented in this research (but whose perspectives on the Charging Regulations were broadly informed by a humanitarian outlook) thought the 2004 amendments represented a politically defensive strategy on the part of Government because, in their view, the alterations to the Charging Regulations had not been informed by an evidence-based approach to policy-making. One key informant reported the belief that there had been "absolutely no consideration for public health... there was no health impact assessment, there was no equalities impact assessment,

nothing. It was a knee-jerk reaction to look tough on immigration[43]." The next section explores evidence in immigration policy-making in more detail.

4.1.3 Evidence-based Policy-making & Health Tourism

The New Labour Government demonstrated a clear commitment to evidence-based policy-making soon after assuming office in 1997. The *Modernising Government* White Paper (1999), which aimed to set out "a programme of reform for the future" [238, Introduction], stated that "government must be willing constantly to re-evaluate what it is doing so as to produce policies that really deal with problems; that are forward-looking and shaped by the evidence rather than a response to short-term pressures" [238, Chapter 2]. A Cabinet Office follow-up of *Modernising Government, "Professional Policy-making For The Twenty First Century"* describes as 'core competencies' policy-making that is "based upon the best available evidence from a wide range of sources" [239]. Indeed, a subsequent survey of policy-makers carried out by the Cabinet Office's Centre for Management and Policy Studies found that across a number of Departments, policy-makers were working to ensure that policy decisions were evidence-based [240].

This commitment to evidence-based polices extended into the health sphere, with a commitment to "setting priorities for future research to improve the evidence base of good practice in sexual health and HIV" in the Department of Health's 2001 *National Strategy for Sexual Health and HIV* [241].

Evidence-based policy-making has been characterised as differing from "opinion-based policy... which relies heavily on the selective use of evidence... or on the untested views of individuals or groups" [242]. Academic, legal, clinical, and NGO key informants interviewed for this research expressed the view that immigration policy in particular was not informed by evidence. One respondent added that in the absence of evidence it was hard to know what might have driven policy-making:

> *There's certainly no evidence base for a lot of what's carried out in the name of immigration policy. So one presumes that it's in response to something else.*

Migrant Health NGO Coordinator, Key Informant Interview, February 2008

It may be that this perception, that immigration constitutes a uniquely evidence-bereft policy area, has been in part informed by statements made by Home Office ministers. In a 2008 hearing of the Joint Committee on Human Rights (JCHR), Liam Byrne, the then UK immigration minister said that he did not always rely on an evidence-based approach to policy-making, but would rely on his own opinion to come to policy conclusions:

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[43] HIV Charity Head of Policy, January 2008

Dr Harris: You said very clearly in answer to that question that you thought that allowing asylum-applicants to work would lead to an increase in abusive claims. What evidence do you have that you can show us in the public domain that that is the case?

Mr Byrne: Well, I arrived at that decision myself on the basis of logic. I think that when you have got a situation where people are able to increase their income so substantially by moving from a low income to a high-income country where we create opportunities to work and participate in the labour market, then human nature is that those opportunities will be thoroughly explored. I just think that is a perfectly logical conclusion to draw.

Uncorrected oral evidence - Immigration and Human Rights [243]

This intuitive approach to problem definition in policy-making may also have influenced the 2004 amendment. Much Government documentation cites 'health tourism' as a reason for the amendment [157, 181], yet many NGO and clinical key informants (who were predominantly 'humanitarian' in their interpretation of policy) felt that evidence of this phenomenon had not been adequately demonstrated:

> *Asylum was a major political issue and one of the weaknesses was a perception of health tourism. That was applied to all immigrants; it was based on zero evidence. If anything, the evidence shows the other way, that there is very little health tourism, if any.*

Migration Policy Analyst, Key Informant Interview, November 2007

Parliamentary groups such as the Health Select Committee have also articulated dissatisfaction with the evidence provided by the Government used to demonstrate the phenomenon of health tourism:

> *Although we have received assurances from the Government that abuse of the NHS by 'health tourists' does take place, it is difficult to place much weight on these assurances since the Government was unable to supply us with any data, not even a rough estimate, of the numbers of people allegedly 'abusing' the NHS, nor of the costs that are associated with this.*

New Developments in Sexual Health and HIV/AIDS Policy [179]

However, it may be that the quarrel between government on the one hand, and advocates for immigrants on the other, that is hinted at by the above two extracts stems less from a complete absence of evidence than from a disagreement as to what it is that *constitutes* reliable evidence. In response to criticisms from the Health Select Committee regarding the lack of evidence for health tourism, the Government stated that it had relied on evidence of a different nature than that requested by the Committee, but that it considered this robust:

> *It is impossible to provide the sort of definitive statistics the Select Committee would apparently like to see, the Government does not accept the argument that this means there is no evidence that abuse of the NHS is taking place. The Committee has apparently placed considerable weight on the examples provided by the Terrence Higgins Trust (THT) and National AIDS Trust (NAT) in their evidence. In the same way... the*

> *Government has placed similar weight on the many, many examples given to it by Overseas Visitors Managers of overseas visitors who approach the NHS every day seeking to abuse its services.*

Government response to the Health Select Committee's Third Report of Session 2004–2005 on New Developments in Sexual Health and HIV/AIDS Policy [237]

And there is a further question around interpretation of the evidence available, as well as a dispute over its existence. For example, government research was used to demonstrate the existence of health tourism in the strategy paper *Enforcing the Rules:*

> *There is evidence of small-scale but very deliberate abuse of the NHS. For example, a sampling exercise last year at one airport suggested that health tourists were being detected at the rate of about 15 per month. This primarily involved heavily pregnant women arriving in the UK with an intention of using NHS maternity services.*

Enforcing the rules - A strategy to ensure and enforce compliance with our Immigration laws [157]

This extract suggests that for government, this was sufficient data to attest to the fact of health tourism and abuse of the NHS. However, the same data were referred to by one of the key informants interviewed for this research. The validity of the evidence was questioned, but was also interpreted as proof that health tourism was *not* an issue of concern:

> *And there's no... pretence anymore that actually health tourism is a big issue. I mean, even Enforcing the Rules, they're talking about 15 women a month coming in. Now how they know when they come in that they're health tourists....presumably that's 15 pregnant women a month who are visiting during the period when they would be expected to deliver, but you know, they could be joining partners, they could be...nobody knows. But that's as close as they've come to any data on... health tourism.*

Migrant Health NGO Coordinator, Key Informant Interview, February 2008

A thorough exploration of what it is that constitutes evidence is outside the scope of this research (see Davies 2004 for an overview). However what is clear is that fundamental aspects of the policy process in this instance (including whether and to what extent policy should be evidence-based, what constitutes evidence, and whether the problematised phenomenon – health tourism – even exists[44]) have been interpreted in wildly divergent ways by different actors. It is this difference of opinion at these primary procedural stages that demands a further examination of why and how this policy was developed through an exploration of the context, actors, and processes contributing to policy development in the health and immigration fields.

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[44] It is worth pointing out that this thesis does not intend to examine in detail whether health tourism is or is not a widespread phenomenon – the focus here is on the nature and interpretation of evidence in policy-making.

4.2 UK Immigration and Health Access Policies – Motivations

4.2.1 Situational Factors

a   Growth in Asylum Applications

New Labour came to office in 1997, when asylum applications had grown to over 32,000 from around 4,000 a year in 1988. There was a severe backlog in the asylum system at that time[45], which increased to a peak of over 100,000 [132]. As discussed in Section 1.4.1, trends in asylum application have also changed considerably in terms of the origin of applicants[46].

There is a clear perception from the New Labour administration that the system that they inherited was not fit for purpose[47] given the changing pattern of global migration at the time that they took office, and that this has had repercussions for all three Labour administrations since 1997:

> *Global migration has doubled since the 1960s, the number of asylum-applicants claiming asylum in Britain experienced a dramatic increase in the mid to late 1990s, and the systems that the Government inherited were antiquated, frankly, so I think what the IND[48] has been trying to do is not only deal with the surge in cases that were experienced in the 1990s but also rebuild a different system.*

Liam Byrne, Uncorrected oral evidence - Immigration and Human Rights hearing [243]

This sentiment that immigration was getting out of control was reflected by one interviewee, a Home Office civil servant:

> *As we saw it in the late nineties, the numbers just went absolutely mad. We weren't managing immigration anymore; immigration was taking over and managing us. It's got to be something that governments control.*

Home Office civil servant, Key Informant Interview, November 2007

Both the HO civil servant and Minister quoted here were concerned about the levels of immigration in the late 1990s and early part of the next decade, and both expressed the opinion that management of immigration was what had been missing; that the Government had to gain control over a phenomenon that at the time was threatening to overwhelm the system.

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[45] There were "50,000 cases awaiting decision and over 20,000 queuing for an appeal hearing" [131].

[46] The numbers of applicants from Europe and sub-Saharan Africa were approximately equal in 1997 (9-10,000 applicants each). By 2002 applications from individuals of sub-Saharan origin had climbed to a peak of more than 29,000, while in the same year applications from Europeans numbered little over 13,000 [26].

[47] It is interesting to note that immigration minister Liam Byrne placed responsibility for the growing number of applications with the outgoing administration, yet a minister from the Conservative Party interviewed for this research characterised the problem as one belonging to New Labour: "... and a government who's trying to get a grip on a problem that became very out of control at one point, obviously it would appear that the government departments were not able to keep up with the number of applications. And that's what I mean about being out of control." *Conservative Shadow Health spokesperson, Key Informant Interview, March 2008.*

[48] Immigration and Nationality Directorate.

Key informants from many sectors interviewed for this research also identified the increase in asylum applications as contributing to an agenda of increased control within immigration and asylum policy. A senior staff member at a refugee organisation felt that the agenda of control had become a priority for the Government:

> *And there was a peak in numbers that meant the system was perceived to be flooded and in crisis... and that's fed into a general sense of immigration and asylum being 'a bad thing' and something that must be controlled at all costs.*

Refugee NGO Head of Policy, December 2007

By 1997, the rise in asylum applications had coincided with an increasing asylum refusal rate [24]; in 2001 the Refugee Council expressed concerns that the high refusal rate reflected an unfair determination process [244]. Under the previous Conservative Government, the high refusal rate had been seen as evidence that the majority of asylum-applicants were in fact economic migrants [24], and this interpretation of asylum statistics continued under the New Labour Government:

> *There is no doubt that large numbers of economic migrants are abusing the system by claiming asylum...*

> *It is in the best interest of genuine refugees that there should be firm action to improve current procedures, including measures to deter or prevent from travelling those who do not meet the criteria for entry to the UK.*

> *Fairer, faster and firmer: a modern approach to immigration and asylum* White Paper [131]

This conviction that the high refusal rates represented false applicants was the basis for an increasingly deterrence-based approach to managing the overwhelmed asylum system.

b   *9/11 and the Securitisation of Immigration*

In the aftermath of the attacks on New York's Twin Towers, security issues became, for most governments, increasingly linked to immigration policy [137, 143]. In the UK, the connection between international terrorism and migration became explicit when the 2001 Anti-Terrorism, Crime and Security Bill was going through Parliament. Beverley Hughes, then Minister for Immigration and Citizenship, held that "all the measures are designed to enhance intelligence and information gathering, to restrict people suspected of involvement in terrorism, **to prevent abuse of asylum,** and to give law enforcement and security agencies powers to tackle the problems that we face" [130, emphasis added].

A small number of key informants identified 9/11 as an event that had altered the direction of the policy agenda on immigration, conflating the issues of asylum and terrorism to a degree not seen before:

It's terrible but 9/11 did change things ...what that did was it focused attention on lots of people who are legitimately here in Britain, have been living here for decades, but then it sort of started to raise this issue of... "who are these people who can perpetrate such acts of atrocities?"... And then when you [get] 7/7 and 21/7 and various other things, there's this emergence that there are people who come to this country, often in cases – 21/7 guys had fled Somalia – given refuge in Britain, and then this is how they're seen to repay Britain.

Home Affairs Editor, National Broadsheet, Key Informant Interview, April 2008

This extract also highlights the problems associated with migrants and refugees in the public imagination, and the concept of a relationship of indebtedness between refugee and host nation. These ideas are discussed in more detail below on page 92.

By 2002, this conflation of migration, asylum and terrorism had affected policy development in the discourse on the introduction of ID cards. The Government white paper *Secure Borders, Safe Haven* avoided explicitly linking the introduction of ID cards to security issues because of the degree of adverse comment the proposed scheme had attracted in the media. Instead, the concept of 'entitlement cards' was put forward[49], the stated aim being to improve identity-checking in the use of public services:

> *After the terrorist atrocities in the United States on 11 September, the issue of introducing an identity card scheme was raised by many people and attracted a considerable degree of media comment. At the time, the Government said ... that the policy was being kept under review and that it was considering whether a universal entitlement card, which could allow people to prove their identity more easily and provide a simple way to access a range of public services, would be beneficial.*

Secure Borders, Safe Haven **White Paper, [133]**

In January 2002 asylum-applicants began to be issued with an Application Registration Card (ARC), and receipt of financial support became conditional on presentation of this card. A consultation paper published in April 2004 outlined the legislation required for the introduction of ID cards in more detail, and cross-governmental cooperation on the development of biometrics for identity once again linked the national identity card scheme and security issues with asylum through the use of biometrics in the Application Registration Cards [246].

The Department of Health published the consultation *Proposals to Exclude Overseas Visitors from Eligibility to Free NHS Primary Medical Services.* Here the link between security issues and the development of ID cards, and asylum and access to public services was made more explicit:

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[49] Notably, both Conservative and Labour parties adopted a similar political stance at this time: In 2003 shadow health secretary Dr Liam Fox advocated the use of entitlement cards for asylum-applicants needing to access the NHS [245].

On 26 April the Home Office announced draft legislation setting out the proposed legal framework to establish a national identity card scheme. The proposals in this document are separate from that proposal and do not depend on the introduction of identity cards, but are intended to dovetail with the proposed new card.

Proposals to Exclude Overseas Visitors from Eligibility to Free NHS Primary Medical Services, A Consultation [186]

By 2006, the connection between security and migration had become unambiguous. In a speech to the Labour Party Conference the then Home Secretary, John Reid, linked terrorism with management of immigration:

Let me tell you where I stand on the big issues of security, crime and terrorism confronting us today... I believe in a Britain where there is no compromise with terrorism. Where immigration is managed fairly.

John Reid, Speech to Labour Party Conference, September 2006

Just as the Government's 2004 proposals on the introduction of identity cards had facilitated the development of proposals to restrict access to primary care for overseas visitors, the prospect of compulsory ID cards for foreign nationals enabled the further development of policy aimed at restricting access to public services more generally for those considered 'not entitled':

We need to make living and working here illegally ever more uncomfortable and constrained. Introducing biometric ID cards, starting with newly arrived foreign nationals, will make it easier to ensure fair access to services and will stamp out fraud and abuse.

Enforcing the rules - A strategy to ensure and enforce compliance with our immigration laws [157]

Identity cards had begun as a response to heightened fears about security issues as terrorism and migration became linked. By 2006 the tripartite connection between the terrorist threat, migration, and identity card schemes as a durable solution had become ubiquitous in Home Office policy documents. In a Home Office review of the then Immigration and Nationality Directorate (IND), identity cards for foreign nationals were presented as key to future strategies in immigration policy:

Identity management and ID cards will remain one of the essential components in the management of migration and the fight against terrorism, organised crime and mass fraud. ID cards will be implemented as rapidly as possible.

Fair, Effective, Transparent and Trusted: Rebuilding Confidence in our Immigration System - An Independent And Transparent Assessment Of Immigration [247]

c   *HIV Epidemic Growth & the Advent of HAART*

The growth of the HIV epidemic in the UK has posed particular challenges for policy makers, especially since the rapid increase in heterosexually-acquired newly-diagnosed HIV infection

has been largely attributed to African migrants [248]. Concerns have been raised that the HIV epidemic in the UK is being intensified by the burden of disease among migrants:

> *Migrationwatch UK argued in their memorandum to the Committee that "the sexual health crisis in the UK is being exacerbated by the unnecessary and avoidable importation of cases of HIV."*
>
> **New Developments in Sexual Health and HIV/AIDS Policy [179]**

The associations made between migration and HIV contributed to a focus on security in the discourse on the disease, as well as on migrants generally. Commonly used metaphors of invasion and war to describe the disease became increasingly linked to the relationship between migrants and HIV, especially in the aftermath of 9/11. One excerpt from *The Sun* was not atypical: *"It is not through letting in terrorists that the Government's policy of mass immigration especially from the Third World will claim the most lives. It is through letting in too many germs ... About 200 people acquired HIV from immigrants last year the same number as were killed in the Bali terrorist bombings"* [249].

Additionally, the advent of Highly Active Antiretroviral Therapy (HAART) in 1996 changed the dynamics of HIV, in extending patients' lives and providing them with potentially indefinite periods of 'wellness' [250]. However, this innovation in the treatment of HIV also had consequences for the financing of healthcare , as newly-diagnosed individuals could now remain alive indefinitely, and contribute to a growing population of people requiring medicine.

Treating a person who has symptomatic HIV with HAART costs around £14 000 per capita per year [251]. One HIV consultant outlined the resource implications associated with HIV epidemic growth and the availability of HAART:

> *Ten, fifteen years ago, our budget for... anti-retroviral therapy would be about £400,000 a year. It's now in the order of £15-16 million, a year. So that money has to come from somewhere, right. So... HIV services are ...unfortunately, are a growth area, so when governments try and limit cost-spending based on inflation, it's just...that is an impossible target in HIV services because... if you have an uplift, which is in-line with inflation, you can't do that with HIV services because... you've got to uplift the budget in terms of the number of people you're treating.*
>
> **HIV Consultant 1, Key Informant Interview, July 2008**

In the context of an increasingly deterrent approach to immigration and asylum, these cost implications were coupled with a heterosexual epidemic driven largely by a population who had contracted their disease outside the UK and who were increasingly framed in a language of invasion. This may have had serious political implications for New Labour's immigration strategy.

The growth in asylum applications in the late 1990s and early part of the next decade were cited by the incumbent Labour government as contributing to the sense that they had inherited a collapsing system. The predominant response to the perception in government that immigration was becoming unmanageable was an increasing discourse of control. Because of the attacks in New York the threat of terrorism was linked with migration and asylum, and facilitated the development of the policy on identity cards and especially identity cards for foreign nationals. The possibilities afforded by technological change coupled with the political will to develop the scheme enabled the use of identity or entitlement cards as a requirement for access to public services, thus feeding back into the agenda of control that New Labour had initiated at the beginning of their first term of government.

Although the HIV epidemic did not directly contribute to this policy process the increase in the infection rate among foreign nationals did have very real implications for the way health and immigration policy developed. This is discussed in more detail below (see section 4.2.4a).

4.2.2   Structural Factors

A number of key structural factors affected policy-making on health and immigration. The United Kingdom's status as a liberal democracy with an independent judiciary and obligations under international treaties and conventions establishes parameters around policy-making. Its free market economy and increasingly privatised delivery of public services, including the National Health Service [252], also has repercussions for the political context of policy-making.

a   Legal context

Policies relating to access to healthcare for migrants have been enacted in legislation and they have been subject to legal challenge. Much of immigration and asylum policy-making more generally necessarily takes place within a human rights framework, which has affected the decisions of Government. International treaty obligations may also have had a substantial impact on the direction of policies; conversely, the Labour government has also sought to challenge its international obligations at times when these have constrained domestic policy-making.

Human Rights Framework

The ECHR and its incorporation into UK law in the form of the Human Rights Act 1998 [253] placed significant human rights obligations on UK public bodies by making it unlawful for any public body to act in a way which is incompatible with Convention rights. These obligations have had a considerable effect on immigration policy-making as well as on the rules governing access to healthcare.

In terms of immigration policy, Tony Blair's new Government was initially committed to the principles of human rights, both in its incorporation of the ECHR into domestic law (this had not been on the agenda under the previous Conservative government and was key to the New Labour election manifesto [254, 255]), and in terms of the undertakings given in immigration white papers. The white paper *Fairer, Faster, and Firmer* repeatedly affirmed the Government's commitment to human rights principles as well as obligations, and emphasised the inclusive nature of the new Human Rights Bill in its application to non-citizens as well as to citizens:

> *The Government has given a commitment that an order-making power in the Human Rights Bill will be used to enable an asylum-applicant whose application has been refused to appeal also on the grounds that his removal from the UK would breach ECHR rights.*
>
> **Fairer, faster and firmer: a modern approach to immigration and asylum, White Paper [131]**

A strong commitment to human rights is evident in the language of immigration policy documents throughout much of Labour's first and second terms. In 2002, human rights were not just identified as a set of obligations informing policy decisions, but also as something to aspire to and help define 'Britishness':

> *The Human Rights Act 1998 can be viewed as a key source of values that British citizens should share. The laws, rules and practices which govern our democracy uphold our commitment to the equal worth and dignity of all our citizens.*
>
> **Secure borders, safe haven: Integration with diversity in modern Britain [133]**

However, by 2005, this commitment appeared to have become attenuated, especially in response to the security imperatives that had come to dominate much policy-making in the aftermath both of 9/11 and later the London bombings in July 2005. In 2007, the HO announced plans to challenge the ECHR where it constrained domestic immigration policy-making:

> *We also plan a range of actions for removing barriers to deportation and removal. We will prioritise action against those who cause the most harm, including foreign national prisoners and people who threaten our national security. As part of this, we will challenge the case law of the European Court of Human Rights which prevents us from balancing the threat someone poses to our security and society if they stay here against the risk of the mistreatment they may face if returned to their own country.*
>
> **Fair, effective, transparent and trusted: rebuilding confidence in our immigration system. An independent and transparent assessment of immigration [247]**

Prior to this, a DH report that examined implementation of the amended Charging Regulations[50] had also demonstrated a relaxed commitment to human rights principles, if not actually to the law. The report had found that the regulations were not easy to implement and that the DH currently found itself in the "worst of both worlds" where funds were not being recouped to any worthwhile degree, while the Department was still on the receiving end of criticism from non-governmental and parliamentary groups [257]. The author of the report suggested that one solution was a fundamental revision of the charging arrangements, but saw international obligations under human rights law as forming the most substantial barrier to this solution:

On the assumption that we are to continue charging overseas patients, we are faced with an effective choice of the following:

1) making some improvements in identification of overseas patients and collection of funds... [although] the potential for abuse will still remain;

2) making a fundamental revision to the charging arrangements (although our hands are tied by treaty obligations and, for example, our wish to encourage people to be able to work here).

Overseas Visitors: Report [257, emphasis added]

What is notable in this extract is the suggestion that it was only obligations and not a commitment to human rights principles that might prevent this course of action; and that human rights obligations seemed to occupy the same priority for DH as the wider managed migration agenda and desire to encourage economic migrants into the UK's labour market, despite this being outside of DH's explicit remit.

However, a later (2007) Government response to concerns expressed by the Joint Committee on Human Rights about the extension of access restrictions into primary healthcare assured the Committee that *"Any new rules will take into account the key preventative and public health role of NHS primary medical care as well as international laws and humanitarian principles".* As with the aims of the 2004 amendments (see page 70), it is thus difficult to identify clarity in the Government's stance on its commitment to human rights.

Human rights then, continue to have an impact on immigration policy-making insofar as Government is bound by its international obligations. However, it is less clear whether the Labour Government has maintained the clear commitment to human rights principles that were articulated at the beginning of Tony Blair's first term.

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[50] This was released into the public domain as a result of requests made under the Freedom of Information Act [256].

Human rights law has featured in some of the legal cases that have shaped policy development on access to care for individuals with insecure immigration status. These cases are examined in more detail in the next section to illustrate the way in which they have influenced policy development.

Case Law

There is a substantial body of both British and European case law relating to access to healthcare for individuals with insecure immigration status. However for the purposes of this research, the two main legal concepts that are relevant are Article 3 of the ECHR, and the concept of 'ordinary residence' in the UK. It is beyond the scope of this thesis to provide an exhaustive summary of cases pertinent to these; instead an overview of relevant cases and their implications are discussed.

ARTICLE 3 OF THE ECHR & THE CASE OF N

Article 3 of the ECHR prohibits "inhumane or degrading treatment or punishment", and on this basis some HIV-positive asylum-applicants have in the past been awarded special Humanitarian Protection on the grounds that deportation to a country where HIV treatment is not available, leading to a decreased quality of, and eventually loss of life, precisely constitutes "inhumane or degrading treatment" [258]. However, this argument is rarely successful today, especially following the House of Lords judgement in the Case of N. 'N' was a Ugandan HIV-positive asylum-seeking woman who was extremely ill on arrival in the UK, but accessed HIV treatment, becoming well and stable. Her doctors argued that were she to be returned to Uganda, where treatment was not available to her, she would die within a year. The House of Lords rejected her appeal, contending that although she might find it hard to access the necessary medications in Uganda as a result of, for example, financial obstacles, HAART was theoretically available in Uganda. The UK was therefore not in contravention of Article 3 [259][51].

The House of Lords decision established a very high threshold for cases of this sort. Following N, to qualify for an Article 3 claim on medical grounds an individual would have to demonstrate either that there was a complete lack of treatment available to them in their home country, or that their case demonstrated an 'exceptional quality'.

Thus case law has a clear impact on everyday policy decisions within the Home Office, as well as for future applicants intending to make Article 3 claims under the ECHR.

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[51] In 2008, N took her case to the European Court of Human Rights in Strasbourg. The Court upheld the House of Lords decision [260].

Free access to NHS treatment is conditional upon demonstration of the criteria required to prove 'ordinary residence'. Anyone not ordinarily resident is subject to the NHS (Charges to Overseas Visitors) Regulations 2004 (amended)[174, 175]. However, ordinary residence is not defined in the primary legislation (the National Health Service Act 1977) that gives power to the Secretary of State to charge those who are not ordinarily resident, and therefore the definition established by case law is commonly utilised. 'Ordinary residence' is a common-law concept.

A judicial review of the Guidance at the High Court in April 2008 (R (A) V Secretary of State for Health & West Middlesex University Hospital NHS Trust) hinged on whether failed asylum-applicants could be considered ordinarily resident, and whether asylum-applicants could be considered to be lawfully in the UK.

As with N, public policy considerations were not absent from the Judge's (Justice Mitting) conclusions. When considering the lawfulness of asylum-applicants' residence in the UK, the Judge decided that only those individuals who made their applications at port of entry (and not 'in-country' applicants) could be considered lawfully resident. However he concluded that the complexity of acknowledging this distinction would "introduce into the management of National Health Service hospitals a degree of complexity which would, given limited resources, be in practice unworkable" [184].

The judgment had immediate consequences for the DH, which issued a letter to hospital trust Chief Executives informing them that Mitting's judgment was effectively the law unless and until an appeal was brought. However, despite the judge's attempt to reach a conclusion that could feasibly be implemented with as little confusion as possible, the DH advised trusts that:

> *The judge did not say that all failed asylum seekers on temporary admission are ordinarily resident, just that in certain circumstances they may be. Therefore, trusts must consider whether each failed asylum seeker that they treat can be considered ordinarily resident in the UK.*
>
> Letter to Chief Executives, Subject: Failed asylum seekers and ordinary residence – advice to overseas visitors managers, [261]

Mitting was concerned that a consequence of the UK's very complex immigration law made it hard for those who were not legal practitioners to implement it appropriately. It is clear from his statement above that this concern informed his decision not to differentiate between in-country and port applicants. It is therefore noteworthy that the guidance issued by DH following the High Court judgment sought to emphasise the legal complexities that remained.

The DH brought the case to the Court of Appeal in December 2008, and the Mitting judgment was overturned in April 2009.

b   NHS Financing and the Public Purse

The increasing marketisation of the NHS and the existence of infrastructure intended to assist debt collection from private patients and between primary care trusts (PCTs) facilitated the development of policies designed to respond to concerns about the consumption of "finite NHS resources" [174] by migrants. These factors arose repeatedly in key DH/HO policy documents and in key informants' accounts of the development of the overlap between health and immigration policies.

As described above, the capacity to charge patients not entitled to NHS care is not new. Section 121 of the NHS Act 1977 gave charging powers to the Secretary of State, and the secondary legislation following from this was enacted in 1989.

The private provision of healthcare to paying patients within NHS hospitals and in primary care also meant that some of the infrastructure necessary to implement a more rigorous charging scheme to overseas visitors was in place prior to the 2004 amendment and primary care proposals. Indeed, the DH consultation on excluding overseas visitors from free primary healthcare services anticipated that the easiest way to administer the proposals would be to utilise the mechanisms for private practice already employed by many GPs[52].

The DH Guidance on implementing the 2004 amendments to the secondary care also recommended utilising existing infrastructure resulting from the private provision of healthcare:

> *The Department of Health strongly recommends that trusts appoint a designated Overseas Visitors Manager to oversee the implementation of the hospital charging regime. This does not need to be set up as a brand new post, but could be linked with other similar roles within the trust. For example many trusts that already have Overseas Visitors Managers in place link it with the Private Patients Manager role.*
>
> *Implementing the overseas visitors hospital charging regulations - Guidance for NHS Trust hospitals in England [181]*

As well as utilising infrastructure emanating from a hospital's private business, this advice also explicitly linked private, charged-for healthcare and income generation with the provision of care to overseas visitors. Indeed, other DH documents reveal that charging overseas visitors has been seen as a potentially fruitful source of increased revenue for Trusts. One DH report

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[52] This was seen to be easier to implement than attempting to introduce charges under section 121 of the NHS Act 1977 (as is the case for chargeable secondary care services), since the latter would have entailed bureaucratic conflicts with the system of payments to GPs under the new primary care contract.

investigating the implementation of the 2004 amendments reported that the investigator had "attempted to find out the priority which individual Trusts gave this area, as well as trying to obtain a feel about the attitudes of staff... The management attitude included the following: - a useful source of income which should be collected" [257].

An Overseas Visitors' Manager (OVM) interviewed for this research echoed this sentiment, but linked the high worth of payments received from overseas visitors to the current system of NHS financing and the existence of substantial yearly deficits in Trust coffers:

> Our debts are £2 million... And it's a problem for ...anyone that tries to run like a business... if you don't try and maintain your cash position, if you're putting everything on paper – you know, the Government used to just like bail you out... – Oh, there you go [smacking sound] 'here's your handout'. That's stopped. And now like, you know, trusts have got to look at their cash positions in a serious way. And anything that gets hard cash in... into the bank is given a priority, which is why I suppose overseas visitors, is given more of a priority than anywhere else, or private patients, you know. Because that gets hard cash into the bank account.

Overseas Visitors' Manager, Key Informant Interview, February 2009

The concept of free healthcare in the UK obscures the structure of NHS financing. Any treatment provided in a hospital is either paid by the patient (if they opt for private healthcare or are not entitled to charge-free care) or is reimbursed to the hospital by the local PCT. Where a patient is entitled but comes from another PCT area (i.e. a British patient resident in Manchester requires hospital treatment in Southampton), it is the responsibility of the treating hospital (in Southampton) to recover the debt from the patient's PCT (in Manchester). This system requires that hospitals have specialist debt collectors to recoup the 'out of area' debt:

> So what we do now is... for the outside of London bills, someone spends four days going through each record, going on the NHS database, and trying to find people and check that we've got the right PCT. It's a mind-numbing job.

Hospital Debt Collector, Key Informant Interview, May 2008

These debt collectors are also charged with chasing the debt owed by overseas visitors that have been identified by the hospital's OVM. For some key informants, it was not just that the existing infrastructure had facilitated the development of policy designed to charge overseas visitors for healthcare, but the converse of this: that the Charging Regulations also facilitated a broader agenda of NHS privatisation:

> And the other thing is, of course, once you can identify groups of people who are outside the NHS, you know, then you're fundamentally into the business of re-defining what the NHS is, and in my view a large part of this is to do with the whole privatisation of the NHS programme... it shouldn't be seen as isolated from that a) reducing access to the NHS, and b) the marketisation of the NHS.

PCT Non-Executive Board Member, Key Informant Interview, August 2008

Although the key informants that discussed this phenomenon saw NHS marketisation as part of a wider neo-liberal economic programme, it may also be that this perceived bi-directional marketisation of the NHS was motivated by a perception of overuse of scarce NHS resources by migrants. The consultation that explored the possibility of amending the 1989 Charging Regulations stated that the loopholes that would be closed by the 2004 amendment would:

> *Ensure that money provided by UK tax payers for the NHS is not diverted to healthcare for those who are not resident in the UK but have taken advantage of gaps in the current rules.*
>
> **Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: A consultation [262]**

Many of the Government policy documents concerned with migrants' use of the NHS employed emotive language: The extract above echoes the concept of 'abuse of the NHS' (see section 'Contested Aims'), and implies that migrant (mis)use of the NHS is mindful and deliberate. In other instances refused asylum-applicants have been portrayed as deliberately 'abusing' NHS services whilst 'illegally' in the UK:

> *The consultation ran for 14 weeks from 29 July to 31 October 2003. Its proposals were aimed at stopping the following abuses:*
>
> - *free hospital care for failed asylum seekers (i.e. those whose applications and any subsequent appeals have been finally rejected) and others with no legal right to be in the country.*
>
> **Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: A Consultation [262]**

It is not the case that all refused asylum-applicants have no legal right to remain in the UK, as demonstrated by the dispute over the definition of 'ordinary residence' discussed above on page 86, and this statement also omits the mention of refused asylum-applicants in receipt of state support under section 4 of the Immigration and Asylum Act 1999 (see note **Error! ookmark not defined.**). The frequent use of the term 'health tourism' by Government when it is not clear to what extent this phenomenon exists also contributes to a framing of migrants as abusers of the system.

It is impossible to discuss this framing of migrants in policy terms without a broader consideration of British cultural responses to asylum-applicants and other migrants. It is not clear whether misleading Government portrayals of asylum-applicants are a response to negative media coverage and public opinion, or whether negative public/media perceptions of asylum-applicants and other migrants are a response to Government policy and language. The next section discusses this in more detail.

4.2.3 Cultural factors

Many key informants felt the perception of migrants by the British public was overwhelmingly negative: In the public mind migrants were abusing services, and also fraudulent (or 'bogus') in most of their asylum applications. This perception was largely understood as a British tendency to scapegoat the migrant; many key informants offered variants of the "racist public" thesis [158], arguing that the UK had always (and would always) be a fundamentally racist nation, and that anti-migrant sentiment was a function of this. Some informants refined this theory, putting forward the idea that asylum-applicants had become a legitimate target in a country that required scapegoats but where overt racism was no longer politically acceptable. The framing of migrants both informed, and was informed by, debates over the meaning of citizenship and what entitlement should entail in a country of immigration.

a   *Perceptions of Migrants*

Many HO and DH policy documents indicated a conviction that it is necessary to take a defensive position on immigration policy. Migrants were sometimes portrayed positively, however this usually occurred within a polarised debate where migrants were either deserving or undeserving; victims or perpetrators of crime; economic migrants who would boost the British economy, or fraudulent unauthorised workers [148, 149, 263]. Migrants and migration were framed in terms of threat to the UK, either as a security threat or threatening in their use and 'abuse' of services. Policy therefore had to respond pre-emptively to this threat, and deter potentially fraudulent individuals from entering the UK or being able to remain here to abuse public services.

One HO policy document acknowledged the polarised nature of the debate on asylum in British public life:

> *The debate on asylum has been polarised between two extremes: those who oppose all immigration and those who oppose effective immigration controls. All asylum seekers are "bogus" to one group or almost all genuine to another.*
>
> *Fairer, faster and firmer: a modern approach to immigration and asylum* White Paper [131]

Although this simplified the public debate on immigration, it implied that the HO saw the issues arising from asylum as more complex than either of the two positions it had identified. It is therefore notable that in the subsequent paragraph of this document, the HO appeared to fall into the trap it had itself identified - of polarising the portrayal of asylum-applicants as either abusive applicants or 'genuine' refugees:

> *Potential abuse and exploitation of the institution of asylum harms the genuine refugee as much as it threatens to undermine proper controls on immigration. It is in the best interest of genuine refugees that there should be firm action to improve current*

procedures, including measures to deter or prevent from travelling those who do not meet the criteria for entry to the UK.

Fairer, faster and firmer: a modern approach to Immigration and asylum White Paper [131]

In Tony Blair's foreword to the document *Controlling our Borders*, abusive asylum-applicants were seen to be threatening the stability of the asylum and immigration system. This legitimised a tightening of controls, particularly since failing to do so would enable those on the extreme right to hijack the debate on asylum and immigration:

This traditional tolerance is under threat. It is under threat from those who come and live here illegally by breaking our rules and abusing our hospitality. And, unless we act to tackle abuses, it could be increasingly exploited by extremists to promote their perverted view of race.

Tony Blair, Foreword to *Controlling our Borders: Making Migration Work for Britain - Five Year Strategy for Immigration and Asylum* [142]

This concern, that a badly managed asylum policy would result in its use by far-right groups, appeared in a number of documents, and was linked to the debate on entitlement. There was a perception in Government policy documents that the British public were labouring under a generalised sense of injustice in terms of the benefits available to migrants, and that this too threatened social cohesion. The foreword to the strategy paper *Enforcing the Rules* by the then Home Secretary, John Reid, summed up Government concerns about the consequences of a poorly enforced immigration system:

Resentment of it [illegal working] breeds discontent and racism. This is especially keenly felt among those who believe they are not getting the economic or social opportunities they should because others, who have flouted the rules and often the law, seem to be getting on ahead of them. That's not fair either.

John Reid, foreword to *Enforcing the rules - A strategy to ensure and enforce compliance with our immigration laws* [157]

In this paradigm, prevention of social breakdown therefore required precise boundaries around the benefits of citizenship.

Some key informants reported beliefs that large sectors of the British public held inherently prejudicial positions against asylum-applicants and other migrants simply because of their status as migrants, rather than because of any benefits that this status might confer. The public was seen to be using asylum-applicants as a scapegoat for societies' ills, given that political change had made it less acceptable to scapegoat groups on the basis of ethnicity or nationality:

People ...do like to have somebody to blame in society, and history suggests it's been everyone from Jews to the Irish to women to all sorts of people. This time round it's the immigrants' ...fault.

However other non-governmental informants felt that rather than being inherently prejudiced, the British public were developing an increasing sense of injustice in response to migrants and migration, and this perspective tallies with government assessments of the public. The extract below acknowledges this concern, but identifies the debate on entitlements and citizenship as a cause of the concern, rather than a response to it:

> *Some elements of the UK population feel quite insecure because of other things that are going on in our economy and society. Which is to do with a concern by the radical centre that you won't maintain citizens' support for the welfare state if it's something that you can access by just getting off a plane at Heathrow.*

Legal NGO Policy and Communications Officer, Key Informant Interview, November 2007

Whether public unease is a response to the messages coming from Government policy or vice versa is not clear. This is discussed in more detail below (on page 107). However a preoccupation with entitlement to public services and the meaning of citizenship seems to have been central to the debate on migration under the Labour Government, and may have informed the 2004 amendments and the proposals on primary care restrictions.

b   The Meaning of Citizenship and Electoral Politics

The linking of citizenship with the concepts of sharing "rights and responsibilities" or "benefits and obligations" has been a central tenet of the Labour government's approach to immigration since 1998 [131, 133, 142, 144, 157]. One aspect of this philosophy has been an emphasis on the privileges associated with citizenship and especially on access to public services. However, towards the beginning of the Labour government there was a more specific concern with welfare benefits, while latterly public services more generally have come under this rubric.

For example, in 1998 the policy objectives associated with the privileges of citizenship related to establishing a parallel welfare support system for asylum-applicants, and there was very little mention of access to other public services in key immigration documents:

> *The Government believes that it must start from the position that people who have not established their right to be in the UK should not have access to welfare provision on the same basis as those whose citizenship or status here gives them an entitlement to benefits when in need. Any support for asylum seekers should operate on a separate basis.*

> *Fairer, faster and firmer: a modern approach to immigration and asylum* **White Paper [131]**

By 2007, one of the main approaches for the Home Office, set out initially in the 2006 review of the then IND had become the far more general objective of *"removing the most harmful*

*people first and **denying the privileges of the UK to those here illegally**"* [247, emphasis added], which was reiterated in the strategy paper *Enforcing the Rules* [157].

It was not only the Home Office that focused on the issue of entitlements. The Department of Health also contributed to the debate, making it clear by 2003 that it too was committed to conditional access to services:

> *Our aim must be to maintain the principle of providing services free at the point of delivery – but to ensure, in the process, that these services are provided only to those who are properly eligible to receive them. We wish to see closer links established between free use of the NHS and UK citizenship or residency.*
>
> **Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: A consultation [174]**

One respondent thought this strategy of restricting entitlement stemmed from an overt ministerial preoccupation with public opinion or electoral concerns (see page 90), because the British public discerned a pervasive injustice in matters as they stood:

> *So they saw a political danger ...in not making services for British residents... People not entitled to be in the country were not entitled to services and that this would save money, that this would insulate Labour politically, and improve other policies, and that this should be applied to everything. This should be applied to – it's not just health – this should be applied to education, housing...*
>
> **Migration Policy Analyst, Key Informant Interview, November 2007**

It is true that Government policy statements invoking these ideas of conditional access often mentioned the public's expectations as the motivation for using service-access to address perceptions of injustice. One civil servant interviewed for this research placed the public's concerns at the centre of this philosophy:

> *The philosophy of the government is that in order to be able to access the full gamut of state benefits, a person should have to be a UK citizen. The public should have a right to expect this in general, and on health issues too. We need to respond to perceptions of unfairness in the system, queue jumping in services, and so on.*
>
> **Home Office Civil Servant, Key Informant Interview, August 2008**

And another civil servant identified a widespread public demand for lower taxes, and therefore reduced use of resources, as constraining much of government policy, because of the imperative to win elections:

> *It strikes me that the solution is for us to be as generous as the people are willing to be. And frankly... the people of this country aren't willing, when it comes to the ballot box, to be particularly generous. They may beat their breasts, but when it comes down to voting, they seem to vote every time for lower taxes. And that, ultimately, is the hard choice that a government has to make.*
>
> **Home Office civil servant, Key Informant Interview, November 2007**

However, another key informant saw the policies less as electioneering and more as stemming from the beliefs of senior Labour ministers that the preservation of the nation-state required clear benefits for the citizenry that would be withheld from non-citizens; this political philosophy had led to the emphasis on entitlements and access to services as a component of Labour's integration policies and its search for a collective British identity:

> And also an idea again, flows from the same quarter, but from Blunkett, that entitlement is a key prop to Britishness, if we have this entitlement card, we'll somehow feel that we all belong because we've got it.

Legal NGO Policy & Communications Officer, Key Informant Interview, November 2007

If this is the case, and entitlement policies were intended to feed into a 'social cohesion' approach to integration policy, then it would appear that there was also some inconsistency in government statements relating to that policy. According to the Home Office, *"the Government's view is that we must make everyone who is settled here feel welcome and valued irrespective of whether they have acquired British citizenship"* [133]. While this chimed with New Labour's shift to focussing on social inclusion, it has been repeatedly contradicted by statements insisting that access to services ought to be dependent on citizenship. The restrictions on access to healthcare and other public services as well as welfare entitlements constituted an active strategy of social exclusion [153]. However, that paradigm shift at the beginning of the Labour Government towards social inclusion also entailed a shift towards obligations rather than rights flowing from participation in society [151, 156], and viewed from this perspective, the emphasis on entitlements makes sense within an integration/social inclusion policy of 'citizenship responsibility' [156]. Policies restricting entitlements thus imply that integration policy only begins once a positive decision has been made on an asylum application [130].

Many key informants reported a concern that precisely this policy of delayed integration would exacerbate the public's sense of injustice: should the primary care proposals become law, migrants would have nowhere to turn for healthcare other than Accident & Emergency services, making their service use very visible:

> I think that's going to lead to increasing discrimination and hostility in the general public because somebody is going to feel: I can't get to A and E – I mean, can you imagine the headlines that will appear because there are twenty asylum seekers in there being seen before me etc?

Refugee Charity Operations Manager, Key Informant Interview, December 2007

Thus policy was seen by some key informants as potentially contributing to the intersection of immigration with health politics. The next section discusses the ways in which key informants

perceived the HIV epidemic and global health inequalities to have contributed to policy development.

4.2.4   External Structural Factors

a   *Global Health Inequalities*

Substantial global inequalities in health, both in terms of the burden of disease and access to resources to combat disease, have a twofold impact on the UK and its policies on immigration and access to healthcare.

First, it is the comparative absence of medication available in many developing countries that has engaged Article 3 for some HIV-positive migrants, and historically may have provided them with a case for leave to remain in the UK. Although the Lords eventually decided in the Case of N that these inequalities alone were not sufficient to engage Article 3, they did attend to the question of to what extent such global circumstances would obligate states under human rights law. Indeed, it was partly the scale of the inequalities that led them to conclude that N's deportation would not constitute an Article 3 breach:

> *Sadly the appellant is not a special case ...the appellant's case as a would-be immigrant is far from unique. As everyone knows, the prevalence of AIDS worldwide, particularly in southern Africa, is a present-day human tragedy on an immense scale. Each case will differ in detail and degree.*

Case of N v. Secretary of State for the Home Department [259]

Second, an awareness of those global inequalities may have led some actors to the conclusion that substantial numbers of people choose to migrate to the UK specifically to seek treatment, and therefore to the development of the concept of 'health tourism', which has had substantial bearing upon the 2004 amendments and the primary care proposals. One civil servant expressed his reluctance to provide care to non-residents as a function of the belief that to do so would be to invite thousands more migrants to seek healthcare:

> *I think that it's almost impossible to operate a system whereby we routinely or even quite generously provide treatment here because it's not available in other countries, because I can imagine that we would be flooded.*

Home Office Civil Servant, Key Informant Interview, November 2007

This belief was echoed by a hospital manager when discussing the absence of HIV from the exempt list of diseases in the Charging Regulations, and the likely outcome of adding it to the exemptions:

> *I don't think there's any easy solution for it, because ... if you opened it up as an exemption in the regulations, then there'd be a massive influx.*

Overseas Visitors' Manager, Key Informant Interview, February 2009

Suggested in both of these statements was an awareness of the relative position of the UK in terms of resources and health provision. This awareness lends itself to the conclusion that the concomitant inequalities flowing from that position coupled with the NHS principle to provide treatment at the point of need, would inevitably lead to a diffusion of individuals requiring treatment from the developing to the developed world.

b   *Universal Access to HAART*

The UK has made a number of commitments to improving access to HIV treatment globally. Prime Minister Tony Blair launched "Taking Action – the UK's Strategy for Tackling HIV and AIDS in the Developing World" for the Department for International Development (DfID) in 2004, in which the UK Government pledged its support for universal access to treatment for HIV [264]. In 2005, at the Gleneagles summit, the UK and other G8 members committed themselves to achieving universal access to HIV treatment by 2010 [265].

Home Office civil servants interviewed for this research cited the UK's support for international development and universal access as evidence of the UK's commitment to providing access to care for people living with HIV (PLWHIV), although one acknowledged the difficulty of providing development assistance in countries where diplomacy had broken down:

> *And DfID are making substantial efforts to improve healthcare in many developing countries. Of course that is only possible where we have a good diplomatic relationship with the country in question, which is not currently the case with Zimbabwe.*

Home Office Civil Servant, Key Informant Interview, August 2008

Some key informants expressed the opinion that there was a mismatch between the UK's foreign and domestic policies insofar as providing financial and political support for universal access abroad whilst withholding access to HAART in the UK seemed contradictory. One advocate expressed his concern about the timing of the 2004 amendments, given their relation to the UK's commitments to universal access:

> *2004 was just the year before the G8 commitment to Universal Access, and I'm sure negotiations and thinking was going on around all these commitments and wanting to support people living with HIV in the best way possible, and I think if you make a policy within your own borders where you're actually discriminating against people living with HIV, it's not really the best thing to promote it.*

HIV NGO Policy Officer, Key Informant Interview, December 2007

Other key informants from a resource protection NGO and from the civil service interpreted the pledges on universal access differently, and saw the UK's commitment to provision in the developing world as offsetting the restricted access that migrants might experience in the UK. Moreover, one representative from a resource-protection NGO felt that there was a problem of equity in providing treatment to the relatively small proportion of HIV-positive individuals

from the developing world that successfully made the journey to the UK. In his view, equity and efficiency demanded that resources were better spent treating greater numbers of individuals in their countries of origin:

> *If we were choosing ...between them suffering the problems of... having HIV in the Third World, or significantly larger numbers having HIV in the Third World because it is cheaper to treat them there, it is more efficient there.*
>
> **Resource-protection NGO, Policy Analyst, Key Informant Interview, May 2008**

Thus the relationship between global health inequalities, UK commitments to universal access to HIV treatment and the Charging Regulations were interpreted by key informants according to their political interpretation (humanitarian or resource protective) of healthcare access policies.

Central to many accounts of the relationship between these events and the policies to which they contributed was an analysis of the role of public opinion, and the power wielded by the public in informing immigration and health policies. The next section examines the role of power and its proprietors in more detail.

4.3 UK Immigration and Health Policy Development – Processes

Much of the previous section, examining the motivations for the development of policies aiming to restrict access to healthcare for certain categories of migrant, focused on the period between Labour's election in 1997, and the publication of the 2004 amendments and the primary care consultation. However, these two policy events were not the end of the process.

The responses to the primary care consultation were not published by government, despite this being a contravention of their own guidelines on the consultation process [266]. As a result, the government's decisions following from that consultation are at present unknown; the primary care proposals have not yet been enacted, nor have they been officially shelved. A joint departmental review of the healthcare access rules for foreign nationals was announced in March 2007, and was due to be published in October of the same year [157]. In July 2007, this announcement was reiterated, with the date for publication of new rules flowing from that review stated as September 2008 [267]. It had still not been published as of June 2009.

The April 2008 judicial review decision was overturned in March 2009 at the Court of Appeal. However, the Court of Appeal decision did alter the implementation of the original Guidance in small but potentially significant ways. The DH decision to challenge the Mitting judgment suggests that there is an impetus within Government to continue with a restrictive approach to policies on healthcare access.

4.3.1 Actors and Influence in the Policy Process

Before it is possible to examine how different actors involved in the development of the rules on healthcare access for individuals with insecure immigration status have influenced policy, it is necessary to summarise the approach this thesis takes to understanding power in the policy process.

High and low politics are concepts relating to how a state develops a hierarchy of issues: the contention is that given the constant threat of force against states, matters relating to national security always take precedence over other areas, and are consequently designated 'high politics'. All other matters of state (social, political, economic) are designated 'low politics', although some authors have argued that economic questions merit the 'high politics' designation [215, 268]. This definition is utilised in this thesis. Hall et al [1975, in 215] suggest a theory of power - 'bounded pluralism' - which proposes that issues of high politics are decided by elites, while issues of low politics may take a more pluralist framework, with participation of different groups during the policy process.

Within this framework, policy on access to healthcare for migrants occupies an unusual position, in engaging both high and low political issues. As discussed above, UK immigration

policy has become inseparable from questions both of security and of resource use, and in this sense it is likely that the policy process is dominated by government elites. However, the 2004 amendment and primary care proposals also bear upon healthcare and service delivery, as well as being enacted through the minutiae of secondary legislation and departmental guidance notes, and these are areas in which there may be more room for non-governmental actors to influence the policy process.

a   *The State and its Agents*

The Home Office and Department of Health both emerge as important figures in the development of the health access policies, and seem to have acted in tandem throughout much of this policy's journey. As described above (see section 4.2.1b), the primary care proposals made explicit the perceived relationship between immigration control (a Home Office responsibility) and health when the use of entitlement cards to regulate access to healthcare were said to 'dovetail' with the Government's plans to roll out ID cards. In addition, in 2007, the Home Office published *Enforcing the Rules,* committing the HO and DH jointly to review the access to NHS care rules for foreign nationals.

Inter-Departmental Conflict

However, it is not clear whether this joint working has proved harmonious. There was a widespread perception among key informants that there was substantial conflict between the two Departments on the matter of the healthcare access rules, and that it had been this tension that had contributed to the delay in the publication of the joint review on healthcare rules for foreign nationals. One respondent described how his privileged access to the Home Office gave him an insight into this conflict:

> *There's a tension between various government departments about the allocation of resources... basically, between the Home Office and the Department of Health... I got a number of...a number of sources within...as the Home Affairs editor, I tend to specialise in talking to people within the Home Office rather the Department of Health, and ... actually the Home Office... effectively confirmed the story... they couch it in, "Yes, there's a debate going on". But they recognise that there was a tension between them and the Department of Health.*

Home Affairs Editor, National Broadsheet, Key Informant Interview, April 2008

However, very few respondents felt that this was a battle of equals, with most key informants reporting either the perception or anecdotal evidence gleaned from their jobs, that the HO was the dominant actor in pushing through restrictions on access to healthcare. As they saw it , the DH was ultimately playing second fiddle to the more influential Home Office, because of the latter's 'high' political responsibilities:

I mean the Home Office was the department... it's probably not the force it once was, but it's still considered extremely important, and ...it is something that is always going to ... win debates with the Prime Minister... politically it's a very, very important area and so the Department of Health will always kind of probably find itself marginalised on that issue.

Home Affairs Editor, National Broadsheet, Key Informant Interview, April 2008

However, respondents did not consider the Department of Health to be totally lacking in influence. The delay in the publication of the review was attributed by one key informant to the DH's capacity to resist the will of the HO by utilising the fact that the rules would ultimately be *health* rules, and therefore come under its auspices:

I think the important thing... to emphasize is, this is the Home Office driving this policy. And I think the Department of Health has grasped the very detrimental effects, both to individuals, and to public health, that these restrictions have already, and will further have if the primary care is denied... And I think the reason that it's been delayed... is that because the Department of Health... is ... holding out, and it has to go out under them.

GP and Migrant Advocate – Key Informant Interview, April 2008

The extracts above chimed with most non-governmental key informant's view of the relationship between the two Departments. For them, the HO was driving the set of policies relating to restrictions on access to care, and the long delay in publishing a joint review on this issue related to the limited power that the DH had to resist the influence of its more muscular cousin. However, this was not the perspective of DH and HO officials, who insisted that although this was an example of 'joined-up working' (since it affected both departments), the DH was central to the policies' development:

Government is a collaborative exercise between ministries and at the end of the process you get a consensus view. It is certainly not true to say that we are hitting the Department of Health over the head with this.

Home Office Civil Servant, Key Informant Interview, August 2008

I mean, there might be agreements, there might be discussion with them, but it wouldn't be, you know, the policy of one government department wouldn't be driven by [another]...

Department of Health Civil Servant, Key Informant Interview, April 2008

However, a key informant, who had an insider's perspective on the policy development as a result of his active participation in the panel that had reviewed the original consultation, reinforced the perspective that the HO was prioritising immigration policy over health concerns, and stated that it was this that was holding up the joint review:

Our recommendations as the NHS don't marry with the Home Office's. They think it needs to be...stronger. We've got considerations for patients ...for health and welfare, health inequalities and all that. Their only consideration is whether people are going to come or go...They've got no other consideration.

Overseas Visitors' Manager, Key Informant Interview, February 2009

It is clear that the DH and HO are central actors in these policies' progress. However, what is less clear is the relative positions of these two departments in influencing policy development in this area. There was a shared belief among key informants, including one DH insider, that the Home Office was the more powerful of the two Departments, and that restrictions on health care access had been led by the HO as part of a wider strategy of immigration control. Civil servants at both Departments disputed this, insisting that although the policy was seen to affect both departments, it was led by the DH. The HO would seem able to exercise considerable influence over the DH in the development of policy; however the DH may not be without agency, being able to utilise its position as, at least on paper, the department that has responsibility for driving this policy.

The Use of Secondary Legislation

The potential for formal opposition to the policies on healthcare access from backbench MPs and the opposition was restricted by the use of secondary legislation for policy enactment, since amendments to statutory instruments and other delegated legislation are rarely debated in Parliament [269]. The increased use of secondary legislation was a cause for concern for both the Labour and Conservative MPs interviewed for this research, primarily because of the limitations it placed on parliamentary scrutiny.

Thus those who did oppose the policies had limited opportunities for direct Parliamentary opposition, and instead often became involved with issue networks; these are discussed below.

Despite these two departments and their associated ministers exerting substantial influence over the policy process in this case, other state agents have at times derailed its trajectory. In analyses of the influence of actors in the policy process, the courts are traditionally classified as state agents. However, given the independence of the judiciary in the UK, decisions taken in the courts have both propped up, and disrupted the apparent strategy of government. The decision of the House of Lords in the Case of N, as discussed above (on page 85) was based both on an impartial analysis of the relevant Strasbourg case law, and on public policy considerations, and could be seen as having tallied with the deterrent approach to government policy-making on immigration and access to healthcare. Conversely, the judicial review of April 2008 temporarily reversed aspects of the impact of the Charging Regulations, in

finding that refused asylum-applicants were entitled to NHS care. It is interesting to note that Justice Mitting, overseeing that judicial review, observed that "immigration law is seeping like a stain into all sorts of areas of national endeavour into which it doesn't have a place" [184, quote not recorded in official transcript]. This comment implies that like the House of Lords in N, Mitting's judgment was influenced by public policy considerations; albeit in the opposite direction.

The Consultation Process

The 2003 consultation that "put forward ... proposals to close ... loopholes and modernise the system" [262, p.2] on charging overseas visitors for secondary healthcare received 141 responses, of which the Department of Health considered 123 to be relevant. The summary of responses to the consultation reported that 55% of respondents supported the proposals relating to the requirement for lawful residence in the twelve months prior to treatment initiation, but interpreted those 45% of responses that opposed the proposal as flawed through a misunderstanding of the proposals:

> *Although, marginally, the majority of respondents, who answered this question, supported this proposal, it nevertheless raised strong opposition from many organisations working to support vulnerable patients. There seems to be a lot of misunderstanding over what the proposals actually mean.*
>
> **Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: A consultation: Summary of outcome [262]**

Despite (as the summary document notes) marginal support for the proposal, the many concerns for the possible public health and other consequences associated with the proposals were dismissed on this basis that respondents had not understood the proposals correctly [179], and the proposals were enacted in legislation four months after the consultation outcome publication. The ministerial submission following the consultation exercise that recommended initiating the drafting of the amended regulations noted that "despite some very real concerns expressed ... the overall outcome of the consultation was favourable" [270, p.1].

However, despite the Government's response to consultation being largely dismissive of those who opposed the proposal, specific concerns regarding the way in which the policy would be implemented appear to have been considered and addressed in advance of the policy being drafted, and as a result of the consultation exercise. For example, the easement clause (allowing those who had been initiated on a course of treatment to continue free of charge regardless of their immigration status) appears to have been considered and enacted as a result of those responses that opposed the proposal:

A number of respondents expressed very serious concerns about the proposal to disapply the 12 months' residency exemption to those found to be in the UK without proper authority... despite the emotive language used, many of the points raised are very valid. We therefore propose that the regulations should be drafted in such a way as to cover only treatment which begins after the patient has been found to be here without proper authority.

Ministerial Submission, [270]

Thus the process of consultation and Government responses to it appear to have taken on aspects of both elite and plural power. Although the Government was able to dismiss the concerns of those opposing the proposals and draft the amended Regulations through its elite power, the influence of multiple individuals and agencies was a consideration in the specifics of policy development, with the easement clause introduced almost to appease those with humanitarian or public health concerns. The next section discusses these 'plural' influences in more detail.

b   Migrant Health Interest Networks

A broad advocacy network has emerged in response to the Charging Regulations and the primary care proposals; indeed, groups that otherwise might have little in common have developed close ties. The network is loosely comprised of clinicians and clinician groups like the British Medical Association (BMA), parliamentary groups such as the Joint Committee on Human Rights, and third sector advocacy organisations (which include migrant support organisations such as the Refugee Council, and health organisations such as the Terrence Higgins Trust).

Advocacy

Although this network does not have direct influence over the policy process, key informants from member organisations felt that their work had served to bring attention to the human rights and public health consequences of the 2004 amendments and possible consequences of the implementation of the primary care proposals. Many key informants (including clinicians and those from HIV/migrant NGOs) identified their advocacy work as having contributed to the failure to implement the primary care proposals. One key informant described his work in a previous role where the organisation he worked for had lobbied the DH to carry out a Race Equality Impact Assessment of the 2004 amendment. He felt that this pressure had contributed to a deliberate decision on the part of the DH to withdraw publication of the consultation analysis:

I was exchanging letters with their equalities people in the NHS. And I'm sure that they got close to publishing it at some point, and then said "oh, we haven't done - ", basically they hadn't done a Race Equality Impact Assessment, "and the CRE's already on our case about the last one, and this might give them an excuse to take us to court for real

dereliction" so I'm pretty sure that at least part of the reason why they delayed it once was through the letters from us at the CRE.

There was a strong sense among key informants involved with advocacy that it was necessary for them to make a lot of noise before the DH/HO review of the healthcare rules had been published by Government. The lesson of the 2004 amendments had proven the difficulty of reversing policy once a decision had been made. One respondent discussed his perception that the advocacy coalition had experienced a growth in momentum as a result of the urgency felt from the need to influence policy makers before the joint (HO/DH) review was published:

> *The more we do, I think the more influence we're having before recommendations come out. Because once recommendations come out it's much more difficult to change that. Although they say they are going to have a full consultation period afterwards, but that doesn't necessarily mean they're going to take on our recommendations after they've already gone public with theirs. So it'll be interesting to see what comes out.*

Another respondent echoed this perspective, but added that she felt the aim of advocacy work was to make Government feel that pushing an unpopular policy through would be more trouble than it was worth:

> *I think there is a sort of inertia, that if you make enough fuss they don't want to change the rules, but if they can change the rules before anybody's made a fuss, they don't care how much fuss is made afterwards... the whole business of lobbying and campaigning, as far as I'm concerned, is to make it obvious to the government that it will be less difficult for them to do what we believe needs to be done than it will be to not do it.*

This prevalent view on the part of third sector organisations (that policy change had to be prevented in the first place, rather than altered after the fact) meant that there was a significant amount of advocacy work going on throughout the course of this research, including provision of support for the April 2008 judicial review, overt lobbying and campaigning, and other attempts to influence policy through involvement with parliamentary committees' scrutiny work.

Parliamentary committees exist to scrutinise the work of government [243], and have in recent years conducted a number of sessions that overlap with the interests of the third sector groups and campaigns outlined above. Although they cannot exert influence on policy directly either, it is likely that they are better able to have some bearing on decision makers, given their proximity to government, and the fact that these committees are themselves comprised of ministers and lords. Although the UK two-tier system concentrates power in the Commons,

the existence of select committees does allow a more plural structure for policy-making [271]. This access to the parliamentary process has facilitated the work of the campaign networks, and one key informant felt that recommendations issued by parliamentary committees lent the advocates a degree of political weight through the committees' perceived objectivity:

> There's been many enquiries and bodies that have reported...a whole list of varying bodies who are not coming from a particular political persuasion, they're not coming from an immigration background or asylum background, they're not a lobbying body, they are making an objective opinion.

GP and Migrant Advocate – Key Informant Interview, April 2008

Clinicians and clinician groups were also seen by respondents to wield some influence over Government policy-making (in the health sphere), and thus to lend more clout to the endeavours of the issue network more broadly. The historical political strength of the BMA, as well as the fact that clinicians could choose simply not to implement the policy if they wished, meant that most respondents perceived that they collectively exercised more authority than other actors in the network, and were seen as an attractive ally. It was considered that it was in large part the involvement of clinicians that had contributed to the delayed primary care proposals:

> I think they had some pushback from doctors and doctors' trade unions and stuff, saying "this is a matter for our members, to refuse services", and I think that just gave them pause for thought.

Migration Policy Analyst, Key Informant Interview, November 2007

Therefore bounded pluralism does not provide a full account of different levels of influence within interest networks, especially when one group, as with clinicians in this case, is both an actor in the policy process, and responsible for implementing the policy on the ground.

c   The Influence of the Media

Many key informants, both humanitarian and resource-protective, cited the media as a central actor in the policy process, both in having a stake in misleading reporting of immigration and asylum issues, and in the extent to which Government policy-making was perceived as influenced by this agenda-setting.

HIV and asylum were issues that were seen to have been mistakenly conflated, giving the public the impression that asylum-applicants were responsible for the UK epidemic. However, many key informants across the political spectrum felt that negative coverage of immigration and asylum did reflect public concerns as often as they influenced them; some identified a tripartite 'refractory process' between the media, public opinion, and Government responses

(with each influencing each other towards continuously increasing restrictive immigration policy-making) as contributing to an increasingly restrictive immigration and asylum agenda.

The tabloid papers *The Sun, the Daily Mail, and the Daily Express,* were most frequently mentioned as contributing to a negative discourse on immigration. In a submission to the JCHR, the Commission for Racial Equality (CRE) said that: *"in certain high-circulation newspapers' coverage of asylum in recent years has often been disproportionate, inaccurate and hostile"* and that *"a significant finding of research on asylum seekers/refugees and the British media has been the repetitive use of certain terms and types of language.* Asylum-applicants are described as a *"flood"* or *"wave"* and as *"bogus"* or *"fraudulent".* The CRE suggested to the JCHR that this portrayal ran the risk of promoting hostility towards asylum-applicants, as well as new migrants more generally [272]. However, a disproportionate focus on immigration was not the sole province of the tabloid press. A broadsheet Home Affairs editor interviewed for this research admitted that he would give immigration stories precedence over other topics, because of the contention they generated:

> *I mean, as a journalist, if I've got a number of topics or stories ... and I've got an immigration story, I'll usually feel quite happy about that because I know it is – and this is a shocking thing to say – but I know it is quite a strong story, it will play well with my news editors, we know it's something that will get readers talking, and it's a good commodity to have. Immigration stories are strong stories.*

Home Affairs Editor, National Broadsheet, Key Informant Interview, April 2008

For advocate key informants though, disproportionate reporting was secondary to the quality and content of reporting. The conflation of HIV with asylum was a particular worry for some of these respondents, since it further demonised asylum-applicants and legitimised xenophobia:

> *The whole issue of HIV and asylum seekers is a very sensitive one, because again there's this idea propagated by the right wing press and politicians that HIV is a problem brought here by foreigners. Including asylum seekers ... And that therefore if you're trying to look tough against asylum seekers... why should we pay them to get better?*

Refugee Charity Operations Manager, Key Informant Interview, December 2007

Indeed, media representations of asylum-applicants were seen by the JCHR to be so overwhelmingly negative that they wondered whether they violated the UK's human rights obligations:

> *The treatment of asylum seekers by the media raises questions about whether the state is fulfilling its positive obligations to protect asylum seekers from unjustified interference with their right to respect for their dignity, private life, and physical integrity, and to secure their enjoyment of Convention rights without discrimination, consistently with the right to freedom of expression.*

The Treatment of Asylum Seekers [272]

The role of the state *vis a vis* media coverage of asylum issues was also discussed by many clinical, legal and advocacy respondents, who reported a view that the Government took media reporting of asylum as *carte blanche* for restrictive policy-making, since it was evidently representative of the views of the UK public. A careful examination of Government policy documents would suggest that there was an implicit assumption that the media accurately represent public opinion. *Secure Borders, Safe Haven* identified asylum as an issue of primary concern for the public because of reporting on this issue in the mainstream press:

> One of the issues which troubles the public most in relation to nationality and immigration is a belief that entry into this country and residence here is subject to abuse. The amount of column inches devoted to those trying to reach our shores through clandestine routes illustrates that the issue of asylum outweighs the much broader debate about migration, nationality and integration.

Secure Borders, Safe Haven White Paper, [133]

Who sets the agenda?

How the media fit into the agenda-setting process, and the direction of influence between the media, government and public was contested by most respondents, who provided varied accounts of the relative influence of these three actors.

Some key informants felt that government policy-making responded almost entirely to media reporting, becoming ever more restrictive as the government's increasingly 'tough' stance on asylum convinced the public and media that there was a problem. One respondent interpreted this as a failure of political leadership on immigration issues, and felt that this was particularly evident in the absence of attempts to defend the principle of asylum or promote positive aspects of asylum:

> I think the government do use it [the scapegoating of asylum-applicants]. I do think there are times when it's happy to stoke these fires because it's convenient for them to do so. I'm not saying they originate with government but there's certainly no sense that they'd do anything about turning the debate, or informing it, or anything. It's almost, they allow it to burn.

Migrant Health NGO Coordinator, Key Informant Interview, February 2008

However, the government did not hold that policy-making on asylum has been responsive to public opinion and media agenda-setting rather than real problems. A Home Office civil servant felt strongly that policy-making had responded to actual immigration events:

> The public concern about irregular migration was growing because of the increase in asylum applications in the late 1990s. In addition there was an awareness of the rise of organised misuse of the system...This government has been responding to real pressures... It is not fair to say that policy has been a response to public opinion.

Home Office Civil Servant, Key Informant Interview, August 2008

Other government accounts (such as the excerpt from *Secure Borders,* above) suggest that public opinion, as reflected by the media, has been a concern for this government. That this evidence emerges from white papers would imply that policy is influenced by these concerns. Conversely, Statham (2003) found that it was government policy messages that most influenced the public discourse on asylum and defined the normative limits on asylum and race relations. Some key informants for this research also identified that public discourse was led by policy:

> And I think that that's where you have a government who are giving a lead on that. And also...particularly, it's been put down in writing in this piece of legislation [the Charging Regulations], so obviously that's going to have an effect. It's basically saying, if you are at all prejudiced against asylum seekers, that's fine. That's the message of that piece of legislation.

Refugee Charity Operations Manager, Key Informant Interview, December 2007

Key informants' perceptions of agenda-setting varied, but their differing accounts suggested that the agenda was not consciously set by the public, press, or state; no single one of these could be identified from their accounts as a point of origin for an escalating and hostile stance towards asylum-applicants. Rather, the agenda was set via a 'refractory' process between all three. One respondent summed up this analysis of asylum agenda-setting:

> I think that the way some of the more right-wing press frame the issue, and then the way politicians react, and then the way that statement and the media then feed back into public opinion is just a very vicious cycle.

Migration Policy Analyst, Key Informant Interview, November 2007

The next section examines the content of the policies that emerged from this respondent-identified cyclical process in more detail.

4.3.2   Immigration Strategy and Policies on Access to Healthcare

Restricting access to healthcare for insecure immigrants helps to fulfil three immigration strategies of deterrence, internal controls, and enforced discomfort (deliberately making migrants' lives uncomfortable). Many key informants identified these strategies as central to the current UK government approach to immigration control, and placed healthcare restrictions within them.

a   *Deterrence*

> "It is sending a signal out, and it is basically that, you know, Britain's doors are increasingly closed."

Home Affairs Editor, National Broadsheet, Key Informant Interview, April 2008

It is clear from document analysis that recent immigration policies have in part aimed to deter individuals from entering the UK, and that this is considered an efficient approach to immigration control. For example, the white paper *Firmer, Faster and Fairer* discussed immigration control strategies under the previous Conservative administration and identified slashed benefit entitlements as having reduced the number of applications in a period when applications were increasing:

> *Applications increased substantially in 1994 and again in 1995 (to 44,000), but, after falling back in 1996 (following the reduction in benefit entitlement for asylum seekers), continued rising in 1997 and early 1998.*
>
> *Fairer, faster and firmer: a modern approach to immigration and asylum* [131]

The implicit assumption in the above reading of immigration statistics is that limiting access to welfare explained the trough in applications in 1996, and therefore that this was an effective control policy. Deterrence became an explicit strategy in later documents, and was often utilised within a polarised characterisation of asylum-applicants once again as either 'genuine' refugees or 'false' applicants:

> *The Government is determined that the UK should have a humanitarian asylum process which honours our obligations to those genuinely fleeing persecution while deterring those who have no right to asylum from travelling here.*
>
> *Secure borders, safe haven: Integration with diversity in modern Britain* [133]

Within this broad strategy, restricting access to healthcare may seem to provide a double deterrence. First, in a context where health tourism is seen to motivate some asylum-applicants, the healthcare access policies may prevent people from travelling to the UK. One overseas visitors' manager expressed his view that a more restrictive approach to the enforcement of the Charging Regulations would eliminate health tourism:

> *People don't go to America to try and seek...you know, and that's like a decent analogy. You don't get health tourists in America, because you know you're not going to get anything.*
>
> **Overseas Visitors' Manager, Key Informant Interview, February 2009**

The Joint Committee on Human Rights explicitly identified deterrence in its summary of hearings on the treatment of asylum-applicants:

> *The Government's approach to asylum has... been based on ...the development of policies which aim to deter and prevent would-be asylum seekers from coming to the UK... through a significant reduction in the welfare and health benefits to which asylum seekers, especially those whose applications have been refused, are eligible to access.*
>
> *The Treatment of Asylum Seekers* [272]

Second, the healthcare access policies serve as deterrents because they aim to prevent those migrants who are in the UK from accessing the NHS and consuming resources intended for the taxpayer. DH documents suggest that central to this strategy was the notion that the 2004 amendments restricting access to healthcare acted as a marketing tool, sending out the message that free healthcare was not necessarily available:

> *The NHS is beginning to get better at fulfilling its legal obligation to ensure that it provides free hospital treatment only to those who are eligible to receive it... Moreover, it would seem that the message is also beginning to get out to patients and the public that if they have come from overseas, they should not assume that they will get free hospital treatment.*
>
> **Government response to the Health Select Committee's Third Report of Session 2004– 2005 on New Developments in Sexual Health and HIV/AIDS Policy, [237]**

And key informants felt that this policy had been successful in its secondary aim of deterring those in the UK from seeking out healthcare; that conflating health and immigration policies would discourage insecure immigrants from seeking out care:

> *The more you set up your health services to act as immigration control, the less likely it is that people are going to seek healthcare.*
>
> **Refugee Charity Head of Policy, Key Informant Interview, December 2007**

This use of public services as an extension of the immigration system was also perceived by key informants as a defined Government strategy. The next section discusses this in more detail.

b   Internal Controls

Many key informants, especially those from advocacy organisations, felt that immigration control had extended its reach from border control into the public sector more generally, and that this was likely to undermine service delivery. They felt that that immigration control ought to be the responsibility of immigration services, and not other public service staff. This sentiment was echoed by Justice Mitting in his judicial review summation:

> *It makes much more sense both in practice and in principle to leave the task of deciding upon need to the provider of health, education or social services, and the task of deciding whether or not a person should be allowed to remain here to take advantage of those services to the immigration authorities.*
>
> **The Queen on the application of A v West Middlesex University Hospital NHS Trust [184]**

The strategy paper *Enforcing the Rules* made clear the expectation that staff outside the Home Office and immigration authority would be expected to enforce immigration rules, by helping to identify and potentially exclude migrants from public service access. Once again, this

strategy was tied to a polarised characterisation of migrants, in utilising service access to privilege the 'legal' over the 'illegal' migrant:

> *We intend to widen the gap between the experience of legal and illegal migrants... As part of this process, we will make it easier for employers, healthcare workers, local authorities, government agencies and service providers like banks to access information more easily and determine whether or not migrants are here legally and entitled to services.*

Enforcing the rules - A strategy to ensure and enforce compliance with our immigration laws [157]

Key informants working in service delivery were resentful of being forced, as they saw it, to act as immigration officials. They felt that they were being used for immigration control because the Home Office was not able to do its job properly:

> *The Border and Immigration Agency's problems... I would have a set of views about the Borders and Immigration Agency, but my point here is, if you can't do your job, right, don't try and devolve it to me.*

PCT Non-Executive Board Member, Key Informant Interview, August 2008

What is clear from the accounts of key informants in advocacy and service delivery is that they perceived the strategy of internal controls as not only inappropriate in its impact on them professionally, but that this was a considered and deliberate (and therefore reversible) approach to immigration control. One key informant with an agenda of resource protection acknowledged that those required to implement the policies might experience professional conflicts in being asked to prioritise immigration control over their other tasks, but felt that this was unavoidable. In his view, the structural factors influencing this strategy were such that there was no option but to exercise a system of internal control; that there was no doubt that migrants would try to deliberately undermine the system (for example, by 'losing' documents), and that devolved immigration control was therefore inevitable. He explained:

> *That doesn't mean that that pressure isn't going to be there for doctors and with all the will in the world about who should be confronting it, if you have a problem like missing documents... there are issues which the Home Office – even if it were run efficiently – ...there would still be those issues.*

Resource-protection NGO, Policy Analyst, Key Informant Interview, May 2008

In this view, it was necessary for the Government to enforce internal controls since only by making it clear to those trying to abuse the system that they were not entitled to (e.g.) healthcare could you expect to regain some control over immigration more generally.

This perspective does not seem to be out of step with much of Government policy-making. A third strategy that is connected to a system of internal controls, and is seemingly intended to

encourage migrants to return home, relies on enforced discomfort, and is discussed in the next section.

c   *Enforced Discomfort*

There is significant evidence to suggest that the Government has been practising a deliberate strategy of making uncomfortable the lives of unauthorised migrants in order to encourage them to leave the UK. For example the Immigration Strategy Paper *Enforcing the Rules* states that:

> *We need to make living and working here illegally ever more uncomfortable and constrained... For those not prioritised for removal, they should be denied the benefits and privileges of life in the UK and experience an increasingly uncomfortable environment so that they elect to leave.*
>
> **Enforcing the rules - A strategy to ensure and enforce compliance with our immigration laws [157]**

The JCHR identified enforced destitution as part of this strategy, and the removal of the right to work for asylum-applicants in 2002, coupled with the reduction in financial support for both asylum-applicants and refused asylum-applicants (who receive £35 weekly in the form of vouchers redeemable at certain outlets [31] was seen to have contributed to significant and deliberate privation:

> *We have been persuaded by the evidence that the Government has indeed been practising a deliberate policy of destitution of this highly vulnerable group.*
>
> **The Treatment of Asylum Seekers [273]**

However the Government took umbrage at this accusation, stating that there was no deliberate policy of destitution, citing the support provided to 'genuine' asylum-applicants as evidence of this:

> *The Government strongly refutes the Committee's claim of a deliberate policy of destitution towards asylum seekers. The Government has consistently stated that genuine asylum seekers are welcome and has put in place considered arrangements to provide support to those in need.*
>
> **Government Response to the Committee's Tenth Report of this Session: The Treatment of Asylum Seekers [267]**

However, it is interesting that the Government did not mention or respond to the Committee's concerns for refused asylum-applicants. It may be because of the assumption by Government (discussed earlier in the section 'Growth in Asylum Applications') that unsuccessful asylum-applicants were individuals who had been deliberately making a false claim. Within this

context, providing support to asylum-applicants is sufficient since it discharges a duty of care to those individuals acting lawfully, and not to those seen to be behaving unlawfully.

One key informant saw restrictions on access to healthcare as forming part of this wider strategy. She was particularly concerned about the impact of this strategy on those from countries like Zimbabwe who could not be deported, but were nevertheless categorised as refused applicants and therefore subject to the same immigration control procedures as any other unauthorised migrant:

> *The health thing is another tool in coercing people to leave the country, who feel for themselves that it's not safe for them to do so, or that it's not viable for them to do so. So it sits alongside destitution as the way that, the Government's deliberate approach to people at the end of the asylum process, who the Government expect to make a voluntary departure, but don't, so end up in a limbo where their limbo isn't being enforced, either because immigration hasn't got round to them yet, or because there's no enforced removals, for example to... Zimbabwe.*

Refugee Charity Head of Policy, Key Informant Interview, December 2007

This perception was reinforced by an Overseas Visitors' Manager who admitted that the healthcare access rules formed a deliberate component of Government strategy to encourage migrants to leave the UK:

> *We've already got rules in place to restrict them, you know, but we'll just strengthen them rules in place, restrict them even further. And see if we can get them to go home. Because that's what current government policy does anyway, you know.*

Overseas Visitors' Manager, Key Informant Interview, February 2009

Some key informants felt that the failure to include HIV in the exempt list of diseases might have been related to the perceived cost of treatment. Others wondered whether it might not have been an accident of the timing of the original Charging Regulations in 1989, when the exempt list was originally drawn up, since HAART did not come about until 1996. However, for another advocacy-based key informant, the failure to include HIV in the exempt list of diseases in the Charging Regulations was also part of this strategy of enforced discomfort, and was designed to encourage HIV-positive migrants to leave the UK:

> *The non-exemption of HIV, it is exactly the same place, they're saying "if you don't like it go home". That's the point.*

Refugee Charity Operations Manager, Key Informant Interview, December 2007

Restricting access to healthcare seems to have been used as a policy component of three separate but interrelated immigration control strategies. However, charting the progression of this policy and its use has shown that a fundamental shift has occurred in the language

explaining the motivation to sustain restricted access to healthcare. At its inception, health tourism and protection of taxpayers' resources were primary in the motivation in making access to the NHS conditional upon migrant status. However, over time and as restricted access to healthcare seems to have been co-opted into a broader strategy of immigration control, Government language has changed and become punitive: access to healthcare is restricted in order to make life uncomfortable and difficult for those individuals who remain in the UK outside the immigration rules.

4.4 Chapter Conclusion

Both Government policy documents and key informants' views indicate that the public are seen to wield substantial influence over the direction of immigration policy. A preoccupation with entitlement to public services and the meaning of citizenship seems to have been central to the debate on migration under the Labour Government, and may have informed the Charging Regulations and Primary Care Proposals. Some key informants felt that the emphasis on conditionality may have been linked to an excessive Government preoccupation with public opinion and electoral concerns. Some respondents saw conditionality as stemming more from an overtly philosophical stance which aligned the maintenance of the nation-state with boundaries around the benefits of citizenship. In this perspective, Labour's emphasis on social inclusion seemed to form part of a wider approach to integration policy, although contradictory statements make it hard to know where in the integration process Labour sees the beginning of integration policy.

The UK does not operate its immigration and health policies in isolation from the rest of the world, and global health inequalities have had an impact on policy. An awareness of health resource imbalances may have contributed to some policy-makers' expectations of health tourism.

The Government used its high political power to enact immigration policy in a low political arena, where it was more likely to encounter plurality and therefore opposition. Conversely, the use of secondary legislation made formal opposition very difficult. Within a bounded pluralist framework [274], policy on access to healthcare for migrants occupies an unusual position, in engaging both high and low political issues, and therefore in being to some extent dominated by political elites, while aspects of the policies are open to the more pluralist influences of advocacy networks. The Government response to the Consultation process exemplified this oscillation between the influence of elites (Government) and other, more plural interests (the advocacy coalition). Clinicians were perceived to be particularly powerful members of the advocacy network, partly as a result of the historical strength of the BMA, and the control they could exert over health policy implementation. The role of clinicians and others in policy implementation is discussed further in the next chapter.

5. Chapter 5 - Implementation of the NHS (Charges to Overseas Visitors) (Amendment) Regulations 2004

This chapter examines the implementation of the Charging Regulations, with a particular focus on the strategies of those actors required to implement them within a clinical or hospital setting. Implementation is thus considered within the context of the three immigration strategies (deterrence, internal controls, and enforced discomfort) outlined in the previous chapter on policy formulation, as well as of the Charging Regulations themselves, and their accompanying Guidance.

As with the previous chapter on policy formulation, both key informant interviews and document analysis were used to explore the way policy is implemented. This thesis takes a top-down approach to understanding policy implementation insofar as it begins with a focus on a policy decision by government (the Charging Regulations) and then asks to what extent the actions of implementing officials are consistent with that policy decision [275]. However, methodologically this research can be characterised as typically more 'bottom-up' in its concern with the experiences, actions, and enactment of policy decisions by 'street-level bureaucrats' (in this case, clinicians and hospital staff).

Lipsky defines street level bureaucrats as "workers who interact with and have wide discretion over the dispensation of benefits" [220, p. xi]. The characteristics they share include: independence in their individual exchanges with clients; a concern with the need to work efficiently; organisational conditions that include insufficient resources; the need to make decisions quickly; 'ambiguous and multiple objectives'; and clients whose participation in the [welfare] system is non-voluntary [276]. Both clinicians and non-clinical hospital staff can be viewed through this prism in their work-roles in general; and more specifically when their clients are caught within UK immigration strategies and therefore voluntary participation is further diminished.

The chapter begins by describing the state's formal efforts to ensure policy implementation, before examining clinic-level processes and strategies associated with implementation of the Charging Regulations, as well as the role of actors and their beliefs in these processes.

5.1 Introduction: From Policy to Practice? Attempts to Ensure Implementation

The Guidance provides explicit information to Trusts on how to implement the Charging Regulations. It repeatedly emphasises that Trusts have a legal obligation to implement the Charging Regulations. This means that they must identify patients who are not ordinarily resident, assess their liability for charges, and then charge those who are liable to pay [181].

The Guidance insists that Trusts will need to have systems and staff with the appropriate skills to carry out these tasks. The Department of Health has repeatedly issued statements indicating that in its view, developing systems to ensure that treatment is withheld until payment is received does not constitute a refusal to treat:

> The Regulations *do not* require hospitals to refuse to treat someone in urgent clinical need solely because they are, or are believed to be, liable to charges and unable to pay. They confer powers to levy charges and to pursue payment of them as far as is considered reasonable in the particular circumstances of the case. But best practice is to ensure that overseas visitors are aware of the expectation to pay charges, and likely cost, before they start treatment – so they can consider alternatives like a return home, if they are well enough to travel.

> **Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: A Consultation [174, emphasis in original document]**

> This is not refusing to provide treatment, it is requiring payment conditions to be met in accordance with the charging Regulations before treatment can commence.

> **Implementing the overseas visitors hospital charging regulations - Guidance for NHS Trust hospitals in England [181]**

The repeated assurances that charging for care and refusal to treat are not synonymous may have stemmed from responses to the DH's original 2003 consultation on amending the Charging Regulations, in which respondents had 'misunderstood' the proposals in thinking that "people will have treatment withdrawn or withheld" [174][53].

Parliamentary Committees conducting hearings on issues relating to the charging regime have found that the Guidance is not a simple layperson's guide on how to interpret the relevant statute. The DH informed the JCHR that the existence of the Guidance itself "had the effect of raising the profile of the charging regime so that more NHS hospitals are carrying out their duties in this area more rigorously" [198]. The Health Select Committee heard evidence to suggest that the Guidance lacked clarity on important issues, such as how to determine what constitutes 'immediately necessary' care, and that this paved the way for clinicians to interpret the rules differently [179]. However, the Guidance has not been immutable. Criticism from the Health Select Committee that the Guidance lacked clarity on whether or not treatment for HIV in pregnancy constituted immediately necessary care was reluctantly accepted by the DH – which felt that the Guidance was explicit already and that the problem lay with interpretation in practice – and the Guidance was reissued [237].

The Guidance specifies in some detail how Trusts should determine whether an individual qualifies as ordinarily resident. Prior to the April 2008 Mitting judgment, paragraph 6.24 of the

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[53] It is worth noting that although 45% of respondents to this consultation were not in favour of the amendment, this large opposition was taken by DH to represent "a lot of misunderstanding over what the proposals actually mean" [174].

Guidance specified that refused asylum-applicants who had been resident for more than twelve months would *not* become exempt from charges; it was this that was found to be unlawful. Although the DH did not formally reissue the Guidance to reflect these changes, it did issue a letter to Trust Chief Executives, informing them of the change in the Law and advising them to "consider whether each failed asylum seeker that they treat can be considered ordinarily resident in the UK, in the same way as they would do with any other patient, taking into account the judge's opinions as to what would be likely to be sufficient proof of ordinary residence" [277].

It is hard to know to what extent the Guidance's lack of clarity and deliberate emphasis on refused asylum-applicants as a group was intended by DH; it may be that the Guidance is a poor reflection of the intentions of the original policy and that implementation has thus steered far from the course intended. Further, the DH's contention that the existence of the Guidance had itself had an effect on the implementation of the Charging Regulations implies that whether or not this effect was intentional, it was considered a positive attribute of the Guidance, and that it should therefore be maintained as a tool for implementation.

The 2009 Court of Appeal decision that found that refused asylum-applicants could not be considered ordinarily resident did find other aspects of the 2004 Guidance unlawful; in particular, it considered that the Guidance did not make it clear enough that hospitals must consider providing treatment where a patient cannot return home and cannot pay for the treatment in advance [185]. However, the DH has yet to reissue the Guidance to reflect this decision, and as such this chapter examines implementation of the Charging Regulations as they are laid out in the 2004 Guidance.

This brief overview of the ways in which the Government has attempted to bridge the gap between statute and practical implementation demonstrates that perceptions of a lack of clarity, legal challenge, and criticism from Parliamentary advocates have affected the translation of policy into practice. However none of these would have occurred in isolation from an appraisal of practice, and its meaning for policy. The rest of this chapter examines the practice of the implementation of the Charging Regulations, and the role of individuals in the success or failure of policy implementation.

5.2 Clinic Level Processes

The Charging Regulations necessarily require that they are mostly implemented in hospital settings and are carried out by hospital staff. In principle, according to the 2004 version of the Guidance, all patients being clerked into a hospital should be asked questions designed to ascertain whether or not they are overseas visitors and might be chargeable. If it is concluded that they are, then any care not provided in Accident and Emergency or deemed 'immediately necessary' should be postponed until a charge or full deposit for the care has been collected, including urgent and non-urgent (routine or elective) care [181].

5.2.1 Identification of Chargeable Patients

Central to hospital-level administration of the Charging Regulations is the identification of overseas visitors, or potentially chargeable patients. The Guidance stipulates that two 'baseline questions' should be asked of *all* patients (to avoid accusations of discrimination) every time they are clerked into hospital as an in- or out-patient, or begin a new course of treatment. These are:

- "Where have you lived for the last twelve months?"
- "Can you show that you have the right to live here?"

These questions relate to the requirement in the Charging Regulations for lawful residence twelve months prior to entitlement to charge-free care. Booking-in and ward clerks are the kind of staff the Guidance stipulates should ask these questions. Where the patient has not lived in the UK for twelve months or there is doubt about the legitimacy of their residence, they should be referred to the hospital 'Overseas Visitors' Team' for further interview [181].

In practice, there is little evidence to suggest that every patient is asked the baseline questions. As one DH report into the implementation of the Charging Regulations noted, Trusts "had concluded it was not feasible at this stage to ask every patient the baseline question...; instead they were taking a targeted and pragmatic approach"[257]. One hospital debt collector's account married with this analysis when he described the approach taken by the Paying Patients' Officer (PPO) (in some Trusts the PPO carries out the tasks associated with an Overseas Visitors' Manager's role) at his Trust. She had been actively searching for patients who might not be entitled to charge-free care:

The paying patients' person was doing searches through the database, and she was doing "no GP", or "just registered in the last 6 months" – and then she was going to interview them. I don't think it was discrimination, but it was wrong. Because she shouldn't have been actively looking.

Hospital Debt Collector, Key Informant Interview, May 2008

Although this debt collector did not feel that the PPO at his hospital had been actively discriminatory (rather that she was trying to be efficient in targeting her approach to identification of overseas visitors), the risk of discrimination in this system was a central concern for advocates. Implementation of the Charging Regulations that follows the Guidance to the letter should avoid discrimination on grounds of race, but one key informant did not believe that this approach would ever be followed in practice, especially since identifying refused asylum-applicants would entail a reasonably detailed understanding of immigration law:

> *I can't see a way that it can operate which isn't racially discriminatory. Because, how does the overseas manager, or any member of the health or hospital staff team, know somebody is an asylum seeker, let alone a failed asylum seeker? They don't ask everybody that goes in to their hospital what their immigration status is, they don't ask white British people. So how do they decide to ask? Well, anybody who looks foreign, they'll pick off - so they'll start asking anybody who's black African, or Middle Eastern*
>
> **Refugee Charity Operations Manager, Key Informant Interview, December 2007**

Advocates' concerns about the potential for discrimination do not confirm its widespread existence as a phenomenon, and evidence collected for this research does suggest that the DH and Trusts were trying to institute processes that would prevent explicit discrimination. The debt collector who above described the discriminatory behaviour of the PPO at his hospital outlined a new system that was designed to ensure the less targeted approach required by the Guidance:

> *So what from the 1st June is going to happen is, all the staff should be getting questions appearing on their screen when people are registering. And they should be asking, "Can you prove your right to live here and are you here legally?" So everyone should be asked that question. And then, once that's in place, if there's any doubt then they'll refer.*
>
> **Hospital Debt Collector, Key Informant Interview, May 2008**

Indeed, the DH Guidance itself, though not legally binding, explicitly discusses the avoidance of discrimination in implementing the Charging Regulations, and encourages Trusts to apply the baseline questioning universally. Staff at Trusts are aware of the potential for discriminatory behaviour; one OVM discussed the need to be careful to avoid discrimination, particularly as it would likely have professional consequences:

> *If you treat someone differently ...you're in trouble, professionally. You wouldn't survive a discrimination case. I don't think anyone would in this day and age, but an overseas manager wouldn't....at all.*
>
> **Overseas Visitors' Manager, Key Informant Interview, February 2009**

However, despite a DH and staff-level awareness of the need to avoid overt discrimination and to institute practices which would limit the potential for accusations of prejudice, the values of individual staff required to implement the Charging Regulations do seem to indicate a tendency towards a fundamental distrust of overseas visitors. The OVM who described his awareness of the need to avoid discrimination also discussed foreign patients in terms that implied a discriminatory attitude towards those for whom English was not a first language. In his view, the absence of English language and the concomitant use of an interpreter indicated that the patient was probably lying:

> *Sometimes you can get a sense whether someone's believable or not. They're talking to you in English. I know it's not a precursor, but generally if somebody is talking on their behalf and they have to ask to ask them their answers... I generally have the impression that they're probably not telling the truth... patients lie, you know. Patients who ...want to get into hospital... generally they'll lie to the...front-line admin staff.*

Overseas Visitors' Manager, Key Informant Interview, February 2009

The approach taken at this OVM's Trust was to ensure that all patients were asked the baseline questions at every stage of their journey through the hospital. This approach was universal in two senses: all patients were asked the baseline questions, and the baseline questions were asked throughout the hospital, by multiple members of staff. However, the practice does appear to have been motivated by a fundamental suspicion of overseas patients and by the imperative to save money as much as to avoid discrimination:

> *If they [go] to another department, like endoscopy or clinical imaging or pathology, if they're waiting around, you know, generally people talk. If they've been in hospital a couple of days, they may think I'm home and dry now so I can relax. At Hospital X, you can't relax. Every single department will ask that question. Everywhere we process a patient, even if, you're an in-patient coming down on a bed, if you need to go for a CT scan, it's £1000 a go. We can't afford to spend that kind of money if we don't have to.*

Overseas Visitors' Manager, Key Informant Interview, February 2009

Advocacy-based key informants also reported case studies from their work that indicated a high degree of suspicion of overseas patients by hospital managers. Evidence heard by the JCHR also suggested that there might be a lack of knowledge on asylum procedures among those generally required to implement the Charging Regulations:

> *Looking at what the law says about who is and who is not entitled to healthcare is one thing, and is a vital tool to working out what the situation is, but actually, there is a question too about whether or not the people delivering those services understand what the laws are.*

Jago Russell, evidence presented to the JCHR, [205]

Given that the role of individuals appears central to the implementation of the Charging Regulations, and the Guidance does not itself bind Trusts to a particular approach, it is likely that there is also substantial variation in the interpretation of the rules in other aspects of their implementation.

5.2.2 Defining 'Immediately Necessary' Care

According to the Guidance, immediately necessary care should be provided without delay, but Trusts should still try to recoup costs after the fact [181]. Although the Charging Regulations themselves place a legal imperative on Trusts to recover costs *after* treatment has been provided, the Guidance strongly implies otherwise – all 'urgent' and 'non-urgent' care can theoretically be postponed until a deposit has been received from the patient. Further, the Guidance is also equivocal regarding the provision of immediately necessary care. It states that 'immediately necessary' care should not be delayed or withheld, and that defining the urgency of care is a clinical question; but goes on to say that clinicians should consider the extent to which treatment is immediately necessary, in order to consider delaying care to allow the patient to return home to avoid charges:

> *While it is a matter of clinical judgement whether treatment is immediately necessary, this should not be construed simply as meaning that the treatment is clinically appropriate, as there may be some room for discretion in some cases allowing the visitor time to return home for treatment rather than incurring NHS charges.*
>
> **Implementing the overseas visitors hospital charging regulations - Guidance for NHS Trust hospitals in England [181]**

As one key informant noted, this equivocation is open to individual clinicians interpreting the Guidance differently:

> *The current regime asks doctors to make a judgement as to whether a treatment is immediately necessary or not. Now in my experience, doctors really don't know what that means. Most of them say "Is it life threatening? Is it necessary to save a life?" Because that's the obvious interpretation and they apply it. Others will take a more conservative view – you know: "You can save your life by going home and getting treatment". So there's room for interpretation there, depending on your view.*
>
> **Immigration Lawyer, Key Informant Interview, November 2007**

What constitutes immediately necessary care in HIV treatment is also not clear. The House of Commons Health Committee noted that this subjectivity did not enable clinicians to treat all HIV-positive patients regardless of eligibility status, and that the provision of HAART to HIV-positive pregnant women to prevent vertical transmission was not automatic in this scheme:

> *The Department also states that its guidance on the application of charges is "explicit that, because of the potential risks to both mother and baby, hospital maternity services should always be considered as immediately necessary treatment. This could include HIV*

treatment where it was considered clinically necessary." However, several memoranda have reported examples where pregnant women have not been able to access HIV treatment.

New Developments in Sexual Health and HIV Policy, [179]

Where a patient is co-infected with TB and HIV and their CD4 is <200cells per µL, the British HIV Association advises initiating HIV treatment two months into a 6-9 month TB treatment regime [278]. Moreover, treating the numerous cases of TB associated with HIV co-infection without treating HIV is not considered cost-effective [258]. There is therefore a conflict between the exemption in the Charging Regulations that allows for the free treatment of TB on public health grounds, but not HIV, since co-infection is not uncommon [279]. Some HIV clinicians choose to interpret the need to provide ART to TB co-infected patients as 'immediately necessary':

> *I sometimes have to sign a piece of paper to say that I think that the treatment that they require is urgent and therefore I've had to treat them with antivirals, and they've got TB and they're eligible for their TB treatment but ...not their HIV treatment. And I quite happily sign those forms.*

Senior HIV Consultant, Key Informant Interview, July 2008

However, although this clinician is utilising the subjective nature of the definition of immediately necessary, her approach does not take account of the finite nature of the justification for providing HIV treatment, as noted by one Overseas Visitors' Manager:

> *The trouble is, you could only provide the HIV treatment while you were treating the TB treatment.*

Overseas Visitors' Manager, Key Informant Interview, February 2009

Indeed, not only does this strategy theoretically only provide for clinicians to treat during TB co-infection, but it also does not take account of the bill that the patient may be given for their 'immediately necessary' HIV treatment. Defining the care that an overseas patient requires as immediately necessary does not exempt them from charges; it allows clinicians to treat immediately without having to delay care in order to ascertain a patient's eligibility for free care or their exempt status. All NHS care not considered exempt under the Charging Regulations can be charged for; Trusts are obligated to provide immediately necessary care, but it is still not free.

5.2.3   Charging Patients

Patients who are not considered ordinarily resident and who do not qualify for an exemption from charging may be charged for any care they require. Once it has been established that a patient is chargeable and that the treatment required does not fall into one of the exempt

categories (see section 1.4.2a), any care not deemed 'immediately necessary' can, according to the Guidance, be withheld unless a full deposit or charge can be collected in advance.

Charging patients has two main components – the raising of an invoice, and the actual recovery of debt, and in this latter aspect of implementation, different Trusts appear to interpret the rules with some discretion. Indeed, despite the Guidance's insistence that all Trusts are obligated to recoup charges, a DH spokesperson interviewed for this research implied that full implementation was down to the discretion of the individual Trust when she said that "it's up to the individual trust as to what action they will take to follow that bill up"[54]. Research carried out by the DH also found that "the proportion of charges already collected and the proportion expected to be collected in total varied significantly between Trusts" [55].

Recovering charges for care provided can prove difficult when patients either can't or won't pay, and although some hospitals may prefer to discharge those who are unable to pay, they cannot always do so if there are physical barriers to discharge:

> *We get people who are... not in a position to pay. Technically they should be... discharged, but they can't, because ...if you've fallen off a ladder and you've got two broken ankles...you physically can't discharge them.*
>
> **Overseas Visitors' Manager, Key Informant Interview, February 2009**

However this respondent reported using novel strategies to ensure that payment was received before patients were discharged from hospital, including being flexible as to the mode of payment, and procuring a mobile chip and pin device for bedside use to make it as easy as possible for patients to pay their debts before they left hospital. In his view, tactics such as these were necessary since otherwise patients would probably not honour their debt:

> *They'll just disappear... we generally, nine times out of ten, we'll get it - a deposit 50, 60, 70%. I always try and go for the whole amount, but sometimes people, you know. I'll take it off ten credit cards, I don't mind. But...it's one of them things, I wanna get paid, I wanna get paid. ...It's like a mobile phone, it's a GPRS thing. People can say, I haven't got any money or I've haven't got any cash, or...and I'm like...that's OK. Fine, you know. You've got a debit card, you like...obviously you flew here. All the credit card machine is, is...if you wanna get paid, you've got make it easy for people to pay.*
>
> **Overseas Visitors' Manager, Key Informant Interview, February 2009**

Another key informant felt that charging destitute individuals made no financial sense, since the most likely outcome would be for Trusts to accumulate bad debt, and this would require Trusts to find some way of responding to annual increases in unpaid monies:

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[54] Department of Health Civil Servant, Key Informant Interview, April 2008
[55] Overseas Visitors: Report, [257]

You cannot charge people who don't have money. And if you do bill them ...all we're going to see is PCTs with mountains of unpaid debt... And at what point do you manage that? Do you write it off every year? Do you send in the auditors to find out why bills are not being paid?

Migrant Health NGO Coordinator, February 2008

When care is provided to a patient who subsequently proves unable to pay, as is likely the case for destitute individuals, Trusts may have to write off the debt. The Guidance does state that Trusts do not have the authority to waive a charge, but can write off bad debt [181]. Once again, substantial variation seems to exist in how Trusts respond to unrecoverable debts:

There's also quite a lot of discretion in what you write off and what you don't write off, and I'm not as au fait as I might be with the various political levers around that, but I'm aware that some hospitals are much better at writing off un-reclaimable debt than others.

HIV Charity Head of Policy, Key Informant Interview, January 2008

However, debts are not necessarily written off lightly. One hospital debt collector described the stages associated with trying to recover debts, and reported that the debt would remain his personal responsibility for three months, after which time it would be passed on to an external debt collector. Only when the external debt collector had given up on chasing the debt would it be written off:

If it goes beyond 3 months then it gets referred to an external debt collector and they try and deal with the chasing. They send out weekly letters, and they also try and telephone them to get money from these patients ...Sometimes they're successful... the policy that I've developed is that when the external debt collector gives up, that's when we write it off. So it gets handed over to them and then they say, oh we can't find this person or we sent letters and there's been no response, at that point it gets written off. So they recommend the write-off back to us.

Hospital Debt Collector, Key Informant Interview, May 2008

The use of external debt collectors was a concern for some advocates, who felt that unscrupulous practices could threaten vulnerable migrants; however most reported finding ways to help their clients avoid being pursued by debt collectors in the first place, or reassuring their clients that the actual power of these collectors was somewhat limited and that they could continue to access treatment:

Patients who've had treatment or are having treatment, but are being pursued very aggressively and are absolutely terrified. I've given them this spiel to explain to patients that the reason they're [debt collectors] barking so loudly is because they can't bite. And once they've advised them about it, the patients are in a much stronger position to continue to access that treatment, rather than go underground, which I think happens a lot.

Most key informants reported that HIV treatment was usually provided as a result of clinicians' insistence that it was immediately necessary, but that charges were usually issued. In fact, the independence (both physical and financial) of GUM centres in the UK was seen to further facilitate clinicians' capacity to provide care 'outside' the rules. HIV clinicians were also seen by some respondents as culturally 'more likely' to bend the rules than clinicians in other specialties:

> There's a disparity between HIV and other areas of payment, and if you're someone with HIV quite often you'll be able to get into a clinic without any questions asked, a specialist clinic... [but] if you have cancer or a number of the other long-term conditions which are life-threatening, their definition of immediately necessary treatment is treatment necessary to get you well enough to be stuck on a plane and sent back wherever you came from, whereas in HIV there is a very clear interpretation of immediately necessary treatment as anti-retrovirals to prevent you from getting sicker.

HIV Charity Head of Policy, Key Informant Interview, January 2008

Further, the two key informants who had a role in identifying and charging patients both asserted that all that was legally required of them was the raising of an invoice. Both observed that the issuing of an invoice did not legally compel patients to pay:

> We don't have a legal obligation to recover the money or do anything else. So it's like, there's only the legal requirements to identify and make a charge. That's the only thing that's given to us by the Department of Health... But there's no legal requirement that compels people who've been given a charge to pay it.

Overseas Visitors' Manager, Key Informant Interview, February 2009

Legal loopholes, such as the absence of a viable criminal charge against non-payment of an invoice, enabled respondents to find ways to circumvent the rules when they felt either that it was not worth implementing them to the letter, or that their own value systems prevented them from implementing the Regulations in particular cases. In the extract below, a hospital debt collector described an occasion where a patient who was very unwell had attempted to leave the hospital out of fear of the debt he was incurring. The treating clinician convinced him to stay, and he recovered. However the patient's family were subsequently sent a bill for his treatment and approached the respondent in a distraught state. He indicated to them that there was no legal obligation to pay:

> We ended up raising a bill for £8000. And the bill went out and his family turned up in my office, quite upset. And they said, "Well, the hospital didn't help because you insisted on keeping him in when he wanted to discharge himself, so you've added to the bill." And I just kept saying to them, "We're required by law to raise an invoice", and they were like - one of the family friends who'd turned up, clicked eventually. And I said, "It's only a piece

of paper. It's an invoice. We're required to raise an invoice". And eventually the family friend went, Aah (laughs). And they went away happy.

Hospital Debt Collector, Key Informant Interview, May 2008

Although this respondent's job required him to recoup debt from patients, including overseas visitors, his delight in recalling this event and the family's relief at being informed that they did not have to pay indicated that he was willing to circumvent the rules when he had personally decided that he did not approve of them. This was not uncommon among clinicians and managers interviewed for this research who had experience of implementing the charging regulations. In this sense, the beliefs and values of individuals were central to the policy's implementation, and the next section discusses in more detail the strategies that respondents used to get round the rules.

5.3 Circumventing the rules

As shown above, the Guidance is open to substantial interpretation, and it has been criticised by Parliamentary Select Committees for the onus this might place on clinicians to determine clinical need. Data collected for this thesis also suggest that the political perspective of individuals with a role in implementing the Charging Regulations can influence their interpretation of the Guidance. Indeed, the two key informants interviewed for this research who had an explicit role in implementing the Charging Regulations in Trusts (an OVM and a hospital debt collector), both discussed the 'interpretability' of the Guidance, and the ways in which they utilised this to fit in with their personal agendas.

Data collected for this research consistently implied that although the Charging Regulations aimed to restrict access to healthcare for those not entitled, and that this was effective under certain human resource conditions, clinicians and some managers found ways to avoid full implementation of the regulations and provide secondary healthcare services. HIV treatment was seen as exemplifying this phenomenon, with few key informants reporting personal experiences of seeing overseas visitors being denied HIV treatment:

> *For people with HIV I've never heard of anybody being – I've got to say I know there are cases, but I personally have never had anybody turned away from a hospital because they needed treatment if they were HIV-positive.*

Migrant Health NGO Coordinator, Key Informant Interview, February 2008

This phenomenon emerged strongly from doctors' perception that there was a conflict between the behaviour asked of them by the Charging Regulations, and their clinical duty of care. One respondent discussed her imperative to care for the patient in front of her. She acknowledged that the belief systems of clinicians in her team did not always support providing free healthcare to migrants who were not entitled, but emphasised that this had never prevented care being provided on the basis of need:

> *As far as I'm concerned I'm not an immigration officer: I'm a doctor; if the patient's there in front of me, I get on and treat the patient. It doesn't make any difference to me you know whether they're eligible or ineligible. That's not my call... I think we have to be sensitive that within the team there are different opinions... certainly in our clinic I cannot give you one instance where a patient has not got the treatment or has had to go without the treatment they needed.*

Senior HIV Consultant, Key Informant Interview, July 2008

This extract also betrays an assumption that to observe the Charging Regulations would entail acting, as this respondent saw it, as an immigration officer; this perception may have reinforced her desire to resist enforcing the Regulations in order to signal more strongly that her role was entirely clinical. Most clinicians felt that their duty of care trumped other

professional responsibilities, and believed that their individual choices were shared by their colleagues too:

> On the whole, I don't think that many doctors are... not treating because of the charging regulations, in HIV, specifically. I think some are, but I think it's a minority. So I think that the clinical care is being delivered.

HIV Consultant, Key Informant Interview, May 2008

Clinicians also felt that they had a professional responsibility to protect public health, and that the failure to exempt HIV from the Charging Regulations meant they had to oppose implementing the Regulations because of the transmissibility of the disease. There were value-for-money arguments associated with preventing its progression:

> I think that's an interest of a healthy society. I think with HIV that's particularly the case because it's sexually transmitted and it's a progressive disease and it's, you know, it's much more cost-effective to give someone £6 or £7,000 worth of antiretroviral therapy than to fund a £20,000 stay in ITU.

HIV Consultant, Key Informant Interview, July 2008

Clinicians interviewed for this research all felt that their duty of care to the individual and to public health trumped other professional commitments. Providing care outside the Charging Regulations was made possible by three main factors: that determining 'immediately necessary' care is a clinical decision; that GUM clinics enjoy more confidentiality and autonomy than other specialist centres; and that clinicians found ways to deliberately circumvent the rules. In the extract below, a senior HIV consultant discussed her approach to patients who were not entitled being presented with invoices for their care – much like the debt collector above, she advised patients who she felt were not able to pay, to ignore the bills:

> But when occasionally somebody has ...been identified as being ineligible for care, and is here as a failed asylum seeker, and they're told they're going to get a bill, well the realities of...they have no resources – they're not going to be able to pay the bill so, I always very much ...I have had patients saying, "look I'm really worried about this", and I just go, "well look, you can't pay the bill: throw it in the bin".

Senior HIV Consultant, Key Informant Interview, July 2008

Although the Charging Regulations require that all secondary healthcare providers, including GUM/STI clinics, make efforts to identify and charge ineligible patients, the historical independence of these sites has made it easier for clinicians operating within them to resist full implementation. As the House of Commons Health Committee pointed out, "a universal characteristic of sexual health and HIV services is that they are open-access, so a person should be able to walk in off the street and have access to a doctor without a referral from elsewhere. Another unique feature of sexual health and HIV services... is that they are run on a highly

confidential basis. Patients are asked for only a minimum of personal information, and are informed that they do not even have to give their real name or an address if they do not wish to"[179]. These characteristics necessarily predicate against asking the baseline questions of all patients and therefore identifying chargeable patients – indeed, one debt collector explained that in the GUM clinic at his hospital "the questions aren't asked"[56]. Financing for sexual health services at his hospital was provided by the PCT on a confidential basis, so that individual patient-level data were not required, thus circumventing those aspects of the internal market that had facilitated the charging of overseas patients in other specialties:

Sexual health and A&E, as you know, we just charge [the PCT]. We didn't have to identify where the person was. So what would happen was... a set of data does get electronically sent to [the PCT], with... some sort of patient-level detail, but the patient-level detail of sexual health is just, I think, ...x number of outpatients, and that's how much we get.

Hospital debt collector, Key Informant Interview, May 2008

The 'walk-in' nature and therefore physical independence of most GUM clinics from their hospitals also facilitated this generalised resistance to the Charging Regulations, insofar as OVMs did not have a role within these sites:

We don't have a Patient Overseas Officer coming along to the clinic. Now that's partly because we're a community-based organisation, rather than a hospital-based organisation. And so ...I've never seen an overseas officer in the clinic, ever. At all. Never. Ever.

HIV Consultant, Key Informant Interview, July 2008

However, although HIV treatment and other GUM services were relatively easily provided in this context, clinicians reported difficulty with referring patients when they required mainstream in-patient care, because of the concerns that the patient would be identified and charged:

The only difficulty comes with the...with in-patient care when we have [hospital] overseas officers asking about that.

HIV Consultant, Key Informant Interview, July 2008

Indeed, the independence of GUM clinics and the obduracy of some clinicians have been identified by the DH as barriers to improved implementation of the Charging Regulations in the sexual health sphere:

Among the people I spoke to i.e. Overseas Managers and Trust management, the main concern was the practicality of implementing the guidance. Most Overseas Managers were facing an uphill struggle because of the traditional confidentiality of the GUM

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[56] Hospital debt collector, Key Informant Interview, May 2008

services and the hostility of some clinicians. In one case, senior Trust management said that the Overseas Manager was not welcome in GUM.

Overseas Visitors: Report [257]

And an OVM giving evidence to the House of Commons Health Committee reiterated this, noting that "the consensus of a lot of overseas managers is that actually to get access into [sic] information in GU clinics and sexual health clinics is taboo: we are not allowed in. There is a lot of hostility against overseas managers even to want dialogue with people in GU clinics"[179]. Thus conflict between managers and clinicians would appear to be a feature of clinicians' attempts to resist implementation of the Charging Regulations.

5.3.1   Clinical conflict

The relative power of clinicians and managers is brought into focus through an examination of conflict between managers and clinicians over the implementation of the Charging Regulations. A Commissioning Manager giving evidence to the Health Select Committee described this conflict as creating "an enormous amount of tension within hospitals between administration and medical staff: Treatment or payment? Who has the loudest voice within the hospital?"[57]

One OVM discussed his contention that in some Trusts consultants had more power to resist the Charging Regulations than managers had to implement them. In his view, a concern about clinicians' power meant that he had to institute a rigorous approach to implementation:

> *Internally in some hospitals the consultants have all the power. Sometimes it's hard to ask a consultant to discharge a patient because the first thing they'll say is, they've taken an oath to make people well, and yes they have, you know. I've got no problems with that. But if the consultant's got all the power in the trust, then the trust management are never going to be able to implement a policy as robust as this. You rise (sic) your head above the parapet and people shoot at you.*

Overseas Visitors' Manager, Key Informant Interview, February 2009

For this OVM, the decision to implement the Charging Regulations as rigorously as possible in the face of opposition from clinicians meant that he had experienced considerable criticism. Indeed, accounts from other key informants would appear to support the view that clinicians can wield substantial power over management. One debt collector recalled that in his hospital the GUM clinicians had threatened a 'walk-out' if they were required to implement the Charging Regulations within HIV care:

> *I: You mentioned that [Hospital X] doesn't charge anyone for HIV care, how does it manage that?*

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[57] [179]

P: I think [Dr X] and the consultants had threatened to walk out.

I: Threatened to who?

P: To our chief exec.

Hospital debt collector, Key Informant Interview, May 2008

However accounts from actors outside the hospital setting did imply that managers had some recourse to respond to threats of this sort. One immigration lawyer who had experience of challenging hospital decisions to refuse care to overseas visitors discussed his perception that although clinicians were resisting the pressure to implement the Charging Regulations, Trust management did also have the means to retaliate:

> *Where I'm challenging the hospital, doctors bending over backwards to give me the most helpful medical report they can for my client, whilst the managers are vigorously defending the case. Or just speaking to doctors... an HIV consultant was talking to me... saying, "Well, at the moment, we're defending our patch, we don't think we should be refusing anyone, and their threats are becoming more and more strong, and now our budget's under threat, we're going to lose staff if we don't cooperate". So there's serious conflict.*

Immigration Lawyer, Key Informant Interview, November 2007

However these kinds of disagreements consume clinicians' time and energy, and may detract from the care they are able to provide to patients more generally. The JCHR heard evidence from a GP that "it is taking an increasing amount of health workers' time in advocating to ensure that people who are vulnerable can receive care"[58], and one PCT board member identified clinical activities associated with the Charging Regulations as a waste of NHS resources when he said "I'm not taking the decision as a board member to spend tens of thousands of pounds to fund people through medical school, right, for them to come out and waste time checking people's passports. That's not what I'm funding them for. I want them with stethoscopes and things, doing what they do."[59] Although the Charging Regulations do not require clinicians (but rather managers) to identify chargeable patients, they do require clinicians to be involved, if only in defining the clinical need (i.e. 'immediately necessary', 'urgent', 'routine or elective') in each case. As we have seen, this in itself can lead to increased patient advocacy as well as an immigration role for clinicians.

5.3.2   Increased Burdens of Care

For one GP advocate, this increased burden of care and the additional roles required of clinicians by the Charging Regulations provided the explanation as to why some clinicians did refuse to treat those who are not entitled. In her view, the discretionary nature of the current

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[58] [198]
[59] PCT Non-Executive Board Member, Key Informant Interview, August 2008

primary care rules enabled overworked primary care practitioners to avoid taking on new patients who would likely require more attention and resources than other patients:

It is very time consuming. And... Primary care practitioners have the option not to treat people, and actually one could see why they might refuse.

GP and Migrant Advocate – Key Informant Interview, April 2008

Other clinicians identified the complexity of migrants' lives within the UK's approach to immigration strategy more generally as contributing to an increased workload when caring for these patients:

So you are compromised in terms of what you can offer...but it's very hard to know where the boundaries as a clinician in HIV medicine are. But if you were to say the doctor's role is around diagnosis, investigation, and therapy, then you do that in a context of ...people understanding where they're at, and of course if... people are accessing nothing, apart from clinical services, you have to make sure absolutely everything happens in the clinic, because there's nowhere else for it to happen, so you find yourself really pushing the boundaries of what we are trained to do.

HIV Consultant, Key Informant Interview, May 2008

For this clinician, the immigration landscape for her patients and the restrictions on access to services that they faced outside the clinic were as much of an obstacle to a simple clinical picture as the Charging Regulations themselves. Treating HIV required, in this respondent's view, a holistic approach that required input from other, non-clinical services; in their absence, the clinic and therefore the clinician had to step in and provide social support, advice on housing and immigration, and sometimes referral to other, non-clinical services.

This clinician also discussed her unease both with the suggestion that she should implement the Charging Regulations, and deny patients care, and with the notion that in resisting the Charging Regulations she was behaving illegally or undermining the relationship with her employer, the NHS:

It isn't going to stop me doing what I think somebody need medically anyhow. But I do sometimes stop and think, this is an interesting position to be in. Where are my responsibilities here? Because as a doctor, you're employed by the NHS, you have a duty of responsibilities to your employer, which presumably by acting in the way I am, I'm contravening... and there's something quite fundamental about the ability to provide care to those that need it. It's a fundamental principle of the NHS. Free care to those that need it. .... So to know that this is not the case, it produces a discomfort. It doesn't necessarily stop you doing it, but it doesn't make you do it well, or happily.

HIV Consultant, Key Informant Interview, May 2008

In this sense, the implementation of the Charging Regulations can cause clinicians a threefold additional burden to their workloads. First, clinicians seem to be engaging in disputes with

Trust management in order to advocate for free treatment for their patients who may not be entitled, and this can be a time-consuming exercise. Second, insofar as the Charging Regulations comprise a component of immigration strategy more generally, in aiming to deter, control, or make life uncomfortable for migrants, they also may have made the provision of healthcare harder for clinicians who feel they have to pick up where other services have left off in supporting migrants. Finally, doctors' duty of care and commitment to first principles of the NHS make it hard for them to implement the Charging Regulations when they perceive that to do so would entail refusal to treat; this however comes into conflict with their role as workers with a responsibility to their employer – in itself a resource-stretched organisation towards which clinicians usually feel an affinity.

The advocacy carried out by clinicians was augmented by non-clinical migrant advocates at NGOs, who also sometimes provided services that aimed to fill the service gap left by the immigration rules.

5.3.3   Advocacy

As discussed in the previous chapter on policy formulation, clinicians and non-clinical advocates worked together in migrant-health interest networks to influence policy. However, these activities were rarely divorced from their roles in policy implementation. The role of clinicians in this has been discussed, above; and although third sector advocates do not have a direct, formal role in the Charging Regulations, they do influence the implementation of them, as well as utilising the variations in policy implementation described above. For example, the variation in the implementation of the rules seen between different Trusts was exploited by advocates trying to facilitate their clients' access to healthcare. One key informant described the relationships her organisation had developed with local Trusts, and how much they had learned about the extent of implementation of the Charging Regulations:

> *You develop a relationship with local doctors and they get to know you, and I mean we sometimes invite them to come and speak to us...We know which hospitals are not as strict.*
>
> **Zimbabwean Community Organisation Staff Member, Key Informant Interview, June 2008**

Most advocacy on access to healthcare consisted of accompanying clients to hospitals and verbally advocating on their behalf to facilitate their access, for example by trying to "persuade people to interpret them [the Charging Regulations] in what we see is the correct way"[60]. Some larger organisations had gone beyond this approach and threatened Trusts with legal action when their clients had been refused treatment:

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[60] HIV Charity Head of Policy, Key Informant Interview, January 2008

What we are doing is advocating on the client's behalf up to the point that we can and then, involving solicitors. And the…mostly the Trust will then back down because what we think is happening is that they're trying to avoid going to court, because they realise that they will lose and a precedent will be set for services.

Advocacy then, has been effective in limiting the implementation of the Charging Regulations, and has relied upon formal legal challenge, as well as developing relationships with, and knowledge of, sympathetic clinicians. This, together with the variation in the rigour with which policy is implemented means that it is likely that some hospital Trusts take on a greater share of ineligible patients than others:

We have to try and work out by word of mouth which hospitals are doing what, and that means that some hospitals unfairly shoulder a higher burden of immigrant care because they are known to be more reasonable about these issues.

Other advocates also discussed the way in which variance in implementation had trickled down to the community level, be that at the level of the migrant or at the level of the migrant advocate who could point clients in the right direction. This was likely creating a greater burden upon certain Trusts:

I guess the way that a lot of people get round the barriers is they know the places you can go where you won't be asked, which is unfair, because they're the hospitals or the practices that will end up taking on more than their fair share of a certain community. …There are some hospitals where even I will say to people, if they're really desperate, "Well, go there because you'll probably be ok."

It is worth noting that like the clinician above who found ways to circumvent the rules in order to treat patients, but questioned her role as an NHS employee and the effect this circumvention might have on NHS resources, both advocates quoted here above acknowledged the additional burden that this placed on those Trusts, and expressed concern about the effects of this. For both clinicians and advocates however, facilitating individual access to care for insecure immigrants took precedence over organisational concerns.

5.4 Chapter Conclusion

The extent of Trust- and individual-level variation in policy implementation, and the power that 'street-level bureaucrats' (clinicians and managers) have to implement the policy in ways that fit with their own 'preferences' imply a weak relationship between policy intentions and policy outcomes. However, prescribed policy is not irrelevant: clinicians, especially, expend substantial energy and time finding ways to circumvent the rules as they have been set down by government, but not all street-level bureaucrats try to find ways to ignore the rules. For Lipsky, clients' (or patients') direct experience of government is via street-level bureaucrats, whose actions *are* the policies they are charged with implementing [220]. In this sense, policies designed to restrict access to healthcare do not universally exist, but they do make accessing healthcare for insecure immigrants a complex terrain to navigate.

6. Chapter 6 – Zimbabwean Women and Immigration Insecurity

6.1 Introduction

This chapter describes the characteristics of the women who participated in this research, and discusses the relationship between their HIV-status and migration decision-making, as well as their situations in the UK post-migration. The effects of aspects of immigration policy on Zimbabwean HIV-positive women's wellbeing are explored towards the end of this chapter.

Migration and the experiences of living as a migrant or asylum-applicant in the UK were explored in this research because of the hypothesised relationship between UK policy, the resources available to the individual, and healthcare access (outlined in Chapter 2). In making an asylum application and becoming caught up in the UK immigration system, aspects of law and policy could act directly on women's lives, thus facilitating or obstructing their healthcare access. While some aspects of these components of women's lives may not have been directly associated with health in a clinical sense (such as the extent of their social networks), they did have the capacity to profoundly affect their wellbeing.

The women interviewed discussed the ways in which their lives were affected by the immigration system: by not being allowed to work, living on low incomes, and, above all, by fears of deportation. They also revealed their views of themselves and how their identities had changed since arriving in the UK, which was sometimes juxtaposed with their perceptions of the British public and how they believed they were seen by UK residents.

6.1.1 Sample Characteristics

Thirteen Zimbabwean women were interviewed for this research. The women in this study ranged in age from 26-57, with most between the ages of 41-50. Women's exact ages are not reported here, to help protect their anonymity. The majority had been living in the UK for more than six years (see Table 1), however all of them reported that they were foreign nationals, as well as foreign-born.

All women's and hospital's names have been changed/deleted to preserve anonymity.

Table 1 Women's characteristics

'Name'	Place of diagnosis	Rough age of respondent	Supported by	Time in UK
Sarah	UK	21-30	NASS	7-8 years
Prudence	UK	41-50	LA	9+ years
Precious	Zimbabwe	41-50	LA	6-7 years
Mercy	UK	41-50	LA	6-7 years
Mary	UK	41-50	LA	4-5 years
June	UK	50+	LA	7-8 years
Judith	UK	50+	LA	9+ years
Joy	UK	41-50	None	9+ years
Jackie	UK	31-40	None	0-1 years
Hope	UK	31-40	LA	3-4 years
Celeste	Zimbabwe	41-50	None	2-3 years
Beatrice	UK	41-50	LA	Unknown
April	UK	50+	LA	5-6 years

6.2 Migration intentions, HIV diagnosis, and circumstances at the time of asylum application

Each woman interviewed had made her asylum application in the UK, but none reported having yet reached the end of the asylum application process (i.e. exhausted her rights of appeal or been granted permanent leave to remain). Only one woman had been granted temporary leave to remain, and that was due to run out within the year. The women had been in the UK from as long as nine years to as little as a year.

Although it was not possible to ascertain the exact stage of women's asylum applications, primarily because of the difficulty with verifying information offered during a face-to-face interview, it was feasible to conclude that none had secured permanent residency or leave to remain. In addition to women's direct reports of their immigration status, their accounts of other aspects of their lives (such as the nature of the financial support available to them) tallied with reports of immigration insecurity.

6.2.1   Migration and Repatriation Intentions

Women in this study discussed their reasons for leaving home, as well as their intentions to return to Zimbabwe. Women reported a variety of reasons for having left their home country, although many cited temporary family visits or study as a primary motivation. While many women reported an original intention to return to Zimbabwe following the conclusion of the reason for their trip to the UK (e.g., the end of a course of study), HIV diagnosis had, in many cases, altered these intentions.

The majority of the women interviewed had entered the UK on student or tourist visas. None of them discussed an original intention to remain in the UK for a substantial length of time, and all stated that they had originally intended to return to Zimbabwe.

One woman explained that she had two adult children living in the UK already, and a third younger child who remained in Zimbabwe. She stated that she had returned to Zimbabwe to collect her son and had intended to return to the UK only until she completed her nurse training course:

> So I came in December 2000 to the UK, on the basis that I was going to do ...this nurse training course. Then after that, I just worked for 3 months I think... Because my intention wasn't to come and stay here permanently, I was, I had my money, I wanted to come here, do my training course and go back, you know?

Precious, 41-50

Sarah's intentions were less clear-cut; however she too had intended to return to Zimbabwe. She had originally come here to visit family, but had then decided to alter her visa status and study in the UK, before going home:

I came to visit my aunt, and then my aunt then told me that, "You know what? You can study here, and then ... you can go back home, and do something when you go back home," so I changed my visa from visitor to student.

Sarah, 21-30

One woman described her life as a student in the UK, and the part-time work she was allowed to do under the conditions of her student visa. She had made the decision to return home, and had even packed for the journey home, but got too ill to leave:

P: I was a student, I was doing business studies and I was working weekends, my twenty hours, yes.

I: And then you applied for asylum first in 2002?

P: Yes, and I was even about to go home, because my visa was going to expire in September 2002, and I had packed already my things, but I got sick so much, I couldn't walk.

Judith, 51-60

Another woman described very similar circumstances. While her original reason for arriving in the UK had been different from Judith's (she had come to see family), she too had discovered towards the end of her stay that she was unwell and felt unable to return home:

When I came here, I just came here for a visit; I didn't know I was HIV-positive... So when I was about to go back home, after six months – that's when I was ill, I had shingles. So that's when I couldn't go back home.

June, 51-60

She had had no intention of remaining in the UK in the long term and expressed the dismay she felt at the decision to remain here, particularly since she had two young children in Zimbabwe:

I didn't want to stay, to live here, I didn't want to stay here, I wanted to go back home... So it really affected me, that I left my place, just leaving everything. And my two younger children were back home.

June, 51-60

The quotes above suggest that these women were keen to convey that they had not anticipated remaining in the UK permanently, and that circumstances outside their control (i.e. becoming unwell) had for most of them been the defining factor in altering their intentions.

Many of the other women in the study also highlighted their desire to return home, and expressed that their HIV diagnosis had altered their plans, since they did not perceive that they would be able to access the medication they required to survive in Zimbabwe. The next section

describes women's experiences of HIV diagnosis, and how this interacted with their repatriation intentions.

6.2.2 Circumstances at the time of HIV diagnosis

Nearly all of the women interviewed had been unaware of their HIV status when they entered the UK. They had been diagnosed only after falling ill. Some had collapsed and been diagnosed in hospital as an inpatient, while others had approached their GP with symptoms they were concerned about and had then been offered an HIV test. Some women said that they had suspected they might have been at risk of contracting HIV, but had ignored their own concerns. Other women had not considered themselves at risk and were very surprised to receive a positive diagnosis[61].

Judith recalled her disbelief at discovering her HIV status. She explained that she had been about to return home because her visa was due to expire when she became ill and was taken to her GP by her niece:

> *And my niece took me to my GP, and then that's how I stopped going home. When they diagnosed me, I was saying, "Oh no! I am going in July".*

Judith, 51-60

She was advised not to leave by her doctor, who was concerned that her health would deteriorate rapidly if she returned to Zimbabwe:

> *My doctor, this Indian lady, she was saying, "You can't go anywhere, because if you go, I won't give you four months to live, because ... your immune system is not alright."*

Judith, 51-60

Thus, according to this account, receiving her HIV diagnosis and identifying the need to remain in the UK were inextricably linked by Judith's clinician. This quote suggests that it might not have occurred to Judith that HIV care would be hard to come by in Zimbabwe in the absence of clinician advice.

Another woman was referred to a hospital GUM clinic by her GP for a thrush test. At the hospital she was tested for a number of sexually transmitted infections (STIs), including HIV. She did not consider herself to be at risk, having only had one sexual partner, and was reluctant to have the tests. As a result, she was shocked to discover that she was HIV-positive:

> *I said, "Oh, let me just go and see if it is thrush"... And then I got to [hospital x], and then they tested for everything! I...felt like saying, "You know, you're wasting your time, because I don't have any of that STDs or all that kind of stuff," because... I had only had*

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[61] In Feldman & Maposhere's research with HIV-positive women in Zimbabwe, most women did not consider themselves at risk until after they had been diagnosed with HIV [92].

like, one boyfriend... so I was like, "I've got nothing" And a week later!... when they called me back, when they told me that I was HIV-positive – I was like, "What??"

Sarah, 21-30

Another woman who was more aware that she might have been at risk of HIV was visiting her sister in the UK when she collapsed and was taken to hospital, where she was tested and diagnosed HIV-positive. She had suspected in the past that she might be HIV-positive since both she and her child had been unwell, but did not want to believe the possibility that they might both be HIV-positive, and so avoided testing:

I had [an] idea, but you know I was afraid, to tell the truth. In Zimbabwe, sometimes I'd get sick. But I didn't want to take it [the test], even my child was sick, but I didn't want to go for the test. I did not go for the test, but I was suspecting... I collapsed. I was just feeling like, chest like, sore I collapsed. And I went into that hospital, that's where I got tested.

Jackie, 31-40

All of these women had tested relatively late for their HIV. As described, many already seemed to have become symptomatic by the time they were diagnosed. A number of women in this research did not consider themselves to be at risk, or ignored suggestions that they might be[62]. Although most of the women had not tested for HIV before arriving in the UK, two had been made aware of their HIV diagnoses in Zimbabwe. Celeste was diagnosed in Zimbabwe after the death of her husband, but was nevertheless shocked to discover that she was HIV-positive, because she had believed that her husband had died of natural causes:

I was diagnosed HIV-positive when I was back home, and it was after my husband passed away some three years ago... I took some samples [to the doctor]... and it was when he told me I was HIV-positive. But I couldn't believe it. I just thought my husband died from some natural causes anyway.

Celeste, 41-50

Celeste's account indicates that disbelief on hearing of an HIV-positive diagnosis was not the sole province of women who were diagnosed late. Celeste appears to have been tested relatively early despite her perception that she was not at risk. While much of the literature on late diagnosis identifies this perception as central to the phenomenon, in Celeste's case it did not seem to act as a barrier to testing [86, 92].

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[62] This perception/suspicion of infection was noted by key informants in Burns et al's (2007) research [83]. Furthermore, the fact that many of the women did not test until their own ill health encouraged them to do so reflects Anderson & Doyal's (2004) study where African HIV-positive women living in London often tested only after either their own or a partner's ill health precipitated the decision [111]. Late diagnosis of HIV among black Africans in the UK is not uncommon and has been well-described in the literature, [84, 95, 162], despite evidence indicating the significant public and individual health benefits associated with earlier diagnosis [79, 88].

Precious was also diagnosed in Zimbabwe. She described having worked for a medical institute that offered its staff free blood tests. Her discovery that she was HIV-positive came when she was donating blood through her employer's blood transfusion service:

There were these people from the blood transfusion service, and they said, "Well, you have to come and you know, give blood", So I decided I have to contribute to that. They took my blood, they tested it... So, that's how I got to know that I am positive, because the doctor called and said, "You have to come in". So that's when I knew about my status from that point.

Precious, 41-50

Neither of these women reported an original intention to remain in the UK in the long-term. Celeste had intended to return to Zimbabwe after visiting her sister, and Precious intended to complete a nurse training course and then return home. Neither woman discussed expectations associated with the availability of HIV care in the UK. Although both of these women knew their HIV status when they arrived in the UK, they both became hospitalised as a result of their HIV. Celeste (as described above) had started taking ART in Zimbabwe, but was refused treatment in the UK because of her immigration status, and fell ill. Precious, though aware of her diagnosis before arriving in the UK, had been unwilling to disclose her status and so wasn't receiving treatment (although it is unclear from her interview whether she had been on ART in Zimbabwe). She too became unwell:

Somewhere along the line, I just collapsed, you know. Though I knew about my status from back home ...I had not told anybody here, and ...I wasn't even taking any medication, from the time I came here. And then I just collapsed when I was at work.

Precious, 41-50

Precious reported that by the time she was admitted to hospital, her CD4 count was very low, but she could not be started on ART immediately because she also had TB:

P: They admitted me in hospital, and they said, "we have to start you on anti-retrovirals as a matter of urgency" because my CD4 count was very very low. So they did that, right, and immediately after that I reacted badly to the ARVs because I had...TB. So they hadn't discovered the TB.

I: They only discovered that after they'd started you on...?

P: Yes, because of the reaction[63]. So they said, "Oh well, we just have to stop this immediately, and we have to treat the TB first. Then after that we can switch you on to the ART".

Precious, 41-50

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[63] Provision of ART is sometimes delayed by clinicians for individuals with HIV/TB co-infection, as some ART can interact with TB drugs, causing toxicity or other drug-drug interactions [278].

Although these two women were diagnosed earlier than most of the other women, they presented late to HIV services, again seeking out ART (despite knowing their HIV status) only after they became ill; both women would have been entitled to HIV treatment under the conditions of their student visas. The next section explores women's experiences of asylum application and their legal status in more detail, and examines the interrelationship between their applications and HIV status.

6.2.3   Asylum Application and Legal Status

When asked about the grounds for their asylum applications, most women said they had based their asylum applications on the ECHR. They reported having made applications for asylum on 'compassionate grounds', premised on the right to avoid inhumane or degrading treatment [280](Article 3 of the ECHR) by avoiding return to Zimbabwe where life-saving anti-retrovirals would not be available to them.   None of the women described themselves as political refugees, or seemed to have made an asylum application under the 1951 Refugee Convention (apart from Jackie, whose experiences are discussed in more detail below). Some women had extended their ECHR applications to include Article 8 (the right to respect for family life) [280], since they had family based in the UK, and often little or few family ties in Zimbabwe. According to their accounts, most had been refused asylum at least once and were at some stage of the appeals process.

Only one woman had made an asylum application on political grounds, and reported having told the Home Office that she was an active MDC supporter and therefore risked persecution in Zimbabwe. However, according to her, this was untrue. She explained that she had made the application after being advised by friends that if she were to disclose her HIV status to the Home Office, she would be deported immediately:

> *P: You know I didn't say about this disease. Because people had said, if you talk about this disease, they will refuse to give you asylum. So I said I was seeking for political reasons, you know with Zimbabwe, the politics?*
>
> *I: What did you say about politics?*
>
> *P: I am wanted to be killed in Zimbabwe... I am MDC supporter, Zanu PF supporters want to kill me, that's what I said: "I have been an active member in the MDC".*
>
> *I: And is that true?*
>
> *P: It's true, I have been supporting MDC. But I was not much into politics, but because I want to help myself here, this is easier. So, some of the systems, you have to lie.*

Jackie, 31-40

It was not clear whether Jackie's friends had advised this approach because they believed that disclosing one's HIV status to the UK authorities would automatically lead to deportation, or

whether the poor success rate[64] for individuals making Article 3 applications on the basis of their HIV status had led to a belief that a successful application would be more likely if politics, rather than health, were cited as the basis for the application:

> They say, "Go back to Zimbabwe they have got treatment,", but it's not true. Because of that, some people, some of my friends, are also HIV-positive, they say, "Don't talk about this disease, just talk about politics. If they ask you 'are you sick?', say 'no, I am fit'". So, I did that. Because they say if you say you are HIV-positive they will refuse to give you, you know, a stay.

Jackie, 31-40

Jackie's account of the advice she received from friends provides another example of the way in which HIV and asylum were bound together for these women. For most women, HIV was a compelling reason to apply for asylum. However, while this was true for Jackie, she also believed that her asylum application's success depended on her ability to hide her HIV from the UK authorities. In both scenarios, HIV and asylum were inextricably linked.

However, all the other women's accounts suggested that they *had* based their asylum applications on their HIV status and therefore in contrast to Jackie had utilised full disclosure of their HIV as a component of their applications. Many women reported that they had applied on compassionate, or what they sometimes described as medical, grounds, given the paucity of HIV medication available in Zimbabwe. Celeste reported that her solicitor had recently re-submitted her application:

> [I applied] on medical grounds. So my solicitor ...wrote a fresh application... on medical grounds and asylum seeking with my situation in my country.

Celeste, 41-50

Celeste's quote implies that the application she described above was not the first she had made, but she did not discuss the details of any previous applications or the circumstances they were based on. It was not clear whether this was because of a preoccupation with the most recent or ongoing application, or a reluctance to discuss an unsuccessful application. Again, this mirrored many women's accounts of their journey through the asylum process, since many had made earlier, unsuccessful applications, but did not discuss these. Two other women (Joy and Sarah) had also been refused asylum following their first applications, and their solicitors were appealing this decision, citing Articles 3 and 8 as the basis for their appeals.

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[64] Article 3 applications made on medical grounds require applicants to show that there is "a complete absence of medical treatment in the country concerned". The Home Office may therefore reject the application if there are limited quantities of treatment available, but at costs that person cannot meet [202].

Sarah discussed her understanding of European case law and was aware of the difficulty with a simple Article 3 application following the House of Lords ruling in the case of N [259]. She had no real family networks in Zimbabwe, having left when she was twenty years old, and having had a breakdown in relations with her mother, and thus her appeal application rested on Article 8 as well as Article 3:

> I: So, talk to me about your immigration situation at the moment, and what's just happened, and where you're at.
>
> P: Oh, that's crap (laughs). I'm going for an appeal on Wednesday ...their argument is that there is medication in Zimbabwe.
>
> I: [The problem is] the case of N?
>
> P: Yeah, the case of N. They're using Article 3, but my application, I'm using Article 3 and Article 8...rights to family life... But, they're saying that there is medication in Zimbabwe, I'm now old enough to, I'm 26 so, I can be as independent, you know, because I came when I was 20. So they're basically saying that I must have established some sort of family, social life back home, which is not the case. Because I came straight from boarding school, to come here, so... I've got my mother, but it's a long story, but we just have our differences, we don't have that mother-daughter relationship, because it's kind of a broken down family thing.

Sarah, 21-30

Sarah discussed the grounds for refusal of her appeal in some detail, mentioning the deteriorating economic situation in Zimbabwe as the reason for the absence of ART there:

> I: And their refusal was on the grounds that the medication is technically available in Zimbabwe?
>
> P: Is available in Zimbabwe ...So in May they refused, they turned down the application, and then we made an appeal.

Sarah, 21-30

Women's insecure legal status had consequences for their perceptions of self and capacity to plan for the future. Women seemed to share a sense of being trapped in the UK because of their HIV diagnosis and fears about the lack of availability of medicines in Zimbabwe. These liminal emotions and experiences, including practical aspects of life as a female asylum-applicant are explored further in the following section.

6.2.4   Living in Legal Limbo

For asylum-applicants, gaining legal status is an important representation both of an individual's right to services and other benefits of citizenship and may contribute to improved psychological health [66]. For migrant women who are HIV-positive and from under-resourced countries, remaining in the UK to access life-saving medication can become associated with long-term survival [111]. According to the women in this study, a significant fear was the

threat of deportation back to Zimbabwe, primarily because of the absence of ARV availability[65]. Based on their accounts, it was only the availability of ART in the UK that made them wish to remain in the UK. Some women had left children and family in Zimbabwe, and felt caught between the imperative to remain in the UK in order to survive and the desire to return to Zimbabwe[66]. A common theme the women discussed was their frustration with not knowing what the future was going to hold for them in terms of their asylum applications, and the possibility that they might face deportation.

They repeatedly indicated that the waiting that accompanied their asylum applications was a source of anxiety, and many women felt unable to settle in their lives in the UK in the face of this uncertainty. One woman implied a sense of imprisonment in the UK as a result of waiting for a decision on her case and the concomitant inability to plan any aspect of her life. Her first asylum application had been refused, and she had been advised that although she could appeal this decision, she would have to receive a letter of removal before she could do so:

I am just... waiting. Because they said I can appeal... When I went back...he said I have to wait for a letter of removal, that's when I will appeal, so I'm just waiting. And it's not easy, you know, I feel like a convict. You are treated like a convict. You know, all I want is to live a normal life. You lose – I don't have a life anymore, you can't plan anything, I don't know whether I am coming or going, you know.

April, 51-60

April's account suggests that bureaucratic aspects of the asylum process had bled into her emotional life, and were central to her sense that her life had become subsumed beneath the outcome of the asylum determination process. Another woman described the frustration she felt at not knowing where she stood in terms of her future in the UK:

It's very frustrating, not knowing what's happening, where you stand, where I stand, it's very frustrating, it's very painful.

Beatrice, 41-50

This frustration over the uncertainty connected with the asylum applications process was a recurring theme, and many other women discussed the problems associated with the inability to plan their lives or make decisions about their futures. Another woman who described this frustration saw the uncertainty that surrounded her immigration status as an additional burden to bear alongside her HIV status:

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[65] Kang et al's research with HIV-positive undocumented migrants in New York City also identified a heightened fear of deportation, especially among undocumented migrants, since HIV treatment was often unavailable in their country of origin. Remaining in the USA had therefore become a necessity for their survival, and not just a path to a better life [107].
[66] Doyal & Anderson also noted that many of the women in their study felt 'trapped' by the very services that keep them alive [112].

Now, the burden I have on top of the burden of being sick, is immigration status. You don't know, you can't plan, because you don't know what they'll say.

Hope, 31-40

This double burden was also borne by other women. Mary explained how she felt that the uncertainty of her immigration situation augmented the fears she experienced as a result of living with HIV:

It's very difficult. It just make you uncertain. And it's like you feel what is going to happen, what is going to happen? You won't feel comfortable, you live in fear – living with HIV and living with fear again.

Mary, 41-50

The uncertainty and insecurity that women lived with while waiting for a decision on their asylum applications was sometimes compounded by the asylum process itself. One woman described having received a favourable decision on her asylum application, but subsequently found that the HO had appealed against this decision. She struggled to understand how it was possible for the HO to appeal against the decision of an Independent Asylum Adjudicator:

After two weeks I received a letter on the door, and the decision was in my favour. And ten days down the line, the Home Office appealed against that decision. And I'm like, this is an Independent Adjudicator, as they term it, she is not even biased you know, she is just doing her work. And now they are saying she made an error. How?

Precious, 41-50

Her case was re-heard by another Adjudicator, who decided against her application. Again, Precious struggled to understand how such a decision could have been made – she felt that she was not making a false application, but asking for a stay on medical grounds which were not unfounded:

She said, "I am declining everything," because she said that this judge made error of law in our good laws. I am thinking "what error did she make? I am a person who is sick, you know? And what error did she make?" She [my lawyer] is not making a fake thing here. I am sick, I am sick, there are no two ways about it.

Precious, 41-50

Precious expressed the concern that this uncertainty was having repercussions for her health, and was forcing her to consider options that might impede her chances of being granted leave to remain in the UK. She wanted to work, and was considering doing so illegally. She was aware of the possible negative consequences if the HO were to find out, and as a result felt trapped between two competing needs:

Maybe it will take another year? I don't know ...My health as well, it's affecting my health... I need to work, definitely. So, sometimes I'm in the middle of thinking, "well, if I

just find a job" - because I have got National Insurance – "what will happen? If they find
out?" – you know, those type of things. You are kind of in the middle, you don't know
what to do.

Precious, 41-50

Precious was therefore beginning to consider actions (getting a job) that she hoped would
mediate some of the difficulties that she experienced as an asylum-applicant, although she
suspected this would prejudice her application. She attributed this to her own concern about a
prolonged waiting time, in combination with the difficulty in predicting whether waiting
patiently would give rise to a positive asylum outcome.

The fear of deportation and worries about what the future might hold also weighed heavily on
Prudence, and was compounded by her experiences in the asylum process (she had been
refused at appeal four times). These concerns were exacerbated by news about other people
being deported:

And you really don't know what the future's gonna be like. You hear of some cases of
people being deported, so it makes you always stay in fear, worry, over that.

Prudence, 41-50

Another woman who also described her fear of deportation and her worries about the chances
of survival in Zimbabwe for her and her children if they were deported discussed how she
coped with these concerns. She coped with this by simultaneously trying to occupy two
different states of mind, constantly considering the consequences of either outcome in her
asylum application:

So I always try to think both ways, what I will do if the immigration status comes
different.

June, 51-60

Most women stated that they had applied for asylum because of the absence of life-saving ART
in Zimbabwe, as discussed in section 6.2.3. This compounded the frustrations experienced in
the UK asylum system, and served as a constant reminder that it was primarily the absence of
treatment in Zimbabwe that prevented them from returning home. One woman described her
wish to return to Zimbabwe to be with her children, and her dislike of the UK:

If the treatment is there in Zimbabwe, and I will have a job to look after my other
children, because I now have a sick child, I will go! It is a nice country, I love my country, I
don't like this country. I will go and look after my children back home. I love my country.
It's only the situation that is there.

Jackie, 31-40

Jackie did also view the economic instability in Zimbabwe as a barrier to her returning, since the absence of paid employment would prevent her being able to care for her children. However, given that one of her daughters was also HIV-positive, it is not possible to separate the desire for an improved economic situation in Zimbabwe from the need to access medication.

This sentiment was echoed by Prudence, who also discussed her desire to live in Zimbabwe rather than the UK, and the obligation she felt to remain in the UK in order to access ART. The waiting she experienced in the asylum system amplified her anxieties:

> *If it wasn't really for, you know, being positive, if it wasn't for the medication part, I really don't think I was going to stay, but just because I fell ill, and I can't afford to go back home to buy the medication, and now this long wait.*

Prudence, 41-50

This amplification of existing concerns by the waiting that seemed to be inherent in the asylum process was discussed by another woman. She talked about the depression that she felt as a result of a sense of being stuck in the UK, and of not knowing what the future held. She expressed a desire for the asylum process to be speeded up:

> *It makes me feel worse. Because I am just depressed each and every day. You can't move on. You will be just stuck on the one stage. I can't do much... At the moment, I really need to know where I'm standing. So, I wouldn't mind if they fast-tracked this immigration matter.*

Hope, 31-40

It is notable that Hope appeared to find her limbo status and the frustrations associated with it so difficult that she was more invested in hearing the outcome of the decision in her case than in whether the outcome was positive or negative.

One way of coping with the uncertainty described by some of the women was to try to occupy two contrasting states of mind, in that they tried to be mentally prepared for either a positive or negative outcome on their asylum applications. However, for some women the uncertainty associated with their precarious legal status in the UK increased their sense of being trapped in the UK and intensified their desire to return to Zimbabwe, bar the absence of ARV availability there. From the emotions they described, it seemed likely that a number of the women may have been experiencing symptoms of depression associated with the liminal and vulnerable state in which they found themselves.

Beyond the stresses of the uncertainty of the asylum process and its interaction with fears of deportation and loss of access to ART, other practical aspects of life as an insecure immigrant added to women's anxiety and sense of vulnerability. For some women, negotiating these

challenges (such as low incomes or restrictions on working) was often exacerbated by the difficulty in understanding the complexity of immigration and asylum law. The next section will explore these in more detail.

6.3 Living with and understanding insecure immigration status

This section describes the women's experiences of living as insecure immigrants in the UK beyond the initial application process. Most women had been in the UK for at least three years, and at least eight women had arrived more than six years prior to this research. As a result, the uncertainty described above had for many women become enmeshed with finding ways to cope with life as an insecure immigrant. Substantial policy restrictions exist for individuals with insecure immigration status in the UK, including restrictions on working, and levels of income support available. Immigration status thus had consequences for many aspects of women's lives, including accommodation stability, managing to live on a low or no income, problems with employment, and how identity was affected by engagement with the immigration and asylum system. These are not uncommon problems for individuals with insecure immigration status in the UK [31, 151].

Despite the fact that Mercy was the only woman interviewed for this research who had been awarded any kind of leave to remain, none of the women were being supported by NASS - the agency then charged with providing financial support to asylum-applicants - at the time of interview. The next section will describe their financial situations and how they were supported in more detail, and will explore the way in which policy ambiguities and limited incomes affected women's wellbeing and capacity to cope with life in the UK.

6.3.1   Incomes and Financial Support

Financial support is provided by the state to individuals with insecure immigration status either through the Borders Agency (previously NASS) or local authorities (LAs), although not all such individuals would necessarily receive support through either of these routes[67]. Indeed, most women interviewed were supported by their LA. However, some women were not receiving financial support from any source, and were effectively destitute or dependent on the goodwill of family members, with whom they were usually staying. One woman was working illegally. All the women interviewed explained that they found it hard to make ends meet on their various incomes. Some of the women interviewed were also caring for children.

There was substantial variation in the amount of money women reported receiving—even between women who were supported by their LAs. April described the amount of subsistence support that she received from the LA, and other benefits that they provided:

> I'm supported by social services. I get a subsistence fee of £62 every fortnight... They pay for my accommodation, and they gave me a freedom pass[68].

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[67] For example, refused asylum-applicants who do not qualify for Section 4 support may be unable to receive any State support [281]

[68] A freedom pass enables free travel in London for anyone over the age of 60 or with an eligible disability [282]

Mary also received this amount, and saw it as *"the other thing [in addition to immigration uncertainty] which is very difficult for me. Because I only get £31 a week to... in two weeks I get £62. And I have no other income."*

Based on their descriptions, it is hard to understand what *kind* of support these two women were receiving – since asylum-applicants supported by the Borders Agency (BA) receive 70% of Income Support – set at the time of interview at £60.50/week: £62 fortnightly is substantially less than this figure. In addition, it is unusual for a BA supported (previously NASS supported) asylum-applicant to be accommodated in London (rather than in dispersal areas).

Judith discussed her experiences receiving vouchered financial support. The amount that Judith had been receiving in vouchers suggests that she was previously being supported under Section 4 of the Immigration and Asylum Act 1999 [283]**Error! Bookmark not defined.**. She xplained that she found it very hard to cope when living on voucher support. She described the problems she experienced at the time, and emphasised the difficulty with no access to cash:

> *It was so stressful. I mean, receiving the vouchers, it was just very hard, but you have to accept it, because sometimes we used to write them a letter to say they can give us...twenty pounds worth of vouchers and ten pounds cash so that we can get also what we want from the market, and our culture food. But they were not accepting that, they said, "No, you have to get the vouchers", and if you go to the shops you can't get everything what you want, there is sometimes...really, really is nothing. And when you have got change for a pound, they can't give you, they say, "You are not allowed to get any change". So I feel [you] maybe have got thirty pee or fifty pee left, you can't pick anything, sometimes you are just going mad, saying if they could just give me this pound, I was going to buy this and this and this. It was so, so so hard. It was so hard.*

This quote illustrates many of the problems that third-sector organisations have highlighted for individuals receiving voucher support, including problems buying culturally appropriate food [31], and not being able to receive change on the value of a voucher [31, 284].

Vouchers can be spent on food and drink, baby milk and food, and toiletries, but not on clothes [285]. This limitation meant that Sarah, who was receiving vouchers at the time of interview, found strategies that helped her to cope with these difficult circumstances, by purchasing items with the vouchers that were not strictly allowed. She hinted at her local supermarket's apparent willingness to ignore the rules:

> *P: Yeah, you can't use it, you can't use it on any – it's only for food, but you have to find your way 'round it.*
>
> *I: What do you do about clothes?*

P: Clothes...? I can't let you into a secret!... You can use it, in [a supermarket].

I: You can, on clothes?

P: Yes, and electronics, everything.

I: Oh, I thought you couldn't.

P: Shhh.

I: Are you not meant to?

P: (whispers): no.

I: But what, the people in [the supermarket] don't care?

P: (whispers): they don't care...I just found out that you know, you can buy all that stuff, you can buy clothes, you can buy electronics -

H: So you can buy anything that [the supermarket] sell with the vouchers?

P: Yeah. But social services say you are not meant to.

Sarah, 21-30

Sarah's ability to identify and utilise strategies as a result of her local supermarket's willingness to bend the rules, enabled her to circumvent aspects of the rules around financial support. This echoes findings earlier in this thesis: once again, where the state relied on agencies or staff who were not directly employed by immigration services, a gap appeared to emerge between immigration policy and its practical implementation.

Some women interviewed were not in receipt of any statutory support at all. One woman had received some financial support until the previous year, but it had been terminated. She was now reliant upon her brother, who she lived with, for support. Another woman, Celeste, also lived with family, and was largely supported by her sister, although this was not consistent[69], and Celeste felt that this was in part because her sister had expected her asylum application to be successful. What worried her above all was her lack of money and in particular the impact of that on her son and his education:

> *So my sister sometimes she said "I don't have any money" as well... She was nice in the first place, my sister, but it's like things changed when my application was rejected, because she thought it was [a] certain thing anyway... at times I don't even have dinner money for my son, and the social worker said, "Before anything is granted, we can't give you...free dinners for your son's school"... many times I keep [food], to give my son for some school dinners. Because I can't just give him a piece of bread and a drink to school for the whole day, I can't, anyway.*

Celeste, 41-50

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[69]ICAR point out that 'good will' support for destitute asylum-applicants "can create strains on relationships, particularly if the resources of the family and/or friends are also very limited" [286].

Thus Celeste's immigration status and the limitation on her entitlements that flowed from that status may have had consequences for the health of her son. For Celeste, these concerns had become paramount, and she reported that they were affecting her mental health. She explained that the fear of not being able to provide for her son was a source of psychological stress that had made her require antidepressants:

> *I: So at the moment is your most pressing health concern psychological rather than physical problems?*
>
> *P: Yes, psychological, because at times I think "oh, what am [I] going to do for my son's dinner tomorrow?"*

Celeste, 41-50

Therefore in Celeste's view, practical difficulties had directly contributed to her psychological problems. Like Celeste, women in financial hardship frequently indicated that their children were a priority. For a woman like Precious, whose son lived with her in the UK, finding the funds to pay for school trips and uniforms was a problem. These concerns were echoed by other women, and did not seem to be related to the type or amount of support that was received by different women. While Precious described herself as receiving 'subsistence support', Beatrice was in receipt of full Income Support, and still struggled with school costs.

Women who had children still living in Zimbabwe expressed similar worries, and wondered how to continue to support them there with the money they received in the UK. According to Jackie, this was her main reason for working illegally. Her eight year-old daughter had been diagnosed HIV-positive soon after she herself was diagnosed, and she felt that her only option was to work illegally in the UK in order to raise the funds to pay for her daughter's medication:

> *You know in Zimbabwe the tablets are costing much much, much money. They are costing, my child is buying those tablets, I am buying them for her, so I have to work to get those.*

Jackie, 31-40

In a context where research suggests that for HIV-positive African women, motherhood is considered to be an important source of legitimacy and identity [287], the emphasis these women placed on their ability to care for their children (whether in the UK or Zimbabwe) is not surprising.

Although Jackie earned only £300 a month from the illegal domestic work she did, this was substantially more than she would have received as an asylum-applicant[70], and she explained

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[70] £42.16 weekly for a single adult over the age of 25 [288]

that she needed to earn whatever money she could to cover the rising costs of medication in Zimbabwe:

> *They pay you 300 only. They don't pay you much. That's why they take someone without visa, because they don't pay, they just mistreat you and they don't pay you much.*
>
> *Now, every time, this economy in Zimbabwe it's getting high, high. Last month it was about 10 billion, I don't know how much here, but they are getting you know, very expensive... Twenty pounds. But in Zimbabwe, that's a lot of money...Twenty pounds, they cost about twenty pounds, those tablets I buy for my child.*

Jackie, 31-40

Other women also mentioned the restrictions on work in the context of a discussion of the financial support they received and their need to support their children in Zimbabwe. April explained that she was able to survive on her subsistence support except that it limited her ability to care for her child. In her opinion there was a contradiction in the discourse on asylum-applicants receiving benefits whilst being simultaneously prevented from working:

> *I: Is it hard to manage on the money that they give you?*
>
> *P: Yeah it is hard, I have a child, I can't ignore my child, I can't neglect my child. It's not easy, but, what can one do? You know, we are not allowed to work, I am not allowed to work, you know. And they complain that we are spending taxpayers' money. And yet, they don't let us work. If we could do something to contribute towards the government...*

April, 51-60

In the context of limited incomes from state support systems, dependent children (in the UK and in Zimbabwe), and multiple sources of anxiety that were exacerbated by having little opportunity for distraction, many women echoed this frustration about being prevented from working. The next section will discuss women's feelings about work, and some of the consequences of being prevented from working.

6.3.2 Restrictions on working

In 2002, asylum-applicants lost the right to work while they were waiting for a decision on their application, and this was largely aimed at reducing the numbers of 'economic migrants in disguise' that were entering the UK (see section 1.4.1b).

Almost all the women interviewed spoke at length about the restrictions on work that they faced in the UK as asylum-applicants, and for many this was a further source of stress. Despite ill health, most of them wanted to be allowed to work[71]. For some, improving their income and becoming self-sufficient was a priority. For others, work represented an opportunity to

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[71] In research with HIV-positive undocumented migrants in New York city, Kang et al found that the importance of earning a living often overshadowed the importance of healthcare for respondents [107]

stop being a burden, as they saw it, on society. Others spoke of a sense of being wasted while out of work, and the psychological dangers they saw in being idle indefinitely.

For many women, the medications they had access to in the UK had improved their health sufficiently for them to feel that they were wasted as essentially able-bodied individuals. Mary explained that since her CD4 count had increased, she could at least work part-time to improve her income, if her immigration status and health allowed it:

> *The CD4 count is up, and it means sometimes you will be feeling better. And if, in any way I had papers to look for a part-time job, I could go to do that part-time job when I'm feeling better. When I'm feeling low, I can't go back. When I'm on medication, it's a sure case that...I think I can be able to work for someone, for a part-time job I can find it, and then I can be able to eat, to get more, at least money to survive on.*

Mary, 41-50

For Precious too, the restriction on work was a nonsensical barrier to a better income and improved life. She explained her belief that many migrants would willingly work if they were only given an immigration status which allowed it:

> *There are a lot of people out here who are even you know... even struggling to make ends meet, due to this thing of immigration, but they are in a position that if they are given status or recognised they say, "Oh well, we can work."*

Precious, 41-50

Many women also stated that they wanted to work because it would demonstrate self-sufficiency, as well as to improve their incomes. Some women emphasised that they came from a society where handouts did not exist, and their disquiet at having to receive benefits. Precious discussed her discomfort with receiving state support, and contrasted this with Zimbabwe, where she had become accustomed to a societal expectation of self-sufficiency. She described the absence of state support:

> *In Zimbabwe there is no government, everything has just collapsed – people have to fend for themselves. You have to pay your own rent, you have to buy your own food, you don't live on any handouts, you know. So we were used to going to work and putting our own food on the table, not to be given money by the government.*

Precious, 41-50

She stated that she found living on benefits quite upsetting, and pointed out that she was unfamiliar with a society where she had to, as she saw it, ask for support; she was used to a more autonomous existence:

> *It's so distressing. Knowing that back home, you, I never used to ask for money from anyone. I would just do my own thing, you know, and here you just have to live on those handouts. It's so distressing.*

From their descriptions, the distress caused by the restrictions on working went beyond an emotional response to having their autonomy diminished. A consequence of the restrictions was that many women struggled to find ways to occupy their time during the day, and at least one woman discussed her concerns that this absence of activity was dangerous for a group of people who also had other fears (i.e. concerns about health and immigration). She felt that the enforced idleness that came from the work restrictions may have had severe psychological and physical consequences for other migrant Zimbabweans:

> *Honestly, you are just stuck in the house 24/7, you have nothing to do, and your mind is all filled up with thoughts, you know? Which is very, very dangerous. Because a couple of people from Zimbabwe, both men and women were found dead in their houses, just like that, because of stress.*

Precious, 41-50

Other women also explained that they struggled to fill their time in the absence of the routine provided by work. The absence of work meant that many women found themselves with little to occupy their days, and partly attributed low moods that they experienced to this lack of activity. Precious felt that the squandering of her skills was affecting her health, especially as it left her "just sitting, doing nothing", with nothing to occupy her time. Some women did attend training programmes, or volunteer in order to feel that they were contributing to the community, and also to avoid developing the low mood that many of them felt was a risk associated with a sedentary lifestyle. Joy described the voluntary work she carried out and HIV education sessions that she attended, partly to keep herself up to date with developments in the HIV field and to help in the community, but also to keep herself busy and avoid doing nothing:

> *And I do a lot of voluntary work in a lot of organisations, and I try to go for trainings wherever they are, to keep myself abreast with what's going on here, in terms of the disease itself, to also like help in the community, and just not to sit and do nothing.*

Joy, 41-50

For many women, the contrast between the autonomy they had had in Zimbabwe and their dependency on the state benefits system in the UK was accompanied by the feeling that their skills were being wasted here. Many were highly skilled professionals, but were prevented from using those skills in the UK by the restriction on working.

Beatrice had been a teacher in Zimbabwe. She felt that she had expertise to offer, especially as she had taught in the less well-resourced setting of Zimbabwe, but had been excluded from using that expertise by the immigration rules:

I feel wasted. Because I have a teaching qualification from Zimbabwe, which I realised is not recognised here in the UK... I have worked with less resources, I would be doing wonders here, I know I could. But then, that asylum thing, it has shut me out, it has shut me out.

Beatrice, 41-50

Here Beatrice explicitly uses the language of exclusion to describe her feelings about this particular aspect of being an asylum-applicant, and the impact that employment restrictions had on her place in society.

Another woman had been an accountant in Zimbabwe, but was now working illegally as a housemaid in the UK in order to send money home to pay for her HIV-positive daughter's anti-retrovirals. She felt that her life had been impaired by the unskilled work she was doing in the UK; she felt her sense of self had been undermined by this change in status:

And I am not doing my job. This is the worst thing. I am being a housemaid, you know, looking after other people's babies. When in Zimbabwe I was, somebody was looking after my baby. I had my life. And I don't have a life here. It hurts me most that ... I don't have a life.

Jackie, 31-40

Other women felt uncomfortable with receiving state benefits, because it made them feel like a burden on society. They wanted to be allowed to work in order to be able to contribute to society. Some of them felt they had a responsibility to contribute towards the cost of their HIV treatment. Precious emphasised again her desire to work, in order to be able to contribute in the form of taxation, and mentioned her medication as one of the costs she would like to be able to contribute towards:

I have even been saying that if they would only allow me to go and work for myself and contribute tax as well, this is what everyone else is doing, towards whatever the tablets are, I don't mind, I don't mind at all.

Precious, 41-50

For Mary, the access to treatment that she had in the UK, and her consequent improving health, meant that she was keen to work in order to contribute towards the cost of her medication:

But because we are being given medication and we are getting better – so, if there is a – if the immigration status is sorted, and if they need us to contribute, like to pay something every month, we could do it. And if we have got a part time job, I am happy to pay a certain amount, even to the hospital!

Mary, 41-50

Both these quotes illustrate how these women were frustrated by their inability to contribute to the society in which they were living, and towards the cost of their medication. However, they also demonstrate that these two women were aware of the way that insecure immigrants with healthcare needs are sometimes perceived by UK society. Precious made it clear that she understood that there was a norm of contribution through tax in the UK, and her inability to participate in that norm excluded her from integration. Similarly, Mary's use of the terms 'they' and 'us' showed her awareness of the lines that are drawn between citizens and migrants by the exclusion of insecure immigrants from the cycle of work and taxation; her willingness to contribute towards the costs of her medication may have been driven in part by a desire to participate in society.

The language that women used when discussing the restrictions on work suggested that this particular facet of the immigration and asylum system was a particularly acute attribute of exclusion, in delineating the distinction between citizen and migrant, and making women aware of their 'otherness' [113]. Thus the restrictions on working are closely bound up for these women with their perceptions of self, both individually and collectively. Women's perceptions of self and of being excluded affected the way that they perceived asylum decisions and other aspects of the immigration system. The next section examines women's understanding of these bureaucracies and how this fed back into identity construction.

6.3.3 Women's Interpretation of Immigration Policy

None of the women interviewed for this research discussed the current halt on returns to Zimbabwe, and many felt that they had viable asylum applications, based on their HIV status and the ECHR; almost none of the women demonstrated an understanding that their HIV status alone was unlikely to be sufficient basis for a successful asylum application[72]. Given the high threshold for such cases (see p.85), it is more likely that the reason that Zimbabwean failed asylum-applicants were not being deported at the time this research was carried out was the suspension on deportation of failed asylum-applicants [289]. A Home Office key informant pointed out that:

> *We haven't deported any failed [Zimbabwean] asylum-applicants, with the exception of one, which we did legitimately during the time when enforced removals was – the suspension ended, and we resumed in, I think it was the 2nd of August. It was on the 2nd of August 2006, and we did the removal on 30th August 2006, and then we suspended again, but that's the only one.*

Home Office civil servant, Key Informant Interview, November 2007

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[72] As a result of the high threshold for such applications that was established by the House of Lords in the Case of N [259].

Although the majority of women did not fully understand why they had not been deported, they did know a certain amount about the asylum process and its possible end-stage (i.e. deportation). This knowledge was sometimes informed by having met other HIV-positive individuals who were closer to that final stage. Judith's encounter with another HIV-positive asylum-applicant who had been threatened with deportation had made her anxious:

> *If you hear someone who is taking medication, or... she will tell you, "I was detained there," or "I'm going to be sent home," and you know that person she is taking medication like me, it's so stressful to me again, it's like it is me, it's not her, when she's talking.*

Judith, 51-60

However, this knowledge, coupled with a belief that an application on 'compassionate grounds' (under the ECHR) might be successful, led some women to become very upset when confronted with their own treatment in the UK asylum system and the threat of deportation. One woman recounted her sense of injustice at seeing other people awarded 'their papers' when they had entered the UK after her:

> *The unfair part is, I have known people who have been like, who came after because, I came here in 1998, I fell ill in 2000, I know some people who have been here ever since 2000, who got their papers before me.*

Prudence, 41-50

Once again, it is impossible to know what the basis was for these other asylum-applicants' applications, but it is likely that they were not basing their applications solely on their ill health[73]; Prudence did not consider the difference between varying kinds of asylum applications, but felt that her length of stay in the UK ought to add some weight to her application. As a result, the asylum system appeared to her to be chaotic and unfair.

This interpretation of the operation of the UK asylum system, especially as it interacted with healthcare services, caused one women to become distressed, and to question the motives of clinicians. She couldn't understand why treatment had ever been provided if the intention now was to deport Zimbabweans:

> *Why were they giving us the medication? What has changed now? Why do they want to send us home? Why?*

April, 51-60

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[73] Individuals making an Article 3 application to remain in the UK do so under the ECHR and not under the 1951 Refugee Convention. Therefore, if their applications are accepted, they will not be recognised as refugees, but instead awarded one of the temporary protection regimes (Humanitarian Protection or Discretionary Leave). In 2006, 2007, and the first quarter of 2008 respectively, fewer than 2 Zimbabweans were awarded Humanitarian Protection in each period, while Discretionary Leave was awarded to a total of 55 Zimbabweans over the same period [4, 290].

As we have seen, Jackie had been misinformed about the reasons for her risk of deportation were she to disclose her status to the Home Office, and had subsequently made a false political asylum application. None of the other women interviewed had this concern, but her sense of injustice and incomprehension at the threat of deportation echoed April's (above). Jackie described what she would say to the UK health minister, if she were given an opportunity to meet him:

> *Not having treatment for someone, it's inhuman, you know? How would you feel, if you knew my situation? Or if your daughter or son, in same situation like me? Not having treatment, not having anything, but she is sick. He [the minister] just want her to go back to her country. When she is telling you that there are not treatment. But you just force her.*

Jackie, 31-40

Women's interpretations of the contradictions they saw in the asylum system, and consequent distress at what they perceived as deliberate attempts to exclude them were also informed by many other exclusionary experiences. The multiple ways in which women experienced exclusion from UK society ultimately contributed to their perceptions of self, and interacted with their HIV status (which also marked them out as 'different' through its stigmatising effects) to undermine their individual identities. The next section explores the way in which exclusion and identity were interrelated processes in more detail.

6.4 Women's social exclusion and altered identity

HIV, it has been said, can take on a 'master status' [96], and HIV was a central issue for the women interviewed during this research. However, their immigration status was more likely to dominate their practical existence, thoughts and perceptions of self than their HIV status. This may be, in part, because of the importance of a positive decision on their asylum applications for their continued survival. For these women, almost every aspect of their lives was governed by their immigration status, the consequent lack of access to (various) services, and their own understandings of how they as migrants were perceived by the UK public. The insecurity of their status governed most, if not all, aspects of their lives; and affected the contact most had with the rest of the world and with their families, who may otherwise have provided a vital source of support. In this sense, participation in the UK asylum and immigration system could be seen as similar to membership of a total institution [291, 292].

Access to many services, other than health, was barred for these women. Beatrice described her encounter with the police after experiencing an incident of domestic violence. Although the police were initially supportive, and promised Beatrice protection, this was not sustained once they learned of her immigration status. Beatrice perceived that the police would not provide the same service to her as they would to a UK citizen:

> *And she said, before she knew my status, she told me I could go to a refuge, I could be protected by law, I could – she promised me a phone that was connected to the police station – if that man walked into the flat I only needed to press a button. And it was only when she was taking my details and it came to the question of immigration status, and I said, "I am an asylum-seeker", and then I saw the case falling apart. There was no refuge for me, there was no phone for me.*

Beatrice, 41-50

Some women experienced this exclusion (as a result of their immigration status) even from non-statutory services. One woman described the difficulty she had encountered in using an HIV peer-support organisation's employment/education support department. She had hoped to be assisted by this organisation, but had found her immigration status to be a barrier. She explained that she was informed that their service was only for individuals who were *both* HIV-positive *and* occupied a less insecure immigration category:

> *There are some organisations like [peer support organisation x], they've got a department for people who help people with HIV to go back to work or get employment and education services. They refer. So if you ring them up, they will say, "Oh, what is your immigration status?", if you tell them they say, "Oh you don't qualify". It's only people who are positive and have status in this country.*

Hope, 31-40

It is possible that this refusal of support was related not directly to the policy of the peer-support organisation, but instead to the limited employment and educational opportunities available to asylum-applicants in the UK. Nevertheless, Hope interpreted this refusal in terms of her exclusion from access to help, and felt that this had detrimental consequences for her ability to progress in her life:

> They are really helping people with status only, not you without status. You don't move on, you'll be just on one stage and that is it. You feel that you are useless.

Hope, 31-40

Although immigration status had 'mastery' over other their concerns, one cannot divorce HIV from immigration for this group, since almost all the women interviewed had based their asylum applications on their HIV status, and hoped to receive a positive decision on their applications in order to have a better life in the UK, and to avoid deportation to Zimbabwe where they believed they would not be able to access HIV treatment. For one woman the constant emphasis on the need to remain in the UK for treatment for HIV meant that all other aspects of her identity had become subsumed beneath this overriding health concern:

> A person is made up of physical, mind, social, you name it. So all we are here clinging to is the medical side of it, and the rest is just buried.

Joy, 41-50

The triple meaning of 'status' in these women's lives, (in referring to their HIV status, their immigration status, and the absence of status that many felt they had in UK society) dominated their perceptions of self. For one woman, these three statuses were not separable. She spoke of her sense of being a nobody in the UK (of having no status) compared to the somebody that she felt she had been in Zimbabwe, in the context both of her lack of an enabling immigration status and of her HIV. She felt she was nothing but a burden as a result of her illness, and this further undermined her sense of self:

> In Zimbabwe, I have got my car, I have got my house, I'm somebody. I had my job, a good job. But here, people, even those who did not go to school, they treat me like shit. Because I am nothing, I am nobody. I have got no status. I can't see my children, I can't have my children. I am just sick, I am a burden, to everyone... I can't do anything, I am nobody.

Jackie, 31-40

Other women also discussed their fear that they were a burden on others. Precious felt that she had been made burdensome by the limitations on her capacity for self-sufficiency as a result of the restrictions on working. It was not clear when she used the word 'status' in this context whether she referred to immigration status or her status in society; nevertheless its

absence, and the restrictions she faced in life as a result of her immigration status, meant that she felt she resided on a very low rung in UK society:

> *I don't want to put the burden on other people. I feel I am a capable somebody. I can do it myself, without asking anyone. But I am being made a destitute because you know, I have got no say, I don't have any status.*

Precious, 41-50

For another woman, these three 'statuses' were inextricably bound together. Prudence feared that even if she were to be given leave to remain (immigration 'status'), she might not be healthy enough to work (because of her HIV status), and working was central to her sense of self and having status in society. However, this fear was overshadowed by that of the wider insecurity of her future in the UK:

> *I was working, and then suddenly for nine years you are just doing nothing... If I am given the papers, will I be able to be working again? That's the other thing – what's going to happen to me? You know? Even if I am not given, for how long am I going to get the papers, and what's going to happen, will I be able to do something? So, it's really a big issue with the immigration part.*

Prudence, 41-50

For some women this limited sense of self was compounded by the perception that asylum-applicants were automatically seen in a negative light by the British public[74]. One woman described her hatred of the term 'asylum-seeker', and her perception that it affected what she could do and where she could go, and how she would be seen by others, because of being labelled in this way:

> *But then no one hears you because they give you this lousy name, I hate it, 'asylum-seeker', you know, so you can't do too much, you can't even go anywhere and you know, and get your welcoming response. Everyone just gives you a negative response.*

Precious, 41-50

She also described her need to reiterate to key actors in her life that she was here legitimately and to distance herself from behaviours and groups (such as unauthorised migrants) that she felt were stigmatised in the UK:

> *Yeah, you know I have even told my social worker, that look here guys. I am not here illegally. When I came here, I didn't start on just going to the hospital to claim you know, whatever, being given drugs or whatever. I used to work, I have paid tax, I have got my National Insurance, everything I have got.*

Precious, 41-50

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[74] Sales argues that asylum-applicants have become a new social category in the UK, and that as a group, they are increasingly portrayed as 'undeserving'; in her view, the policy initiatives that have led to this perception have also served to isolate asylum-applicants from society and have led to substantial social exclusion for this group [151].

This distancing of self from stigmatised groups suggests that Precious had a heightened perception of the way those groups were seen by some members of UK society, and wished to make it clear that she was not among them. Grove and Zwi have pointed out that refugees and asylum-applicants are often portrayed as needy, and as a drain, and that this contributes to the Othering of these groups [113]. In this context, it is unsurprising that Precious sought to distance herself from those stereotypes.

She also referred to the way that asylum-applicants' use of health services was portrayed in the UK media. She felt that asylum-applicants were depicted as wasting resources:

It is frightening in a way because you know with this media business they are saying that you know we are wasting the NHS money blah blah blah all that stuff.

Precious, 41-50

Her statement that this depiction was 'frightening' suggested that she had concerns that media portrayal of asylum-applicants could have very real consequences for her continued healthcare access; her awareness of negative portrayals meant that she perceived a possibility that her healthcare could be withdrawn as a sop to the portrayal of migrants as 'resource-consumptive'.

Another woman's perception of her difficulty in accessing treatment was that this might be because of racism, and a desire to withhold treatment from Africans:

[If] they have got a heart, they would consider those people who are sick, who are HIV, they would take them and feel for them. But they don't have a heart, they don't feel the... Maybe they want them to die, because they are Africans.

Jackie, 31-40

This interpretation of the motivations of those withholding treatment inevitably affected this woman's own reading of the way she was likely to be perceived as a member of that group (Africans), and therefore led her to distrust British people generally for their capacity to dehumanise her as a member of that group:

The British people, they don't like people, they don't ... consider that you are human being. They think that ...you are nothing.

Jackie, 31-40

Women interviewed for this research believed that the labels attached to them by the UK public ('asylum-seeker', 'African', 'HIV-positive') collectivised them and affected the way they were seen in society only as members of those groups, and this interacted with their own shifting senses of self as members of those groups, and especially as migrants – whether as 'asylum-applicants' or 'Africans'. Together with the HIV stigma (see section 8.4.3) that they

perceived both among the UK public and within their own communities, their identities were substantially altered by their experiences as migrants in general, and within the UK immigration system in particular.

6.5 Chapter Conclusion

Zimbabwean women who participated in this research reported no original intention to remain in the UK in the long-term; for most, it was only after discovering that they were HIV-positive that remaining in the UK became inextricably bound up with their migration intentions, and continued survival.

Late diagnosis of HIV among African migrants in the UK has been well-documented [84, 95, 162], and an important explanation for this phenomenon has been individual perception of (HIV) risk. Few women in this research had perceived themselves at risk, and had only been tested for HIV as a result of becoming very unwell or developing conditions (such as shingles) that sometimes indicate HIV infection. This echoes Feldman and Maposhere's findings from Zimbabwe, where most women did not consider themselves at risk until after they had been diagnosed with HIV, or a partner or child had become unwell. In their research, women associated risk with 'other' types of women [92]. There are substantial individual and public health benefits associated with earlier diagnosis [79, 88], and some of these benefits are highlighted in the present study, since at least two women had to delay initiation of ARV therapy as a result of TB co-infection.

The asylum-health nexus that had been established for these women, both by circumstance and by the nature of the basis for their asylum applications, served to augment an already powerful sense of being trapped in the UK. This finding reflects that of Doyal and Anderson: that many of the women in their study felt 'trapped' by the very services that keep them alive [112]. Most women revealed what they saw as their own powerlessness to control the situation they had found themselves in: wishing to return to Zimbabwe, yet caught in the UK for their own survival. This powerlessness was worsened by the many uncertainties associated with life as an insecure immigrant in the UK, and their participation in the asylum process.

Women's experiences as insecure immigrants varied substantially. The discrepancies in their incomes and the state support that they received reveals an inconsistent and 'Kafka-esque' [293] system, and left some women near-destitute.

Women's discourse on the restrictions on working revealed a strong sense of exclusion from UK society, and this had consequences for their perceptions of self as migrants and of their understanding of the ways in which they were perceived by the UK public. Timotijevic and Breakwell have pointed out that migration itself does not necessarily threaten identity, but

that where an individual moves into a social context where the bases for continuity, self-esteem or self-efficacy become unstable or disappear, identity can become threatened. This is heightened where the new country is opposed to the immigrant, and where defining one's position in society requires the use of categories such as 'immigrant', 'guest', 'foreigner' or 'refugee' [9]. This identity of exclusion sometimes had consequences for, and was in turn affected by, their interactions with bureaucratic processes and their analysis or understanding of UK immigration policies.

These structurally-determined senses of self and of UK society sometimes had repercussions for the ways in which women interacted with systems and bureaucracies, and perceptions of deliberate attempts to exclude them also rose to the fore in their interactions with healthcare services. Policy-related effects on access to HIV services and health services more generally are discussed in detail in the next chapter.

7. Chapter 7 – Policy-related Health Experiences

7.1 Introduction

This chapter describes the women's access to healthcare and discusses the ways that the Charging Regulations and the accompanying Guidance may have influenced experiences accessing healthcare. Experiences of successful and unsuccessful healthcare access are discussed, followed by women's responses to policy-related barriers to healthcare. Finally, the consequences of policy-related barriers to care are discussed. It is worth noting that it was sometimes difficult to interpret what occurred between doctor and patient when only one participant's account was available.

Not all the women encountered policy-related barriers to HIV/other healthcare services, but for those who did, problems included refusal of HIV treatment, difficulty getting medical referrals for non-acute conditions from general practitioners, and having the treating hospital contact the Home Office.

As described above, there is substantial variation in implementation of the Charging Regulations and Guidance [294]. Thus asylum-applicants' and other insecure immigrants' experiences accessing healthcare (and HIV treatment) can also vary. This variation is often increased when individuals move through the asylum/immigration system, thereby occupying more than one immigration status category (i.e. unauthorised migrant, asylum-applicant, overseas student) over the course of their healthcare experience while in the UK.

7.2 Healthcare Access and Policy Barriers

The majority of women in this study did not experience difficulty accessing HIV services under the Charging Regulations. Although they arrived at HIV services through a number of different routes – GP referral, referral from walk-in clinics, or having been admitted as an inpatient in hospital – most of these women did not have problems being referred for treatment for their HIV or in accessing a GUM clinic, although accessing other secondary healthcare services was sometimes more difficult.

One woman described what happened immediately after her HIV diagnosis at her GP surgery. She was introduced into HIV services very rapidly following her diagnosis, and she was not even made to wait for a confirmation of her diagnosis to be given a referral:

> *So she [her GP] told me she was going to refer me to a sexual health clinic, where I can meet a consultant, the consultant will take another HIV test again, just to confirm. But, meanwhile, they will consider me positive, it's just a confirmation.*

Beatrice, 41-50

Another woman described a different route to HIV services (she was diagnosed in a hospital, having been admitted for treatment as an inpatient, and introduced to the GUM clinic there). Her path to seeing a GUM consultant and receiving treatment for her HIV was similarly smooth:

> *It was easy for me, because I was admitted at [hospital x] in another department... so the health adviser came and showed me that if I decide to start treatment – he said I should come and see the consultant, to see what was going on, because I was HIV-positive[75].*
>
> *When I was in hospital, I was introduced to the GUM clinic...at [hospital x].*

Mary, 41-50

Despite the existence of policy barriers, both these women were able to access HIV services with ease. Neither seemed aware that in principle, obstacles could lie in their way to receiving treatment for their HIV disease. The routes to HIV services that they both passed along were very similar to those that a British citizen would follow[76]. This relatively smooth encounter with HIV care access and their consequent confidence about their entitlement to care is exemplified by this woman's explanation of her route to HIV services, where her HIV had been diagnosed at the hospital in which she later received treatment at the GUM clinic:

> *Because when I was diagnosed I was diagnosed there, so I became their patient, so they just, they arrange appointment for me.*

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[75] Allan & Clarke (2005) also note the importance of health advisers for HIV-positive asylum-applicants, especially around diagnosis of HIV [200].

[76] Allan & Clarke found that both asylum-applicants and UK citizens had the same level of satisfaction with HIV services in their study of a particular clinic in Leeds [200].

Mercy, 41-50

While *most* women had little difficulty receiving care, some of the women interviewed did report experiences where their immigration status seemed to act as a barrier to them receiving care. These barriers ranged in severity from being asked questions about immigration status before care would be given, to outright refusal to treat.

One woman was refused ART because of her immigration status. She had been diagnosed HIV-positive in Zimbabwe and started on ART there. She came to the UK in 2005 to visit her sister, and went to hospital in the UK only when she became unwell and her medication was close to running out. She was admitted as an inpatient:

> *I was started on ARVs back home. In July of 2005 my sister, it's when she invited me... it was a six months visa, and I thought, "oh, I will just go back home after the graduation"... I went to [hospital], it was an emergency, I was feeling weak, vomiting, diarrhoea, then I went with my prescription, I think it was just five days left medication. ... Then I was admitted for about two weeks... when they took my CD4 count it went up, within two weeks it was about 450.*

Celeste, 41-50

She described being told at this point that her immigration status and the magnitude of her CD4 count (450/μl) meant that she would no longer be treated, unless her CD4 count dropped below 300/μl:

> *Then [the hospital] said, "we can't treat you anymore, because of your immigration status, what you are doing now is like, seeing as your CD4 count is 450 now, in this country, we are not entitled to give ART when your CD4 count is 300 and above, but when it's 300 and below is when we give you the ART."*

Celeste, 41-50

This respondent's recollection of having ART withheld suggests that her immigration status was at least in part a factor in the decision to withhold treatment. It is possible that in this instance, the hospital trust was unsure how to interpret the Guidance term 'immediately necessary treatment' [181], or that clinicians were following British HIV Association (BHIVA) recommendations that a patient is started on treatment before her CD4 cell count drops below 200/μL [295], which this patient's had not. On the other hand, she had already been started on ART in Zimbabwe, and BHIVA do not recommend treatment interruptions [295].

Another woman described having been started on treatment, which was later withdrawn because of a charge she had accumulated when she was first diagnosed HIV-positive in the UK. She had been found to have pneumonia at this earlier time and therefore received a bill towards the cost of her associated stay in hospital:

P: I go there to take my tablets. But this time they said they are not going to give, because ... I have got a bill.

I: Because of?

P: Because I am a visitor...I was still in hospital, just before they, I was still sick, they treated me, but they were asking me about the money, when they know I didn't have the, you know. They come to me in hospital, in my bed, saying, "Do you have status here?"

Jackie, 31-40

She felt unable to pay this bill, and told the hospital trust where she had been receiving treatment, and who were seeking to recover the debt she owed them, that she did not have the funds to repay it. The Trust contacted her family in Zimbabwe in an effort to recoup the money:

They are saying I should pay it — they will take it to, you know, they will take it further? But I said, "I don't have money, I am not working, what do you want, I can't, I don't know." They even phoned in Africa.

Jackie, 31-40

She reported that her immigration status also prevented her from registering at a different hospital where she hadn't incurred a bill:

I: Would you consider registering at a different hospital?

P: I tried, but they said they can't ... because of my status.

Jackie, 31-40

Another participant described how her hospital appointment led to the Overseas Visitors' Department from the hospital contacting the Home Office:

When I went to [hospital], I was referred to go to the X-ray, so when I went there...they sent me to the overseas department, and I went there, they called, I was there for some time, they called Home Office you know.

April, 51-60

It was clear from April's discussion of this incident that she had not been prepared for this, and that she was taken aback to discover that the Home Office was somehow involved in her healthcare. Similarly, referral to other secondary services was sometimes less straightforward than some women's experiences of referral to HIV/GUM services. One woman described her difficulty in being referred by her GP to appropriate secondary services for her back pain, and her feeling that it was her immigration status that was the main obstacle to her receiving the care she felt she needed:

But then the GPs... I went there I said, "Why can't you refer me to this?" Then she was asking me about my immigration status so I just said to myself, "Oh, does it mean to say those who've got their matters solved are the ones who get that?" So she never, she didn't refer me.

Prudence, 41-50

Many respondents reported friends who had experiences such as these, even if they themselves had not. One woman described the kind of charges that people she knew had faced:

I have met some people who have got bills... And they have got bills of £40, 000. Oh yeah.

Joy, 41-50

And another woman specifically described how friends had been refused ART at a clinic that they had attended for some time:

P: They started to have people who asked about your immigration status...

I: Why did they do that?

P: I don't know – but they were asking and telling people that they couldn't have the ART.

Precious, 41-50

Although women's immigration status at time of diagnosis was not always clear, it is worth noting that the majority of women who seemed not to have met any policy obstacles to access to HIV care reported that they had entered the UK on full time student visas, which would have entitled them to exemption from charging under the Regulations and their associated Guidance [175, 181]. Where there were policy obstacles (as described above) the women were more likely to have reported entering the UK to visit family and would therefore have been in the country on visitor's visas and would not have been entitled to exemption from charging under the Regulations.

The next section will describe the women's *responses* both to being refused treatment themselves, and to the knowledge that other people they knew had been refused treatment or incurred a bill as a result of being categorised as an overseas visitor. Exploring women's responses to policy barriers in this way facilitates a better understanding of the way they interpreted these experiences and therefore of the impact of policy on women's access to healthcare.

7.3 Women's Responses to Policy-Related Barriers

The women's responses to being refused care or to encountering immigration policies when they sought healthcare varied. A number of the women were very distressed by the denial of care. One woman became so frightened that she subsequently attempted to avoid contact with services altogether. Another became very upset by being refused care, and saw it as evidence of her own marginalisation in UK society generally. Other women were able to take advantage of other aspects of health policy or of loopholes in the Guidance to ensure that the care they received was satisfactory, or they would identify other ways of coping with experiencing refusal to treat.

Being refused care or presented with a bill caused some women to become fearful and to avoid further contact with services. Jackie described her desire to leave the hospital as soon as staff there began to ask her questions about her immigration status:

> Yes, they come to hospital and ask my status, and I didn't want to stay anymore in that hospital, because they were just asking, "Who can we contact? Did you claim asylum?" you know, so many questions about my status, when I am sick.

Jackie, 31-40

In fact, since this experience she had avoided all hospital services apart from the GUM clinic where she went to collect her ART, because she was scared of being asked to pay[77]. This included an investigative procedure that her doctor wished her to undergo, and routine screening:

> That one [the GUM clinic], it's the only way I go...You know, the other time my doctor said I should get an operation, I didn't go.

> They wanted to test, because I had develop a... sort of a lump, here. So he wanted ...a test. So I was afraid to go to that hospital, and didn't go. And he asked me, I said, "I don't want that operation, I am OK." The other time they wrote a letter I should go for a PAP smear. I have never been there, I am afraid.

Jackie, 31-40

Jackie had come to the UK to visit her sister for her graduation, and while here had fallen ill and been diagnosed HIV-positive. She had made an asylum application the day before I met her, but had been living in the UK illegally for a year before that. She had only made the asylum application because her GUM doctor had advised her that if she did not, he would not be able to continue treating her HIV.

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[77] The Refugee Council (2006) have expressed concerns that vulnerable individuals faced with a charge might respond by avoiding further contact with services [182]; Dunstan outlines anecdotal evidence suggesting that many women receiving section 4 support have broken contact with antenatal services after receiving a bill for their care [31].

Yesterday, I have been at Home Office, you know. I was seeking asylum. I have never seeked (sic). I was afraid to go there to look for asylum. I didn't, I never go there, my doctor told me to go there, and I was saying, "I am going, I am going".

Jackie, 31-40

Although Jackie was an exceptional case, in that none of the other women interviewed had been living in the UK illegally and had therefore had better entitlements to care, other women had heard of friends having a similar response:

But they asked people, and now no Africans will come here, they are scared that they will stop the drugs, because of this immigration thing."

Precious, 41-50

Thus both Jackie's account of her own responses, and Precious' report of her friends' experiences suggest that encountering immigration policies in the health sphere – even when this amounted to as little as being asked questions about one's status – could encourage individuals to avoid further contact with services.

However some women were able to take advantages of loopholes in the Guidance. Joy recounted how her HIV consultant had told her that everyone was entitled to ART, and how having started on this course of treatment before her application was refused meant that it could not now be discontinued:

I: How is it that you are able to get the anti-retrovirals if they say that you are not entitled to the other things that you need?

P: Anti-retrovirals, they say that everybody should get it.

I: That's what the consultant says?

P: Yeah. Everybody should get anti-retroviral. And, another thing is they couldn't stop it, because it had already started.

I: So you started on it before you applied for asylum?

P: Yeah, before my application was refused.

Joy, 41-50

Contrary to what Joy reports her consultant having told her, it is not the case that policy recommends that everyone who requires ARTs should be treated with them – in fact the Regulations and Guidance are quite specific that while HIV testing and counselling should be made available to all without charge, treatment should not [175, 181]. However, the easement clause does protect individuals who have started on a course of treatment while legally entitled [181].

One woman successfully took advantage of the choices available to her in the current NHS system, and changed hospitals when she felt dissatisfied with the treatment she was receiving because of having been labelled as having 'visitor' status:

> I go to [hospital x]. I used to go to [hospital y], but I noticed that my file was the only one that was labelled as a Visitor, and yet I'm not the only visitor that goes to [hospital y]... And then, I decided to change hospitals.

April, 51-60

Thus April indicated that despite unpleasant experiences (i.e. being labelled a 'visitor'), she was able to utilise strategies that reduced the likelihood of a recurrence of such experiences.

Unlike Jackie above, who felt that she couldn't circumvent the problems she had in accessing care because of her unauthorised status, Prudence felt that her registration in 'the system' gave her some freedom of choice, and echoed April's approach above to changing the site of her treatment:

> Because now that I am in the system, I can go like, even changing the hospital, they say you can go to whichever hospital you feel comfortable with.

Prudence, 41-50

Both Prudence and April discussed their care in language that suggested they felt relatively confident of their ability to continue to receive care, and to navigate their way through the options available to them within the NHS.

Some women responded emotionally on being refused care, or, in the case of one woman, upon discovering that the hospital she went to for treatment had involved immigration services. Responses ranged from fearing that the treatment they were currently receiving would be curtailed, to deeper fears about being seen as worthless by medical staff.

Here Precious discussed the concerns she had that treatment could be withdrawn at any minute, because of her immigration status:

> Well sometimes you just go there and think that the doctor will say I am not treating you anymore... Or can we see your status. Something like that. So it's not 100 percent.

Precious, 41-50

Celeste interpreted the news that she was not going to be given ART pragmatically, and tried to find ways to cope with it, but was nevertheless upset:

> I was down. I didn't know what to do. I [thought] just maybe, "it's the policy in one country, it's their policy", it was said like that anyway. I tried to eat food, whatever I get. Maybe I could keep going.

Celeste, 41-50

Not all women had such a matter of fact response to being refused care, and felt that the refusal was evidence of their worthlessness to UK clinicians. This participant became distressed when recalling how a hospital she was attending for an x-ray contacted the Home Office:

> *I was there for some time; they called Home Office you know. Why did they even start treating us? Why didn't they just leave us, let us die? What has happened now? They've done all their experiments on us, now they don't care.*

> *If - because why do they – if – I'm human! You know, if it was a dog or cat, they are prepared to take care of it. Not a human being, they have to contact Home Office to find out. I'm a human being! I want to live a normal life!*

> *Maybe... I'm not worth being treated, it's not worth it, it's like wasting the medication or the services.*

> **April, 51-60**

April interpreted her experiences as evidence that she was not considered 'worth' treating. Her use of the word 'us' (in the first quote) implies that she perceived this worthlessness to exist partly because of her membership of a particular group. In this case she may be referring to the fact of being HIV-positive, an asylum-applicant or a Zimbabwean. As discussed above, the perception that membership of (any of) these groups affected how you were perceived as an individual was an important component of these women's identity construction in the UK. In this context, for April, experiencing treatment refusal may have exacerbated the perception that UK society viewed her as little more than a member of one of these stigmatised groups.

Women responded differently to being refused treatment, or to discovering that their immigration status affected their experience of healthcare access. While some women responded pragmatically, or found ways to circumnavigate the rules, others found the conflation of immigration with their health entitlements more distressing. However both these extremes (and the range in between) represent a choice on the part of the women. Other outcomes associated with these barriers were less in women's control – the next section explores these consequences of policy barriers to healthcare access.

7.4 Consequences of Policy-Related Barriers

This section describes some of the consequences for women arising from the difficulties they encountered in getting access to health services because of their immigration status, or being refused treatment for HIV under the NHS (Charges to Overseas Visitors) Regulations 2004. While the previous section dealt with steps that women had taken to respond to these circumstances, albeit sometimes passively, this section outlines the consequences that the women interviewed were less able to control.

As shown above, Celeste was one of two women who had been refused HIV treatment outright. During the period when she was not receiving anti-retrovirals, she was repeatedly hospitalised for a number of different reasons, and required treatment for TB and psychiatric problems:

> *June, 2006, I was admitted again at [hospital x] for three weeks, and they just give me some pain killers on the ward. Then my doctor at [hospital x] thought that maybe we have to do some more investigations, "We're referring you to [hospital y]". So in August last year I was referred to [hospital y], and I was admitted for a month...Their first diagnosis...they said, "You have got a possibility of TB". So in September to April this year I was on TB tablets.*
>
> *When my CD4 count was at 220 I couldn't even walk, I was in hospital, and I was even referred to the psychiatric department of the hospital, they tried what they could do.*

Celeste, 41-50

Celeste's experiences of treatment refusal and the outcomes for her health were unusual among the women, but they do represent the possible consequences for HIV-positive women who are refused care. Although this extreme was not experienced by the majority of the women in my sample, who were able to get treatment for their HIV, many had problems accessing other secondary healthcare services.

One woman reported that her eyesight had deteriorated because she had not been able to access an optician, and as a result she could no longer read:

> *I can't access any other, I can't access any other health, I can't access the dentist, I can't access the opticians, although now I have realised my eyes are becoming... sort of blind? I can't see very well. I can't read (laughs).*

Beatrice, 41-50

Beatrice (above) had experienced a relatively unencumbered route into HIV treatment and care, and had entered the UK on a student visa. Her difficulty in accessing these other services suggests that her asylum application may have failed by the time she sought them, as asylum-applicants are entitled to free NHS dental treatment, free NHS sight tests, and financial support towards the cost of glasses or contact lenses [296]. However, there were measures in

place to support failed asylum-applicants in accessing these services even before the judicial review in April 2008, although these measures (filling in an HC1 and associated forms) have been criticised for being cumbersome[78] [299].

Joy, who also described herself as an asylum-applicant, was another who believed that she could not access an optician, and felt that she was going blind partly as a result:

> I would have loved to go for, for my eyes, because I think my eyesight is deteriorating. Whether it is from HIV, or whether it is just something – but because you don't have the money, you can't. So eventually you will be blind.

Joy, 41-50

In Beatrice's case, her inability to access these services was compounded by the asylum application process – when she went to try and register with an optician, she was asked for her passport, which was being held by the Home Office, who had not sent her the necessary documentation she needed to prove her status:

> Every time when I try to go there [to the optician's], they ask me for my passport. The moment I say my passport is at the Home Office, they say, "Go and wait for your passport, or bring something from the Home Office", and the Home Office hasn't responded to my application yet, to get the form to say that I am an asylum-seeker.

Beatrice, 41-50

Thus despite Beatrice's attempts to actively seek out the healthcare that she felt she required, bureaucratic obstacles associated with her immigration status prevented her from being able to actually receive treatment.

Not all women encountered immigration rules or obstacles when accessing health services; however, for those who did, the consequences were often severe, with difficulty in receiving care and associated deterioration in their health and eyesight sometimes occurring.

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[78] Some refugee agencies have expressed concerns that insecure immigrants may not know that these forms, and the secondary services they lead to, even exist [297]. A Refugee Council study on asylum-applicants with special needs found that fewer than 40% of respondents had registered with a dentist, and fewer than 26% with an optician [298].

7.5   Chapter Conclusion

Many of the women interviewed for this research had found it relatively simple to access HIV services. Moreover, most of these women had reached the end of the asylum appeals process by the time they were interviewed for this research, but were continuing to receive treatment. It may be that this is because of the easement clause laid out in the Guidance [175].

However, some women did seem to have encountered problems with successful access to HIV care as a result of their immigration status. One woman was refused treatment when she first required it in the UK, despite having been previously initiated on HAART in Zimbabwe, and the risk that treatment interruptions can promote drug resistance and treatment failure [128].

The variation in women's experiences accessing care did seem, to some extent, to reflect their immigration status when they first arrived in the UK (i.e. whether they had arrived under student or visitors' visas). This variation in experience depending on legal immigration status reflects Doyal and Anderson's (2005) finding that legal status had a substantial impact on African HIV-positive migrant women's daily lives in London [112].

Women responded differently to being refused treatment, or to discovering that their immigration status affected their experience of healthcare access. One woman in particular interpreted her experiences as evidence of her worthlessness to UK clinicians, and this may have exacerbated her sense of membership of a marginalised group. Erwin & Peters have identified concerns around discrimination among HIV-positive Africans in London as giving rise to distrust of clinicians and fear of experimentation by clinicians[95]. Foley found that in the USA, some African migrant women with HIV also perceived animosity from service providers [97], and Meadows et al see absence of discrimination as a crucial component in the development of overall "social, psychological and spiritual health" (p. 1457) [49].

Although some women were able to circumnavigate aspects of the Regulations and assert their wish for satisfactory healthcare, others found it hard to reach HIV care and other services. Opticians and dentists were particularly difficult to access for some women, although it is not clear whether this was directly related to policy or to their ignorance of their entitlements. Aspects of the asylum process and bureaucratic interaction with the Home Office sometimes compounded these problems. Women did not necessarily experience direct policy obstacles to care – more, these obstacles reflected the 'ghosts' of policy, and individuals' (both women's' and service-providers') perceptions of policy.

8. **Women's Perceptions of Structural and Clinical Contexts: Effects on Health Service Access**

8.1 Introduction

The women interviewed for this research reported many obstacles to, but also facilitators of, access to healthcare that did not necessarily relate to UK immigration policies. They came across these facilitators and obstacles in two main distinct, yet interrelated environments: The clinical setting, and their wider structural circumstances. Inevitably, however, their responses to these factors were filtered through their own interpretations and perceptions of themselves, of HIV, healthcare and society more generally; in this sense, therefore, women's internal processes and expectations were as important to their experience of healthcare as was the healthcare itself.

It is impossible to separate entirely the clinical context from other structural contexts within the framework of this research – for example, women sometimes saw clinicians as occupying a unique position in their lives, and at other times conflated them with broader support services. However, insofar as a differentiation can be made, 'structure' is conceived of here as social relations and enduring patterns of behaviour by participants in a social system in relation to each other. This encompasses all persistent relationships between both individuals and groups [300], and as such would include family relations, relations between the individual and the state and its agents, as well as relations between peer support group attendees, and individual attendees and the group itself [301].

While relations between doctor and patient are, in this sense, social relations and therefore structural, they do take place in a clinical environment. The clinic environment is seen here as a significantly different context to the rest of lived experience for PLWHIV (especially for women with insecurity of access, since the importance of encounters in this setting can take on additional weight). As such it is discussed here separately from other structural explanations and encounters. The clinical setting, for the purposes of this research, encompasses any interactions taking place in a clinical context (i.e. primary or secondary healthcare), and events relating directly to clinical care.

8.2 Structural facilitators

As we have seen, the women interviewed for this research described many aspects of their lives that they found difficult and hard to manage, and that could interact with their access to healthcare in complex ways. However, most of them also reported having substantial resources that they could draw on for emotional, practical and bureaucratic support. Although the existence of these support structures did not completely mitigate the obstacles to healthcare access that these women faced, they did alleviate them and acted as a prop that facilitated those women's attempts to seek out better healthcare. These resources arose primarily from the relations that women fostered with their families and with external support agencies.

8.2.1 Supportive Families

Most women reported having family members in the UK. Although a majority said their relationships with these family members were difficult, some women did receive support from their families which helped them to manage their lives here, as well as their HIV. Siblings and (adult) children were mentioned most often as sources of support, and especially of practical or financial support.

One woman described saving her money in order to heat the house in which she lived. However, it had remained cold, and she felt she had become unwell as a result. Her sister had offered to provide her with the money she needed to buy medication:

> *I remember there was a time when the house was very cold ... I couldn't afford to put the heating on during wintertime, and I started developing this terrible cough. And... my sister came, and she said 'Why are you not buying some Lemsip?' I said, 'I don't even have the money to buy Lemsip,' so she said, 'Well: tomorrow – can you come to my house and I will give you some money to buy Lemsip?' ... And I said to myself, 'Honestly – is this why I came into this country? To be a beggar or a destitute?' I started crying.*

Precious, 41-50

Although Precious was clearly grateful for the offer of support from her sister, it also suggests that she saw it as a sort of poisoned chalice: whilst it was immediately useful to her in providing her with the money to buy medication, it also served to reinforce her sense of vulnerability in the UK, and the extent to which she was reliant upon the help of others.

However, not all women who received financial support from siblings felt undermined by having to rely on others. One woman reported, in very matter-of-fact terms, that her sister provided her with food to eat:

I: So how are you managing to pay for food and travel?

P: Which food? I eat it, my sister buys food.

I: OK, so your sister is supporting you at the moment?

P: Yeah, I just eat, she buys her food and I eat.

Jackie, 31-40

These two examples illustrate that being supported by members of their family elicited very different responses: one woman feeling vulnerable and a burden, the other apparently simply accepting the support. Both women needed it, but the emotional repercussions that resulted were dissimilar.

Family members were also sometimes important for women's first HIV-related contact with health services, having escorted them to hospitals for testing and other care. One woman described the support that she had received from her son. She had avoided disclosing to him immediately following her diagnosis, and had only told him about her HIV status later on. He was upset with her for her initial withholding of this information, but she wanted to emphasise that nonetheless, it had been her son who had accompanied her to hospital.

Other women also reported relying on adult children or siblings for this kind of physical support, they too having been accompanied to GUM clinics; one woman said that it was her sister who had informed her of their existence. Women also reported having difficult emotional responses to their first visit to a GUM clinic, especially since this often coincided with the HIV diagnosis itself, and would describe themselves as having been '*very distressed, very angry*' (Judith, 54) as a result. As such, some women emphasised the roles that their family members had played in supporting them to seek care for their HIV in the first place, and this may have been particularly valuable in the context of their initial nerves and subsequent emotional reactions to attending the GUM clinic.

For Judith, familial support went beyond the emotional. She also described it as pivotal to her capacity to manage her illness on a daily basis. She discussed having struggled with adherence, until her niece intervened to help with reminding her to take her medications:

> *My niece always reminds me every day. Up to now, they are reminding me to say 'take your tablets', at quarter to nine, they ring me, they make sure they ring me, and they put besides my bed a poster which is 'don't forget your tablets' and then she wrote all the names there, yes. So it's easier now.*

Judith, 51-60

For those women who received support from their families, it ranged from the financial, to the emotional, through to the practical details of living with and managing HIV. Although, as we have seen, one woman felt that needing financial support from her sister reinforced her sense of dependency and vulnerability in the UK, most implied that, on the contrary, the various

types of support they got made them feel cradled by their families, and not alone in surviving with their HIV in the UK.

8.2.2   Experiences of Peer Support Groups

While few women reported receiving support from their families, most described some contact with, and often concomitant support from, HIV peer support organisations. Support groups seemed to provide many functions to different women, and these are discussed in detail below – however, all these forms of support taken together provided the women with a sense of community, and buttressed their capacity to cope with and manage their illness. Nevertheless, it may have been the peer aspects of the support that these organisations offered which contributed most to general wellbeing; for one woman, whose account is examined towards the end of this section, it was the absence of this specific aspect of the peer support group process that may have contributed to her sense of marginalisation as a person living with HIV.

Support groups were a significant source of information about HIV and HIV treatment for many women with the result that their knowledge of HIV improved, enabling them to manage their illness better. Some women even became 'expert patients' with the concomitant self-efficacy in clinical encounters that followed from increased confidence about HIV management.

Health and HAART were the main topics covered in support groups, and education usually occurred in group formats, either at courses or in meetings:

> *Sometimes health, sometimes drugs, they can teach us about these drugs, how they work. They can organise a lot of courses, and sometimes meetings to discuss... about the diseases that can affect women – that can affect everyone.*

Mary, 41-50

Mary's account above suggests that not only did she benefit from learning more about HIV at these sessions, but that this new knowledge also served to provide a counter-stigma message, and to remind those attending the sessions that they were not pariahs for having contracted HIV.

Another woman described her support group providing information in a similar way, and emphasised that this approach had galvanised her to improve her own ARV adherence. She said that learning more about the consequences of non-adherence had encouraged her to maintain her own health as far as possible:

> *It's really helped me because sometimes you can be keeping the medication and think 'OK, I'm OK, let me not take it'. But now you know that if you don't take them, the virus can escape... which can cause drug resistance. And [they] tell us about how you can keep your health.*

It was also information provided in their support groups at the kind of presentations described by Mary and Mercy above that influenced some women to approach their clinicians and ask for a HAART regimen change (see p. 209). Beatrice recounted attending a support group where she learnt that Efavirenz (Sustiva) may be contraindicated for African populations, because of their heightened risk of adverse drug reactions (ADRs) from this particular treatment. She reported that the person giving this presentation explicitly advised those in the audience to advocate on behalf of other HIV patients who had been prescribed Efavirenz, in order to prevent their initiating this course of treatment:

> I went to a support group... where they were talking about medication, and that's when I realised: they said for African women to be put on Sustiva, Sustiva does something to our mental health, it gives us pains... he said, we should know when we are taking people, to advocate for them, if they are an African woman and the doctor is suggesting Sustiva. Say no, immediately.

Beatrice, 41-50

Women who had attended Expert Patient Programmes or who had developed a sophisticated understanding of HIV through peer support group education, described those resources in terms that suggested they were highly valued. One woman explained the change that she observed in her own and others' perceptions about HIV, following the sessions (often called 'training(s)' by the women interviewed for this research) provided by peer support organisations. She articulated the difference between her own previous understanding of HIV in Zimbabwe, and in the UK following peer-support organised information sessions. She felt this transition contributed to the reduction of stigma:

> I think perceptions is another thing for HIV. People don't really know what it is all about... some think it's through promiscuity, some think it's, it's just got so many, it's such a big big subject. But it depends on who thinks what and where they are. People are different. When I was there, in Zimbabwe, it was HIV and it was HIV and it was there! [Pointed to the other side of the room]. It was distant... But when you come here after training you find it can be anybody.

Joy, 41-50

Joy also discussed at length her concern that much of the poor healthcare that individuals living with HIV had received was related to their own lack of understanding of their health and illness, and consequent inability to demonstrate self-efficacy in the healthcare context. She felt that the training received at support groups empowered individuals to demand better care for themselves:

> I have noticed, if people are not inquisitive and people are not... do not probe, things do happen to people. Like, somebody is taking a nebuliser. They do not know why they are

taking a nebuliser instead of taking cotrimoxazole, maybe they are allergic to sulphur in the cotrimoxazole. They don't know, and they are not told things like that, because they don't ask. So if people don't ask, people will just get on with it... in terms of empowering... when you go for these trainings you get empowered and then you will be able to ask some of the questions like I have been saying that people need to ask.

Joy, 41-50

Although support groups are not the only source of information about HIV for HIV-positive individuals, many women gave the impression that they valued the knowledge gained in these groups, and some felt that they had substantially altered their perceptions of HIV as a disease. Knowledge gained at support groups also seemed to have helped one woman to feel empowered to seek better healthcare for herself, and she felt that this could also benefit others.

Some women also reported receiving help from HIV peer support with navigating the bureaucratic aspects of their lives in the UK. These often did not directly relate to their HIV status, and in this sense, the peer support organisations attended by these women provided a service that went beyond their express remit as HIV support organisations.

One woman, on being asked during my interview with her whether she would recommend attending support groups to a friend, provided a detailed response as to the services that she felt were provided by peer support organisations – they spanned many aspects of management of life in the UK, from advice and referral to other external agencies who could help, to specific assistance negotiating free travel:

I will recommend that person to come over here and then she can get help, they will tell her where she can get help like benefits or housing, or tell her about this support group also, and other organisations, which that person might be able to go there, and ask her whether she can have her freedom pass, and where she can go and get the help, so that to get the bus pass so that she can manage to travel to these different areas. When the support groups will be there, yes. I do recommend them.

Judith, 51-60

The services that women reported receiving from peer support organisations often entailed facilitating their access to other, state-run services (such as accommodation provided by social services). Referral to these outside agencies and support in this referral may have benefited these women's capacity to manage their illness, by minimising the negative effects of other hard-to-manage aspects of life in the UK.

Many women also recounted their experiences at peer support groups in terms that suggested they received a substantial amount of emotional support in this setting. This aspect of the service worked in two distinct ways: women described specific anxieties that were allayed by support group staff, who often appeared to operate an informal counselling service; and

women also felt that it was often only at the support group that they were able to meet and make new friends away from the stigma that they feared encountering elsewhere – these friendships frequently served as a means of reflecting the women's own experiences, and reminding them that they were not isolated in living with HIV.

For one woman, using support groups was also a means of being bolstered when she felt depressed. She listed a range of services available to her, but saw them all as useful in assuaging her negative moods:

> It's not like you're going to go there every day, you go there when you feel down, to have massage, to have acupuncture, to have shiatsu, to have all those kind of therapies, advice, housing... all that kind of stuff.

> **Sarah, 21-30**

However, this formal aspect of the support group was mentioned far less often than the bolstering that women felt they received simply by meeting with other PLWHIV. Many women talked about the support groups as a social environment that felt safe, and away from the threat of stigma.

One woman described having consciously extended the security afforded her in her social interactions in the support group to other contexts. She felt an affiliation with the HIV-positive people she had met there, and this had given her a confidence and a sense of safety that enabled her to build a social life outside the group:

> You are in the same boat. So it's really helpful. Yeah, I would say that most of my friends now are HIV-positive, so makes it, like, an easier place. You can talk, even on the phone, or meet, or go anywhere.

> **June, 51-60**

Many women spoke of this sense of affiliation experienced in meeting others with HIV. Prudence summarised the value of this exposure to similar others when she described the informal sharing of information between PLWHIV at her support group. She felt it aided her understanding of her own disease, and helped to minimise the risk of feeling isolated in her experiences of HIV:

> You end up really understanding most of this stuff, or even sharing with others, you know, the experiences. You know, because there are some things you – like...the aches and pains, most of positive people are complaining about it. You will be thinking it's just you, not knowing the next person feels the same.

> **Prudence, 41-50**

For one woman, this social function of the support group provided a much broader sense of inclusion — not only did it minimise the isolation described above, but it reminded her that despite the difficulties she faced daily, life could carry on:

Because going to the support groups, talking to people, then I know there's life there.

Mercy, 41-50

Not all women were regular support group attendees. One woman, who reported having gone to support groups in the past — but almost exclusively for help in dealing with finances and bureaucracy — discussed her physical complaints. She had not heard others complain of similar symptoms (as she might have done in a peer support setting), and consequently felt very alone in her suffering. Her isolation had led to her contemplating suicide, and she felt that a passive approach to ending her life would be to discontinue her ARV treatment:

I'm kind of thinking, but why is it that these things just keep on you know, bothering me. I haven't heard a lot of people complaining about you know, 'I've got this, I've got that, I've got this', but it's only me, so sometimes I just think, 'why bother? Let me just take my life'. Sometimes I think of just stop taking the medication.

Precious, 41-50

Precious was unique amongst these women in her fatalism, and in her non-attendance of support groups, and as such provides further evidence that the peer support sector provided the rest of these women with much needed emotional support. This, in turn, may have had a substantial effect on their levels of self-efficacy and health behaviour.

For many women, the interactive and social aspect of support groups was a crucial element in their coping strategies and emotional lives, but conversely, it also had the capacity to augment existing concerns and fears. Prudence described her awareness of the discrimination that peers had encountered outside the support group. It was exposure to stories such as these, in the peer support context, that had convinced Prudence that venturing outside the safety of the peer support group context was not advisable:

So this is why we just, you know, of course you hear some other people making friends who are, but they've got problems you know, about disclosure and just because of the way they will be like, talking about HIV-positive people. So this has made me just to make friends with them. You know, people who are positive.

Prudence, 41-50

This kind of informal information transfer, though largely positive, also had the capacity to reinforce women's expectations of prejudice and hardship in the 'outside world', and was a potential source of misinformation more generally.

Support groups provided three main functions for these women: information provision, assistance with bureaucracy, and emotional/social support. This last function provided an important refuge for women away from the insecurity and stigma that they anticipated and feared in their daily lives, and served to buoy them against the isolation that they otherwise might have felt. Encountering other PLWHIV in a safe setting enabled the development of friendships which themselves often became another source of information and education about HIV, although the limited geographic context of these friendships may have also convinced women that support groups were the *only* safe space. Women's positive support group experiences complemented the aspects of the clinical experience that facilitated their healthcare access, in empowering them and providing them with the knowledge that they required to take full advantage of the clinical services available to them. The next section describes these clinical facilitators of healthcare access in more detail.

8.3 Clinical facilitators

Women reported many experiences in the clinical environment that facilitated their access to healthcare, and their proficient use of health services. Following the definition of access to care described above, good access to care is seen in this research as encompassing successful use of health services, as well as merely being in contact with services, and in this sense measures taken in the clinical environment to provide information about HIV, and to support women in the wider management of their HIV disease, were seen as factors facilitating good healthcare access.

8.3.1 Information provision

Many women interviewed felt that they had good access to information about their illness at their HIV or GUM clinics, and that this contributed to their education and understanding of HIV. Women often considered that the information available to them in this setting complemented the information they received at support groups (see p. 184).

Some women appreciated the availability of pamphlets and HIV-relevant magazines at their HIV clinic. Other women preferred to discuss their illness with staff at the clinic, and used contact with staff to improve their knowledge of the disease. Hope described her access to information as a mixture of discussion with staff and taking materials home to read. She was satisfied with the ability of the staff at her clinic to clarify anything she hadn't understood.

Judith also utilised both these resources, and described the time that clinicians and pharmacists spent explaining HIV medications to her. She saw her HIV knowledge and access to information as coming from three sources: staff at the clinic, reading materials available at the clinic, and visits that clinicians made to support groups to conduct education sessions:

> *Your doctor, and the pharmacist also, they will just – you know, for few minutes, like to say this tablets is that, and the side-effects may be this and this. And they will give you also what is written about this medication, particular medication which you are taking. And then you can also get some leaflets from there, and some magazines, Positive Nation, and also some of the doctors, they will come to these support groups, and they are invited to tell us more about the medication, about the side-effects, about the new medication coming on, and so on.*

Judith, 51-60

Information transfer in the clinic improved knowledge of HIV, and helped women feel that they had access to resources that would educate them about the disease, especially in conjunction with the resources that women were able to access in the support group environment. The improvement in the women's knowledge of HIV garnered from both the support groups and the clinics was valuable in and of itself (especially since research has shown that knowledge of anti-HIV treatments is substantially lower among HIV-positive

Africans in the UK than among their white British counterparts [93]). However, it also helped in the management of their HIV, and therefore with treatment adherence.

Some women reported interactions they had had with staff at their clinic that had helped them to understand better the minutiae of their treatment regimens and the steps that they, as patients, would have to take to successfully adhere to the antiretroviral drugs. Celeste described the careful steps that her clinical team had taken when she was first prescribed the drugs to explain to her the biology of HIV, the advantages and disadvantages of antiretrovirals, and how to manage her medication:

> *Before I was given the tablets I see my consultant, he explain my viral load, CD4 count, then at some time before I leave, I was taken again to discuss with my consultant and the pharmacist, we three, the advantages, whatever, you have to eat this, they even called a dietician to explain what I should eat, what times I should do tablet, what I will do, at least they really explained everything.*

Celeste, 41-50

Improved knowledge of HIV was valuable to these women beyond simple management of their disease. For some women, access to information had entirely changed their perspective on HIV, both in terms of a better understanding of issues like onward transmission risk, and a realisation that life-prolonging drugs exist. One woman acknowledged the change in her understanding of HIV – from believing that HIV could be transmitted through simple touch to a better grasp of the mechanisms of transmission. She had learnt this information through attending her HIV clinic:

> *Because what I knew was just hearing stories that if somebody is HIV, you can't share cups, or you can't share the same bed. To me it was something that can be transferred even just touching, so I got the knowledge from the HIV clinic.*

June, 51-60

Good access to information was important as a means of improving knowledge about management of HIV and HIV treatment, but also to dispel erroneous beliefs about HIV. Findings in the *Project Nasah* research with HIV-positive Africans living in the UK have found that talking with clinicians and accessing reading materials from HIV clinics were the most universal means of receiving information about HIV and HIV treatments [93].

8.3.2 Satisfaction with clinical staff

Many women expressed satisfaction with the care they received from their clinical teams, and it was often the case that when women described satisfaction with care, a clinical team member (consultant, GP, nurse or pharmacist) had taken an active role in providing attentive care, referring women to the appropriate services, or in communicating clearly with women about their HIV and the treatment they were receiving. Effective communication with patients

has been shown to be important for health outcomes, and the effects on emotional health have been shown to be particularly pronounced [302].

Women often mentioned how much they valued clear and honest communication from their clinical team in terms that suggested this was a valued quality in patient-doctor interactions, and this was sometimes framed in opposition to instances or examples of less satisfactory experiences of communication. Joy discussed the way that her clinician communicated with her about her treatment in positive terms, but emphasised that she had had to work with her clinician to achieve this level of communication. She felt that her consultant had not been easy to talk to at the start:

> *Now he is sort of like, because I ask questions, now he's sort of like, 'Oh well, yeah', he's opened up a bit. But naturally he is not a very welcoming person.*
>
> **Joy, 44**

Joy contrasted the effort she had put in with her consultant with the ease with which she communicated with her pharmacist, and emphasised the importance of a good relationship in this context for understanding her treatment regimen:

> *Take the pharmacist for instance – she's really nice, we sit down, we talk, we discuss the medicine, and she wants to know if I have got any problems in taking it, where do I store it, do I know what the side-effects of it.*
>
> **Joy, 41-50**

June described the importance of honesty in communication with her clinicians. She felt that although her GP did not have a sophisticated understanding of HIV, he had at least been honest about it, and this had in turn enabled her to discuss this with her HIV clinician, who was subsequently able to contact her GP with the aim of improving his knowledge:

> *Because my GP was honest enough to tell me that he didn't know much about HIV. Yeah. So that's when my consultant said, 'Oh, what I will do, I will write to your GP and explain'.*
>
> **June, 51-60**

Precious described the importance of feeling that her clinician was listening to her. For her, other factors relating to the doctor-patient relationship (such as the gender of the treating physician) were secondary, and she felt that being listened to was sometimes sufficient to improve her spirits even when medication could not be provided:

> *We need to be heard, so that we will feel good, even though we are not given anything, but the effect that at least somebody has listened to you, will make you feel better. I don't mind, I don't mind [what my GP's gender is], as long as he listens, is prepared to listen to whatever, I don't mind. I don't mind at all.*

For many women, clear communication and honesty from clinicians was considered a vital component of satisfaction with the healthcare they received. Proactive care and a willingness to enquire about satisfaction with medications made women feel that their concerns were being considered. The importance of feeling listened to, and of receiving patient-focused care made some women feel better, even when treatment was not available for a particular complaint. It is possible that 'being listened to' helped women to trust their clinicians.

As discussed above, women were empowered to take advantage of the positive aspects of care that they encountered in their clinics partly because of the support that they got there, but also from family or support groups. For some women, these latter resources were more limited, and their experience of healthcare was sometimes as a result less successful.

The next section will discuss structural obstacles to successful healthcare, and the interaction of these obstacles with those encountered in the clinical context.

8.4 Structural obstacles

Women interviewed for this research encountered broad structural obstacles that could affect their wellbeing, self-efficacy, and their access to healthcare services. Their living conditions often made management of their illness very complex, and highlighted the limitations of their capacity to act with agency. Equally, stigmatising encounters and anticipated stigma often acted to quash women's competence in managing their social worlds and interaction with their HIV. For those women whose access to peer support was limited or declining, their need for practical and emotional support was often unmet. This unmet need arose from limited access to support services (the gap, or 'unmet' aspect of this phenomenon), accompanied by the 'need' – other aspects of these women's lives that they felt were problematic, and that affected their health.

8.4.1 Limited Access to Support Groups

Many women discussed at length the recent funding decline in the HIV sector [303], and some were loosely aware of this in policy terms. However most women reported encountering the funding decline through the direct impact it had had on their access to support services, and the level and extent of service received in this setting. As discussed in Chapter 6, many women reported having been in the UK for a substantial period of time when this research took place, and so had witnessed a reduction in the levels of service.

Many of the women who discussed this perceived drop in service explicitly cited the funding decline as the reason for it, and some attributed the cuts in funding to changes in perceptions of HIV from an acute, terminal condition to a chronic one. Nevertheless, they still saw the decline of the support group as problematic:

> *They are saying the funding [is decreasing] because they are saying HIV they are not treating it as chronic or whatever it is. But they don't know that people, they are living longer, but living longer with problems... If they destroy support group[s], it's going to be difficult. Sometimes you don't have appetite to eat on your own, but if you are seeing other people, you can eat.*

Mercy, 41-50

Mercy did highlight the social function of the support group, but also emphasised the importance of support groups for health and resilience. She felt that the increased longevity brought about by the advent of HAART did not eliminate other problematic aspects of living with HIV; the existence of that social space had to some extent become her raison d'être.

Some women discussed the funding declines in analytical terms, considering the consequences of a fall-off in the provision of support services. These women frequently voiced the concern that reduced support services would place an increased burden on the NHS, as a reduction in

the educative and risk prevention work carried out by support groups could lead to an increase in opportunistic infections for PLWHIV. The offsetting of anxieties that many women felt was a key function of support groups was emphasised again by Sarah, and she was worried that reduced emotional support could also lead to increases in mental health problems and a heavier burden on mental health services:

> *You'll find out that there's going to be more mental instability, people with mental issues in the hospitals, besides HIV, what they call you know, opportunistic infections, they're going to be on the rise again... If they cut down services, out of hospital services like that, it means that people that have no outside support other than the hospitals, where in the hospitals they're not giving out those kind of services. So, they shouldn't do that. That's what we're fighting for at the moment, that: 'No, don't do that'.*

Sarah, 21-30

Sarah drew a clear distinction between the services provided to PLWHIV by the NHS, and by third sector peer support organisations. However she also revealed substantial drive among HIV-positive women to ensure that peer support organisations would not simply fade away, and was involved with campaigns to try and halt this decline. Sarah was not unique among the women interviewed for this research in her active involvement with advocacy on behalf of herself and others living with HIV. This propensity to engage with political processes that potentially affected the lives of PLWHIV also demonstrated a capacity by some women to see beyond the difficulties of their own immediate circumstances, and act on their concerns.

Despite this demonstrated agency on the part of some of the women who participated in this research, there were other aspects of their lives in which they seemed less able to exert their will. One of these related to their living conditions, which few women described as satisfactory. The next section will explore women's living conditions and the powerlessness that many of them felt to alter these.

8.4.2   Living conditions

The women's reported accommodation situations varied quite substantially: some lived with family members, whilst others were housed by their local authorities. Beyond this lay further important differences. Of those who lived with their families, some spoke of a sense of being unwelcome and were perceived as a burden, whilst others felt propped up by the close network of support that family provided. Some women housed by their local authorities reported substantial problems with the private landlords who had been contracted to provide accommodation on behalf of the council. Accommodation experiences were often characterised by, on the one hand, women's willingness to try and alter their situations for the better by complaining to the appropriate authorities; and on the other, the frequent futility of these complaints and the women's inability to actually effect change for themselves in the face

of a system over which they had little influence. Although women's housing situations varied, a noticeable similarity across women's accounts of their housing circumstances was the absence of control.

This notable lack of control was referred to explicitly by some women. Hope described the process of receiving LA accommodation. She was unhappy about the nature of the accommodation she had been allocated, as well as the no-choice approach:

> You don't choose. They just give you whatever they have for you. So, whether you like it or not... I've been to two houses at the moment. You find that there is dampness in the house. So my children and I we are always coughing coughing, flu, one after another, so, it's no good. And the floor. You know those wooden floor? There are some gaps in between. You can actually see the soil (laughs), so it's not hygienic. Rats all over, big ones.

Hope, 31-40

Hope's power to effect change on her circumstances was further undermined by what she felt was a dismissive culture of blame on the part of the LA. She described the difficulties that she faced in getting problems with her accommodation fixed, since she felt that complaining had resulted in the blame for damage being directed at her. She repeated her earlier statement that her housing circumstances were characterised by having 'no choice':

> If there is a damage in the house, or something to be repaired, it's the thing that they will start to blame you first, before they will repair it. It will take time again for them to repair it. You don't have a choice, you just keep quiet if there is any damage, because if you say it they will start to blame you again, so... They always blame! They always say, 'Oh, that's why most property owners they don't want social services people, because you are not responsible'.

Hope, 31-40

Whether this dismissive approach was part of the institutional culture of Hope's LA housing department or actively discriminatory is unclear. However some women did encounter discrimination in their interactions with those responsible for maintaining their properties. One woman described the unhygienic disrepair she had lived with for some months, and reported that this had continued for so long because her landlord had not felt it was necessary to respond rapidly since she was African and ought, in his mind, to be grateful for the bare minimum:

> In the flat where I used to live, there was a time when I went for three months, there was a blockage in the shower, and I couldn't wash, I couldn't have a shower, I couldn't go to the toilet in the flat, because the landlord was an Asian guy. And it's like, when I went to complain he would look at me and say 'You are from Africa, at least you are free, you should be happy you have a roof over your head' sort of thing, 'you shouldn't complain about such things, after all you come from a worse situation', so... (laughs).

Beatrice, 41-50

Although Beatrice laughed when recounting this and in so doing attempted to make light of the experience, it had nevertheless caused her considerable inconvenience. Further, in trying to make light of this discriminatory encounter she hinted at an attempt to mask the distress it may have caused her. She was unable to exert any control over her circumstances in the context of the attitudes of her landlord.

Other women, who also frequently recalled events in ways that suggested they were capable of exerting some force in effecting change in other aspects of their lives, described their housing histories in similar terms. They did not 'move house', but 'were moved', usually by social services:

> I went to social services, so they were just moving me and my children from one place to another.

June, 51-60

> After three days he said he'll phone me again, then I said, 'How long am I going to – when am I going to be moved?'

Celeste, 41-50

This passivity was often accompanied by an effort to emphasise that they were grateful for the accommodation they had received, despite simultaneously listing its defects. This attempt to appear positive was again in contrast to other areas of their lives (such as their healthcare experiences) when they had been dissatisfied. Beatrice described the hostel she lived in with her daughter, and aspects of it with which she was unhappy; she concluded by stressing that despite these features, she was thankful that she was not a rough sleeper:

> It doesn't look like a home, because in every room there are sinks and taps, so it looks like it was an old people's home, or a home for people with learning disabilities, OK, I am grateful I have a roof over my head, I am not living rough!

Beatrice, 41-50

Women who participated in this research did not operate in a vacuum, and as such it is likely that they knew about negative media reporting on asylum-applicants and in particular the media's coverage of migrants' access to social housing as one of the central battlegrounds for these debates [304, 305]. This demonstration of gratitude for being housed, despite often highly unsuitable conditions, may have been in part informed by an awareness of the societal discourse around the housing of asylum-applicants and migrants.

Many women said they lived with family members in the UK, or had done at some stage since their arrival in the UK. Most of these women described experiences that suggested that they had not been made to feel welcome by their family members, either because they were seen

to have remained in their families' homes for too long, or because their HIV diagnoses had occurred whilst living with family who stigmatised their illness. Two women described circumstances in which living with family was more stable and less threatened than the picture outlined above; however, even for these women the living conditions were far from ideal.

Most women who described having lived with family members at some stage since their arrival in the UK had been actively made to feel unwelcome, and had consequently left or been asked to leave the family home. While stigma was sometimes a factor in ending these arrangements, women also reported more benign reasons for their being evicted. One woman recalled the months immediately after her HIV diagnosis, when she had stayed with her sister for some months. Eventually her sister asked her to leave, citing her own inability to continue to support Precious and her children:

> Then I came out [of hospital], and I was staying with my sister all along, until my sister said, cos she has got her own kids as well, she said, 'I can't keep looking after you and your family. You have got to find yourself an accommodation.'

Precious, 41-50

Precious did not report a rift between her and her sister following this, and was able to arrange alternative accommodation for herself and her family. Celeste described similar experiences, and understood that being asked to move out did not mean that her sister had stopped loving her, but did not wish to have the burden of responsibility of looking after her:

> In the first place she [my sister] was very supportive, but when my refusal came, she just changed her attitudes towards me. It's like I'm struggling to stay there because I don't have anywhere to go. She's my sister, she loves me, but she said she wants to stay with her own sons and have freedom.

Celeste, 41-50

While Celeste understood and accepted her sister's request for her to leave, she was reluctant to do so since she did not feel there was anywhere else for her to go. Although Celeste did not report that she had experienced any stigma, she did suggest that it was the change in her immigration status that had precipitated her sister's decision to ask her to leave.

Immigration status and status changes also affected Jackie's relationship with her family. She had been living with her sister and brother-in-law. Her visitor's visa was soon to expire, and her brother-in-law asked her to leave, threatening to contact the Home Office if she did not:

> [I was living] at my sister's place... After some time, my brother in law started to complain, wanted me to go back home. Said, 'Your visa is now getting expired, so the time you have visited us is enough'. I said, 'I am sick. How can I go back home? I know I should be home'. At the work, I was working at NSSA, as an accountant, in Zimbabwe. So

I was supposed to go to my work, but because of this disease I can't go. He said, 'No, you have to go. If you don't go, I am calling the immigration.'

Jackie, 31-40

Jackie felt that her brother-in-law was being unreasonable in his demand that she return to Zimbabwe, since she now knew that she was HIV-positive and felt that she couldn't return. Her explanation in this extract of the reasons why she knew she should return to Zimbabwe may have been motivated by a desire to prove (both to her brother-in-law and in her interview for this research) that she had some credibility in this belief: that she wanted and needed to return home, but was required to stay in the UK almost against her will, because of the need for appropriate medical care.

Other women described experiences that suggested HIV proved to be more of an obstacle to their continuing to live with family members. June recalled being evicted by her sister as soon as she became aware of her HIV diagnosis:

But I went through a lot to get where I am now. Because when I was diagnosed I was living with my sister, so abruptly she decided not to live with me.

June, 51-60

Jackie also reported being evicted from her family's house as a result of her HIV status. After being asked to leave her sister's house, she went to stay with her brother. However her brother's wife was uncomfortable about Jackie's presence there, and Jackie felt that her sister-in-law was convinced that it was she, and her HIV status, that had caused her nieces and nephews to become ill:

And I have got a brother. I went to stay with my brother and the wife, and also his children. I stayed there, things were not well. I think the wife didn't like me, because of this disease... She was saying I am the one who is causing the children to get sick. Her children, one day they had diarrhoea, she said it's me who caused those children to get like that... So you know all my life I have been bitter, by that disease, people have deserted me, they have rejected me, well I was going through bitterness.

Jackie, 31-40

Jackie thus felt she had been ostracised by different members of her family, both because of her immigration status (see p. 198), and because of her HIV. She felt the consequences of this very acutely, and felt rejected by everyone around her, because of her HIV status.

Women's experiences of stigma and its consequences also went beyond their immediate living circumstances, as the next section will describe in more detail.

8.4.3 Stigma

Women reported experiencing stigma from many sources: from family and friends, in the healthcare context, and from society more generally. For some women, the expectation of stigma ('felt' stigma) was as unnerving as other women's very real experiences of stigmatising encounters ('enacted' stigma [100]). This sometimes made them fear circumstances in which stigma might occur – not least in healthcare settings.

Some women, who also acknowledged that their knowledge of HIV had been limited before arriving in the UK, being diagnosed with HIV, and attending support groups ('*I used to be in that sea before, and I would be looking at people with HIV, and for me it was, I would not share a cup with them, I would not share my plate with them, I would not share my spoon with them, because for me they were equal to death' – Beatrice, 47*) now used an explicit, support group-informed lexicon of stigma:

> *I was very unwilling to meet anyone from Zimbabwe, because I know the stigma people from Zimbabwe have.*

Beatrice, 41-50

Interestingly, in the first of the two extracts above, where Beatrice acknowledged her own previous, stereotyped view of HIV, she was careful to depict exactly what those preconceptions had been in very descriptive language. By the time she came to describe her fear of meeting other Zimbabweans, and had located herself in the present, where she had received her own HIV diagnosis and was a regular support group attendee, she had begun to discuss the phenomenon in more overt terms.

For some women, stigma was a daily occurrence, especially when their family members overtly enacted their own fears of the possibility of HIV transmission through casual contact. One woman, April, described living with her half-sister soon after her HIV diagnosis, and her half-sister's efforts to avoid contracting HIV herself. These actions made this participant very upset – her half-sister's HIV-avoidant behaviours extended to avoiding breathing the same air as April:

> *When I came, I was staying with my half-sister. But when I fell ill, every time I used the bathroom, she used to put bleach. Every time I sat on the toilet, she would wipe it with bleach, and she had taken all my clothes out of her closet (crying). And I used to sleep on the floor, and she would open the window in her bedroom, you know, because she didn't want to breathe the same air as I.*

April, 51-60

These HIV-avoidant behaviours humiliated April, and had consequences beyond transmission prevention. Lekas et al classify these kind of acts as 'hygienic degradation' [102]; insisting that

April sleep on the floor may have been a way of overtly acting out disapproval of April as a person living with HIV, and augmenting April's exclusion from the household.

April's experience was unusual, insofar as most women who remained living with family members after their diagnosis reported that their family members were supportive. However, many other women acknowledged that stigmatising attitudes from family members, and especially in-laws, meant they had to alter their living circumstances. As with April's sister, irrational fear of contagion was a common symbol of stigmatising beliefs.

Celeste reported that her disclosure to her parents-in-law resulted in them rejecting her, and blaming her for their son's (her husband's) illness and death. She was no longer welcome to live with them:

> My husband's parents and relatives thought I am the one who caused my husband's death anyway, so they couldn't stay with me anymore, so I have to go and stay with my parents.

Celeste, 41-50

This may have been a gendering of responsibility for HIV transmission, as other women experienced rejection by their in-laws for similar reasons: they were blamed for their husband's HIV infection. In Jackie's case this had stark consequences for her children as well as herself. She reported that her children had remained in Zimbabwe when she migrated to the UK, and that one was diagnosed HIV-positive after she discovered her own HIV status. Jackie's husband (from whom she was separated) had also left Zimbabwe, and his family refused to help look after her children (their grandchildren), because of their association with Jackie, whom they held responsible for their son's HIV infection:

> The family is [blaming me], but he has been married before. And the wife died, before me. But they are blaming me, because they don't like me... They said, 'We don't want anything to do with that woman and her children, we don't want, why did she get pregnant at first?' They said, 'It's that woman who brought that AIDS to our brother, so we have got nothing to do with her'.

Jackie, 31-40

Jackie felt that this wholesale rejection of her and her children was not only a function of HIV stigma, but was possible because she was anyway not liked by her husband's family. In the above quote, she distanced herself from the stigma that came with this blame by pointing out that this blame was misplaced, since her husband had been married previously, and his first wife had died.

Distancing self from what were seen as stigmatising aspects of HIV or HIV transmission was a common coping strategy for these women. Although many women employed the rhetoric of

the support group and discussed stigma as a concept in overt terms, they were also often quick to distance themselves from what they saw as stigmatised associations with the illness. Beatrice was keen to emphasise that the behaviours that had resulted in her becoming HIV-positive were 'what everybody else does'; she emphasised that blame is not appropriate where transmission risk was encountered naively:

> *I didn't do anything extra, I didn't do anything less, it's what everybody else is doing. And I got it... And if, innocently, unknowingly, you get it from someone who gives it to you unknowingly, like someone did to me.*

Beatrice, 41-50

In emphasising this, she may have been hinting at the blame that is ascribed to some groups (i.e. sex workers or injecting drug users [110]) for their own HIV status, and that can augment the stigma experience for PLWHIV more generally. This was suggestive of women's internalisation of stereotypes associated with 'morally reprehensible behaviours' [100] that are sometimes seen as resulting in their contraction of HIV.

One woman discussed her awareness of these stereotypes while simultaneously revealing her own perceptions that perpetuated such preconceptions about specific at-risk groups. She discussed the preconceptions that society has about HIV-positive women and gay men:

> *Sometimes men are, especially when they are HIV-positive, they are associated to gay, to the gay community, and women are associated to promiscuity and all that kind of stuff... But men are more reckless. You find out that gay men, they can, after the diagnosis, they can sleep with as many [people as they want]...*

Sarah, 21-30

Sarah's account of the differences between HIV-positive women and gay men revealed a belief that gay men were likely to behave recklessly even after a positive diagnosis, and therefore contributed to an existing stereotype about one sub-group of the HIV 'community'. In this sense, it is not possible to frame these women as simple victims of the process of stigmatisation, but also as perpetrators of it. By distancing themselves from modes of transmission that they knew were associated with blame and further stigma, and by sometimes overtly describing the 'reckless' ways in which certain groups behaved, they were almost suggesting that those groups were, in fact, to blame for their HIV infection.

Meanwhile, some women continued to blame themselves for their own disease, and in so doing revealed an internalisation of wider societies' view of PLWHIV. Mercy's account of her strategy to avoid stigma revealed a literal internalisation of the stereotype that promiscuity could be inferred from an HIV diagnosis:

If you diagnose me HIV, I will die internally, not trying to tell people, because they will say, 'Oh, that prostitute.'

Mercy, 41-50

Mercy's efforts at non-disclosure, designed to avoid encountering some of those societal preconceptions of PLWHIV as deviant, had here taken on a psychological 'master status' [96], and her actual HIV diagnosis had to some extent become subsumed beneath this greater concern. Conversely, another woman felt that the stereotyping of PLWHIV resulted in their homogenisation, and that *'people living with HIV are blanketed in one blanket, whatever they say about these people that are living with HIV', Joy, 44* (although her use of the word 'these' once again suggested a desire to distance herself from the wider HIV-positive group or community). This had particular implications in the healthcare context, where felt stigma often came to the fore.

One woman described her feelings about GUM clinic attendance early on in her HIV diagnosis, and felt that clinic attendance itself could make 'you hate yourself, you start to blame yourself'. The semi-involuntary disclosure associated with GUM clinic attendance and the set-up in waiting rooms where names would be called out before patients went to see their consultant meant that she was fearful of being identified as an HIV-positive person:

I was scared sick. You feel that everybody's watching you; they are just pointing a finger, going, 'That one is HIV-positive!'

Hope, 31-40

Many women feared being identified as HIV-positive by their HIV status in this way or because of other aspects of HIV (such as a changing physical appearance or their HIV medication). Although the potential consequences of this involuntary disclosure would be similar to those related to chosen disclosure (women feared social alienation and were often uncertain about how people might react), the absence of control associated with exposing their status caused women to feel quite anxious about the spheres in which they chose to disclose. Healthcare was therefore a locus of particular concern about possible stigmatising encounters, since women could not choose to disclose there – everyone that they encountered knew their HIV status, and might treat them differently as a result: opportunities for concealment were removed. Felt stigma was therefore particularly acute in this context, as every new health encounter carried the potential for discrimination and labelling as a deviant, or as a vector of disease.

Mary described her experiences receiving primary care, where she reported having encountered substantial discriminatory practices – regardless of her appointment time, she

was always shunted to the last appointment of the day or offered the last appointment when she booked:

> *P: The other thing I discovered when I — that surgery, if you go there, like I am, I'm the last person, even [when] my appointment is at first they offer some people who come late. I know there are some people who are meant to be looked before me, because of some reasons. But I have discovered that I am the last person – since I had all my visits, I am the last person to be seen.*
>
> *H: And why do you think that is?*
>
> *P: Because of my status. HIV.*
>
> *H: So you feel that the GP surgery is pushing you back because of the HIV?*
>
> *P: Yes. Yes. And I'm not the only one. There's another lady who I one day accompanied too, because she has got arthritis... I accompanied her, because she is my friend, she wasn't feeling well. I went with her. She was also the last person to be seen, though... she wasn't feeling well. And when we discussed it, it was the same experience.*

Mary, 41-50

Mary's account of attending her GP surgery demonstrates how the healthcare setting can easily become a locus for both enacted and felt stigma. Mary's report of her own and her friend's experiences suggest that there is discrimination as a result of HIV, since insisting that HIV-positive patients are seen last could be seen as contravening the Disability Discrimination Act [306]. However, unlike some patients who have reported this same practice when seeking dental care [62, 307], Mary was not told explicitly that her appointments were delayed because of her HIV status; rather, she inferred it from her expectation that her HIV status would result in discrimination and stigmatisation. In this sense, the experience that she reported demonstrates the interaction between, and difficulty there is in teasing apart, enacted and felt stigma: although a discriminatory act seemed to have taken place, Mary's response to it, and interpretation of it, was partially informed by her own expectations and fears. Once again, Mary's account reveals a community-level awareness of these phenomena – she felt she had to shore up her account by also describing the experiences of her friend, insisting that these were not isolated incidents, but commonplace and therefore expected.

In healthcare settings, where women did not have the freedom to conceal their status, this amplification of everyday stigma experiences had substantial repercussions for women's responses to experiences and interactions in the clinical setting. The next section will discuss these and other obstacles in the clinical setting in more detail.

8.5 Clinical obstacles

Women interviewed for this research described many experiences that acted as obstacles to their successful access to, and use of, health services. Particular problems often seemed to arise at the level of primary care, and in continuity between primary care services and HIV/GUM clinics. Women also reported problems with treatment regimens, primarily as a result of the side-effects they had from their anti-retroviral drugs, although this was sometimes exacerbated by problems with communicating these concerns to clinicians.

8.5.1 Knowledge of HIV in Primary Care

Many women voiced concerns that their GPs were not sufficiently knowledgeable to manage HIV patients[79], and that they were sometimes dismissed by GPs because of this. Some women thought that the negative experiences they had in primary care were because of ignorance and the stigma associated with HIV, and that consequently they were not receiving the level of care they felt they should.

One woman discussed her perception that GPs are not well educated about HIV care; she felt, moreover, that this lack of education was augmented by HIV stigma. She was surprised to reach the conclusion that levels of stigma among GPs were equal to those found among the general public:

> But it looks like the GPs out there, they are, I don't want to sound rude, but it looks like some GPs are quite ignorant about HIV. It's like the stigmas that we find in the layman is equal to the stigma we find in the GPs.

Beatrice, 41-50

Another woman also expressed a concern that poor HIV knowledge among GPs was pervasive. She felt that her HIV status meant that she received poor quality care from her GP more generally, and described an occasion where she had gone to her GP with a minor complaint and had been ignored:

> I think most of the GPs don't know much about HIV. Because I also had another GP, I had ear-aches, he didn't even look at me.

April, 51-60

For April, this sense that her GP was not providing a satisfactory level of care (and additionally her conviction that he was not *able* to provide a satisfactory level of care) meant that she was also dissatisfied with the frequency of appointments at her GUM clinic. As she saw it, her HIV

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[79] Burns et al's research into poor utilisation of health services by HIV-positive African migrants in the UK found that some key informants felt that GPs were failing to address HIV with their service users, and that more generally, clinicians outside GUM settings were often reluctant to offer HIV testing and tended to refer on where testing was thought necessary [83].

was not well looked-after in between GUM clinic visits (by her GP), and therefore would have preferred to be seen more often by her HIV Consultant:

H: Why would you prefer to go once a month [to the GUM clinic]?

P: Because the GPs don't know much about HIV.

April, 51-60

Some women reported particular problems during contact with primary care nurses. One described having made an appointment with the nurse at her GP surgery. She said that when she got to her appointment, the nurse was reluctant to treat her because of concerns that she herself would become infected, and was dismayed that this woman had requested a nurse:

When she saw my HIV and my problems, because I have got a lot of problems about Hep C and other things, so she said, 'Oh, I have to make sure that I'm not going to be infected – why didn't you book the doctors?'

Mercy, 41-50

One woman expressed more explicitly the concerns described above – that GPs were not adequately caring for individuals with HIV, primarily because of HIV stigma:

Lots of people are always complaining the way that GPs, you know, are handling them, just because of stigma, they don't know, you know, about HIV.

Prudence, 41-50

Precious characterised her GP as 'not HIV-friendly' – she felt that her GP did not give her enough time in appointments. This concern, that she was not being listened to and that her GP was not equipped to manage HIV, meant that she had ceased contact with her GP altogether:

I haven't been seeing my GP ...'cause that one that I am seeing, she is not HIV-friendly, she doesn't give you time to explain, you know.

Precious, 41-50

Here Precious had interpreted the limited GP time available to her as proof that her GP was not 'HIV-friendly' – while it is possible that her GP's attitude to HIV patients was discriminatory, it is also possible that she had limited time to spend with any patient. Several of the women interviewed also interpreted similar events that that may have had multiple explanations, through a lens of stigma.

Many women reported a concern that one of the consequences of this perceived poor knowledge of HIV and stigma in the primary care sector was that they were passed back and forth between services. They felt that their GP was unwilling to treat them (either as a result of poor HIV knowledge and therefore reluctance to treat patients with complex clinical needs, or

as a result of more overt HIV stigma), and therefore referred them to their GUM clinics. However, their accounts suggested that they were often referred for conditions that the GUM teams felt were more appropriately treated in a primary care setting, and so sent them back to their GPs.

One woman described this phenomenon, and highlighted her frustration that she was being made to feel a burden upon the GUM clinic, despite suspecting that it was not always an appropriate venue for non-HIV related treatment. She felt that this related to the poor understanding of HIV in the primary sector outlined above:

> If I have a problem, and I go to my GP, my GP will say, the first thing when I walk through the door is: 'You are HIV-positive, we have referred you to the other place, didn't we?' So it's like, I am now the burden of the sexual health clinic, although it's nothing to do with HIV. But it's like, I feel I am being shunted around. And I feel this is because of lack of knowledge.

Beatrice, 41-50

Another woman described her early HIV management experiences with her GP. She reported his reluctance to treat her after discovering that she was HIV-positive, and his rapid decision to refer her to the GUM clinic:

> The GP, where I reported initially, before he referred me to the consultant at the GUM clinic was a bit... like, 'Oh, I can't'. When he found out that it was sort of like an HIV issue he was like, 'Oh go to GUM clinic, no I can't handle that here.'

Joy, 41-50

As a result, she became unsure as to where she should present when she became unwell. She described approaching her GUM clinic for care, where she was told that she ought to see her GP instead. When she went to her GP, she was referred back to the clinic:

> One morning I woke up not feeling well. I went to the GUM clinic, and they told me to go and see my GP. The GP told me to go to the GUM clinic, and I was like back and forth, back and forth.

Joy, 41-50

This lack of clarity around where care should be provided was discussed by many women. This participant described the same phenomenon, with neither provider (GP or GUM clinic) willing to provide care:

> They [staff at the GUM clinic] keep on saying, 'Go to the GP'. If my GP say[s,] 'Oh, we can't give you because we don't know what's causing this diarrhoea, maybe it's...your medication'. And then the consultants they will say, 'Oh go to, to get this, we are not supposed to give you anything for this, you have to go to your GP'.

Judith, 51-60

For many women, the perception of a lack of GP HIV knowledge and the overt stigma that they sometimes encountered in primary care, coupled with their traversing of this medical gulf between GP and GUM clinic meant that levels of trust in clinicians were very low, despite the satisfaction that some women expressed above. Although stigma has been identified as a barrier to care [82], it has usually been framed in terms of patients, and their reluctance to disclose their status or present for HIV testing in the first place; in this case, patients' perceptions of stigma in their clinicians acted as a substantial barrier to care and affected their treatment-seeking decisions and relationships with clinical staff.

This breakdown in trust also had consequences for the extent to which some women were willing to tolerate unpleasant side-effects arising from their HAART, and perceiving stigma in the clinical setting engendered suspicion in women of their clinician's motives.

The next section will discuss women's concerns around HAART side-effects in more detail.

8.5.2   Treatment side-effects

Women interpreted the side-effects of their treatment in different ways, and for some, even though these were often very unpleasant, they were a symbol of a happy alternative to being without HIV medication altogether. However, other women struggled to cope with side-effects, and saw them as emblematic of their illness. Mistrust of clinician's motives and suspicion that their concerns as patients were not a clinical priority exacerbated this and increased these women's resentment both of ARV medications and the ways in which they were administered.

The way many women discussed their medication implied that the HAART had become more of a concern to them than HIV itself. Some women reported neuropsychiatric side-effects from one drug in particular (Efavirenz), and found this to be very debilitating. One woman discussed the depression that she had had since starting on the medication, and though she wasn't certain that this was caused by the medication, struggled to come to terms with the notion that this was an unavoidable aspect of her particular drugs regimen:

I don't know if it's part of the medication that we have to be depressed, or whatnot whatnot.

Sarah, 21-30

Many women taking Efavirenz described similar side-effects, and some studies have suggested that Africans taking this ARV drug are more at risk of neuropsychiatric adverse events than Caucasians [308, 309][80]. This information had, to some extent, trickled down to the community

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[80] However, other research has suggested that quality of life and health-related quality of life are improved following initiation of an Efavirenz-containing anti-retroviral regimen [310, 311].

level, and some women were aware of research that has implied that Africans should not be prescribed Efavirenz. This woman recounted her shock on being told about the increased risk at a support group, particularly since she was on an Efavirenz-based regimen herself:

> The man who was giving the talk said, 'African women should not be put on Sustiva [Efavirenz]', because he was talking of the different classes of HIV medications... And then I said, 'No! I am taking Sustiva myself.'

Beatrice, 41-50

This community-level awareness of some of the possible adverse events associated with Efavirenz, in particular, meant that many of the women on this drug were unhappy with it above and beyond their own individual experiences. This woman discussed her concerns about the drug in language that suggested an awareness of a collective anxiety about social aspects of life (such as asylum application outcomes), and a collective worsening of that anxiety for those on this drug regimen:

> But also when you have got the state of mind which we have, and then you are taking Sustiva, it aggravates... You think, when people are not stable enough, when people have got too many worries like that, they wouldn't want to take things like Sustiva [Efavirenz].

Joy, 41-50

Some women found it hard to communicate effectively their worries about side-effects to their clinicians. This woman described the concerns she had about Efavirenz, and the side-effects she had experienced on this regimen. She had tried to discuss this with her doctor, but reported that her regimen had not been changed:

> I have tried to talk to the doctor. I have talked about my pains, even to my counsellor, because they introduced me to a counsellor, who wrote [to] the doctor, but he still believes it is nothing to do with HIV or the medication...In the end, we end up being drugged, we end up with problems. So I said, 'I have been trying to tell my doctor, my memory is going, feet feel funny, and when I take the tablets at night, I can't sleep, and my feet feel hot, I have to wrap them in a wet towel'. It's hell.

Beatrice, 41-50

Beatrice's frustrated attempts to communicate her concerns to her HIV clinician and achieve the outcome she was hoping for (i.e. a regimen change) had also, as implied in the above extract, led to her collectivisation of those she saw as experiencing unpleasant side-effects. It is notable that it was only when discussing her fear that the treatment was harmful ('*we end up drugged, we end up with problems*') that she used the plural pronoun 'we'.

Women on other drug regimens also had concerns about the potential and actual side-effects of HAART; they too reported not being able to convince their clinicians to alter their drug regimen. This woman had been informed of the risks of hepatotoxicity associated with a

Nevirapine-containing regimen, and had spoken to her clinician about changing to an alternative regimen, but without success:

> They said it was good for me, but I have attended – had people come at a support group from NAM, and they tell us all these things, and last week there was a doctor who came, and she was telling us about medication, and she did mention about Combivir that it damages the liver... I am taking Nevirapine, and they say Nevirapine does damage the liver. And they won't change it for me.

April, 51-60

April's account demonstrates the conflicting priorities of doctor and patient – while her primary concern as a patient was to effect a regimen change because of her fears about possible side-effects, her clinician was reluctant to do so, probably because as far as s/he was concerned, the treatment was effective and as yet had not produced any untoward side-effects. In this sense, concerns about side-effects may often carry more weight for patients than for clinicians, who are likely to prioritise reduced viral load and increased CD4 counts. The next extract illustrates this discrepancy in priorities – while this woman's clinician considered her ARV combination successful because it was controlling her viral load, she felt that it was not, because of the side-effects that she was experiencing:

> My doctor was saying my viral load was undetectable, and then he said, 'I can't change you from this combination because your viral load is now undetectable', so he was thinking like the medication is working, but it was working but it's giving me a lot of side-effects.

Mercy, 41-50

The women who participated in this research were often suspicious of doctors' motives in following a particular clinical pathway and were sensitive to the notion of HIV stigma on the part of their GPs. Consequently, for some, encountering what they perceived as refusal to alter a drug regimen which they had learnt could have serious adverse events associated with it may have led to a worsening of that mistrust of clinicians.

For some women, the physical side-effects they experienced in conjunction with their existing social anxieties were too much, and they had considered discontinuing the medication as a result. One woman described the way her expectations had been confounded: she had started on HAART believing that they would improve her life, but the side-effects had compounded her other problems, and she had consequently considered coming off the medication altogether:

> But then there are some things that I'm starting to realise, you know, are not actually the way I was expecting – you know what I'm talking about? So, sometimes, I just feel what's the point, what's the point of taking the medication?... Sometimes I think of just stop taking the medication.

Many women struggled to cope with the side-effects that they experienced on HAART, and this sometimes exacerbated other, structurally based anxieties. Enacted and felt stigmas, and discrimination both inside and out of the clinical context fed into most negative clinical encounters and these were in turn interpreted by women through the prism of stigma. As a result, mistrust of clinicians was commonplace, and when clinical decisions were made that were not in line with women's preferences, this too was interpreted as further evidence of malign intent. These circular processes were stoked by information that women received about particular drugs from other sources, and some women had become pre-emptively concerned about possible side-effects as a result of this information. For some women, the side-effects that they already experienced were becoming too much to bear, and as a result, one woman was considering discontinuing HAART.

8.6 Chapter Conclusion

Some women interviewed for this research reported receiving support from their families that helped them to manage the bureaucratic and emotional aspects of their lives in the UK, and their HIV, although not all women were able to accept this support without feeling burdensome. However, most women described problematic family relations, and the discriminatory treatment that some women experienced from their families marked the beginning of an expanding circle of both enacted and felt stigmas.

Although most women did have access to resources (in the form of peer support groups) that could to some extent offset the isolation and marginalisation that they felt as a result of those stigmas, their capacity for resilience and self-efficacy was repeatedly undermined by them. This was particularly apparent in women's accounts of their housing situations, when they frequently employed the passive voice – a noticeable continuity across women's varied accounts of their housing situations was an absence of control. Attempts to alter their accommodation circumstances proved futile, and housing was another site for discrimination.

Many women spoke positively about their access to HIV information at their HIV or GUM clinics, and felt that this facilitated their HIV education and complemented the information they received at support groups. Further, the sense of inclusion and safety that many women reported experiencing in the support group environment facilitated a trusting response to information received in this setting. Conversely, the insecurity of access, perceived stigma, and experience of unpleasant ART treatment-related side-effects encountered in the clinic setting sometimes meant that information provided in these environments was viewed with suspicion. When the information provided in these two settings appeared to conflict, there was scope for women to view this conflict as evidence of further malign intent on the part of their clinicians. This phenomenon did not seem to occur as a result of a generalised mistrust of clinicians, since those providing the information in support settings often were clinicians themselves; rather, this was a contextual phenomenon, with trust relations proving dependent on the setting. Therefore, whilst on the whole support groups facilitated women's access to services, both directly and indirectly, the very self-efficacy that women reported as a consequence of support group attendance also had ramifications for their clinical care that were not always positive. Furthermore, the social aspect of support groups, whilst predominantly a vital component of women's coping strategies, also had the capacity to augment women's existing preconceptions about HIV stigma in society and therefore to remain isolated in an effort to avoid encountering future discrimination. Lekas et al note that support groups are often a venue where 'stigma consciousness and expectations [are] formed'

[102p. 1178], and it is likely that support groups play a significant role in re-framing women's perceptions of and language concerning HIV stigma and stereotyping.

Women did express satisfaction with the care they received from their clinical teams, and clear communication and honesty from clinicians was considered a vital component of satisfaction with the healthcare they received. Indeed, Thiede has described 'communicative interaction' as crucial to the development of trust between patients and doctors [223], and in this context, it is likely that 'being listened to' helped women to feel that they were participating in an interaction about their healthcare, rather than a unidirectional transfer of information. Clark has also described 'empathic care' as a requirement in the development of trust between doctor and patient [121], and notes that a common complaint against doctors is that they do not listen to patients. Women were empowered to take advantage of the positive aspects of care that they encountered in the clinical environment in part because of the support that they received there and in other contexts, such as from family or support groups.

Healthcare was a particular locus of concern for stigmatising encounters since disclosure was inevitable and not something the women could choose. HIV knowledge among GPs was perceived as poor, and some women reported overtly discriminatory treatment in primary care. This belief (that some GPs were both ignorant and stigmatising) led some women to seek care elsewhere, which may have placed an additional burden on GUM clinics. Many women reported being 'shunted around' between services in this situation, and this combination of experiences augmented some women's sense of rejection and exclusion, and contributed to a breakdown in trust relations between doctor and patients. This in turn worsened some women's responses to HAART side effects, as did the perception that some clinicians did not listen to women's concerns.

The data presented in this chapter illustrate the difficulty with the separation of clinical experiences from the structural context for these women: stigma encountered in the healthcare context can be characterised as a clinical obstacle, since it occurs in that setting, or as a structural obstacle, as stigma is socially constructed as well as enacted by individuals on other individuals, or on groups in the construction of stereotypes. Similarly, neither of these arenas can be clearly delineated from women's individual perceptions and responses.

However, unpacking how these spheres interact has implications for practice as well as this thesis, insofar as women's experiences, perceptions and beliefs can bleed from one context into another. The women interviewed for this research presented accounts that suggested that their perceptions of clinicians were capricious – at times the same women who described deep satisfaction with their clinicians also reported feeling suspicious of them. Women's

perceptions of clinicians were defined by trust, and within that, transparency. When women spoke of their clinicians in positive terms, it often related to a perceived honesty in communication from doctor to patient; conversely, women were dissatisfied or mistrustful when they felt that their concerns had not been heard or were not considered a priority – when clinicians did not adequately explain their reasoning for clinical decisions or reassure women that they were receiving appropriate care. Some women were quick to assume that clinicians who did not conform to their expectations were actively discriminating against them, and it may be that these assumptions were formed because of their experiences of stigma and discrimination in other contexts. In short, understanding the structural experiences of HIV patients will have implications for clinical practice.

9. Chapter 9 - Discussion

9.1 Introduction

Immigration and healthcare are both subjects that are highly politicised, not least when the two converge. This study is among the first to explore empirically the use of healthcare as a tool for immigration control, as well as the experiences of migrants with healthcare needs. It offers findings on the nature of the immigration policy process, as well as on the way that individuals targeted by the convergence of immigration and healthcare policies are affected by them.

Taken together, this research identifies: the structural and cultural factors contributing to restrictive immigration policies in the UK, and highlights the development of the use of health (low politics) as a tool for immigration control (high politics); the gap between policy intentions and implementation, especially when a lack of clarity enables 'street-level bureaucrats' to interpret directives in ways that fit with their personal and professional objectives; the mediating effect this 'street-level bureaucracy' may have on the relationship between policy (the Charging Regulations) and HIV care access for individuals with insecure immigration status; and the nuanced and complex effects of insecure immigration status on health and wellbeing more broadly. The findings on policy formulation lend themselves to a re-examination of Kingdon's Multiple Streams approach, with an additional focus on social constructionist approaches to problem definition. These findings further draw attention to the importance of individual perceptions of policy in studies on access to healthcare. They highlight the limitations of existing theoretical approaches which have negated the perceptions of the individual, and as such, suggest a need to look beyond a purely behavioural or structural approach.

This chapter begins by exploring the role of the researcher in qualitative research, as well as the way in which the process altered my perspective on the often acutely contested area of health and migration. It discusses the limitations of both components; then, building on the conceptual frameworks described in Chapter 2, this discussion section outlines a theory of how vulnerable migrants access healthcare services in the UK, and how this is likely to be affected by policy, structural, cultural and internal identity processes. A theory of the limited direct impact of policy on migrants' access to health services in the UK, and the way that the perceptions and actions of individuals mediate policy, is discussed later in this chapter. Finally, it discusses the implications for policy and practice and makes recommendations for further research.

9.1.1 Reflexivity in Qualitative Research

It is of great importance to be 'reflexive' and examine the role of the researcher when collecting, analysing and reporting qualitative data [228], especially since qualitative analysis is inherently subjective as the researcher is the unit undertaking the analysis [312]. The process of moving from the respondents' voices to writing up the research findings inevitably involves selection and interpretation and therefore it is important critically to examine my own role in this process. Alongside the theoretical concepts which informed this research, I acknowledge there is likely to have been a personal component in how I chose to report analytical themes. Although participants' words have, as far as possible, been allowed to speak for themselves, I have, of course, had an 'editorial role' [313] in reporting and constructing their accounts in order to make them accessible, and to generate theoretical insights. As discussed above, it is important to consider the ways in which who I am may have affected data collection in terms of participants' responses to me as the researcher. However, it is also important to consider the ways in which my own preconceptions and values may have influenced data collection and analysis.

My maternal grandparents were European refugees and my father fled to the UK from Czechoslovakia in the 1970s. As a consequence, I have a natural sympathy for and understanding towards those who find themselves outside their countries of origin. My family's experiences may have provided me with some insights into the experiences of migrants and established my initial political views on entitlements for 'overseas visitors'. However, my background differs significantly from the Zimbabwean women I interviewed. I am British-born, and therefore have never doubted my own entitlements. The insights available to me as a result of my family background are therefore limited. However, during the research process, I felt that I should try to remain aware of the way in which the experiences of some of my family members might inform my interpretation of policy documents and women's experiences. As previously indicated, the focus of this thesis is highly political, politicised, and value-laden. Despite striving to maintain objectivity, I could only hope to approach this research with an open, rather than empty mind. Maintaining an awareness of the factors that could influence my preconceptions helped me to 'bracket' myself when I engaged with the data. Further, by using a hermeneutical, repetitive approach to data analysis, I was able to revisit my comprehension and interpretation of the evidence in light of my evolving understanding of the emerging themes.

The potential for a partisan approach to the data might have been exacerbated by my reading early in the research process of the available literature on access to healthcare for insecure immigrants in the UK. It was limited largely to reports by NGOs or opinion pieces by

sympathetic clinicians since academic research on this subject was in short supply. This meant that although I aimed to approach the construction of research tools with an apolitical stance, I had definite views on the public health and humanitarian implications of withholding healthcare. I therefore struggled to understand the logic in developing policies that aimed to restrict access to healthcare. This leant itself to a theoretical 'open borders' stance [25] and a difficulty with understanding how freedom of movement could reasonably be restricted. However, the process of the research itself, and in particular the interviews with Zimbabwean women did have an effect on these views.

Listening to women's stories elicited substantial personal sympathies. However, the nature of their asylum applications (i.e. the fact that none had been politically active in Zimbabwe and were therefore unable to make Refugee Convention applications) led me to question my previous views. While the distinction between voluntary and forced migration may not be important for the psychological responses of migrants themselves [9], it does bear on asylum decision-making. In the context of this group of women's experiences, I increasingly perceived that enabling all asylum-applicants who fell outside the bounds of Refugee Convention-defined persecution to remain in the UK would be a politically and economically impractical decision for any government. This did not affect my perception that there were nevertheless public health imperatives for providing healthcare to all 'overseas visitors' for the duration of their stays. However, it did affect my previously-held 'open borders' approach regarding international migration and the roles that could be expected of the nation-state in a bounded international system. Rather than focusing on normative values of what *ought* to be, I had become increasingly concerned with what *was*, and the realities of decision-making on politically complex issues. However, I did continually question the ways in which data were coded and analysed. I was mindful of clarifying what exactly had been asked of participants, the wording of respondents' answers, their meaning, and the need to 'bracket' myself in order to attend to respondents' accounts with an open mind.

9.2   Challenges and Limitations

The limitations associated with the research with HIV/immigration key informants are discussed first, followed by limitations in the research with Zimbabwean women. Finally, limitations common to both components of the research are outlined.

9.2.1   Limitations in Policy Analysis – Key Informants and Documentary Analysis

The primary limitation of this component of the thesis was the approach to sampling, which may have led to biases in the data towards particular perspectives. Key informants were sampled using semi-purposive snowballing methods. This meant that it became very hard to 'break out' of, for instance, advocacy networks, since snowballing by definition ensures that those identified for recruitment are networked with one another. This may also have given a political bias to the policy analysis, since advocates and clinicians tended to hold the same views on the development of UK immigration policy and its implementation.

Attempts were made to overcome these biases by purposively identifying potential respondents from politically diverse organisations such as MigrationWatch and the Refugee Council, who are known to hold very different views on the treatment of migrants. However, despite repeated attempts to recruit participants with a more resource-protective (as opposed to humanitarian) political stance, most declined to participate in the research. It is likely that limited representation from this section of the political spectrum means that this is a limitation of the policy formulation and implementation analyses.

Another limitation that was unique to the key informant research related to the location of interviews. Interviewees often asked that interviews take place near or at their work, at times convenient to them. This meant that they were often carried out in mutually convenient and therefore frequently very public locations. As well as the risk that this may have limited what interviewees were willing to discuss, given the lack of privacy, these locations were often noisy cafés or canteens. Conducting interviews in these settings limited the 'flow' of interviews, and made subsequent transcription very difficult.

'Sampling' of publicly available policy documents was less prone to potential bias insofar as it was more possible to identify and include the 'universe' of documents relating to a particular policy question. However, documents that were not in the public domain were harder to access and the FOI process is itself prone to nuances of interpretation by those charged with complying with requests. It is impossible to know to what extent the FOI request resulted in a complete set of internal documents relating to the policy formulation process for the 2004 amendment.

Related to this problem was the risk that my personal views on immigration and healthcare access might have been perceived by interviewees as different to their own. This might have affected the responses they provided. I attempted to ensure that I approached this research objectively and apolitically. However, it is possible that when researching such a politically contentious subject there might be occasional interviewer/interviewee dyads in which political differences might be perceived by either party. This could have affected the dynamic of the interview and therefore the responses provided.

Given that the policies and politics under scrutiny in this thesis were changing rapidly during the course of the research, interviewees' perspectives may have also changed or been influenced by these changes. Consequently their recall of events or processes in the past may have been prone to recall biases [314]. Key informant interviews were thus designed to elicit their *perspectives* on the formulation and implementation of policy at a given historical moment, and should be viewed as cross-sectional in approach [315]. Further, key informants may have indicated their opposition to or support for a particular policy while covertly holding a contradictory position [314], especially if they viewed me as partisan. Similarly, document analysis cannot be viewed as providing "simplistic data about reality" [232, p.39], but rather provides another window through which to understand and *interpret* policy and political processes at a given historical moment or context. An awareness of the context in which those documents were produced was thus key to their understanding.

9.2.2 Policy Shift

As described in Chapter 3, key informant and documentary data were initially coded openly, with subsequent coding largely relying on the framework established during this initial coding period. A significant challenge in conducting this research was the 'moving target' nature of the particular policies being examined. The judicial review that actually reversed the effect of the policy for a year, before being overturned towards the end of the study, is a case in point. Much of the fieldwork and coding took place prior to the March 2008 judicial review, and therefore in a context where current policy explicitly restricted access for unauthorised migrants. However, the event of the judicial review substantially changed both the questions asked of interviewees, and which issues they saw as imperative in policy terms. This meant that other than questions that referred to key informants' perceptions of why something had occurred historically, many of the codes and categories that had been established prior to the judicial review were suddenly no longer applicable to data collected after this event. Therefore a new coding framework had to be established that encompassed interviews pre- and post-judicial review.

9.2.3 Limitations in Research with Zimbabwean Women

a Recruitment

As with the research conducted with key informants, the primary limitation of this component of the thesis was problems with recruitment and sampling. Recruitment was extremely difficult, leading to a small sample size: thirteen women were interviewed. Ideally I would have interviewed twice this number, since the original aim was to recruit a sample of women through the Department of Sexual Health at Homerton Hospital. This additional sample was intended to provide a comparison between those women who were definitely receiving care with those who might not be (since they were identified through a community organisation rather than their HIV clinic). Further, it was originally intended also to recruit a small sample of men through the HIV clinic. Recruitment in the clinic context failed almost completely. There are a number of possible explanations for this:

1. Patients viewed attending the clinic as a stressful and potentially risky undertaking, in terms of the scope for involuntary disclosure. Therefore they did not wish to protract their time there any longer than necessary for their HIV treatment.

2. Patients were anxious about the research from the outset since it clearly stated an interest both in their HIV experiences and their immigration status/experiences. Despite clinician reassurances that participation was confidential, patients may have considered the clinic to be solely concerned with their HIV care. They therefore did not wish to risk a connection being made between their two 'statuses' (i.e. HIV-positive status and insecure immigration status).

3. Identification and recruitment of participants was dependent on clinician awareness of patients' immigration status. Clinicians had a tendency to identify potential participants who did not meet the inclusion criteria. This was often because they had been given refugee status or ILR. This highlighted a fundamental problem with the approach to recruitment, in that it relied on a good understanding amongst clinicians of immigration status differences and therefore some knowledge of immigration law. This understanding proved to be limited, which is particularly notable since clinicians are also required by the Charging Regulations to have some understanding of immigration law.

Despite these problems with recruitment in the clinic setting, effectively rendering that site irrelevant to the research, I was satisfied that the smaller sample gleaned in the community setting did provide 'saturation' of data on the key questions of the research. I did not feel that any additional themes would have influenced the results overall. Had I spent more time with clinicians, briefing them on the research and recruitment criteria, some of the problems

identified above might have been reduced, but I was also concerned not to interfere with the clinical process by taking too much of clinicians' time. With hindsight I would not persevere with clinic-based recruitment for future research with migrants where alternative approaches were possible, especially given the protracted ethics process for research conducted in NHS settings and therefore the time and resources consumed.

I did have concerns that awareness of the reimbursements being offered had spread throughout the community and was acting as an incentive for participation despite the fact that all these women were also associated with the community organisation (indicating that the sampling methodology was not substantially undermined). Although I was apprehensive about the ethics of the effects of these reimbursements, my concerns were assuaged by women's capacity to exercise their agency far beyond the initial agreement to participate in the extent to which different women chose to reveal their experiences of life in the UK. It was repeated often that they could terminate the interview whenever they wished, and while no woman chose to terminate the interview, those who did not feel comfortable reporting certain of their experiences were able to use silence to their advantage. Lammers has noted that the assumption that financial reimbursements might exacerbate existing power imbalances to the extent that research ethics are called into question assumes total powerlessness on the part of the asylum-applicant or refugee participating in the research [316]. She questions whether this assumption stems less from real power imbalances and more from our failure as Western researchers to escape a post-colonial psychology that will only ever allow us to see participants from the global South as the powerless 'Other' [Bachrach & Baratz, in 316, p. 21]. In this view, the establishment of trust relations between researcher and participant is *dependent* on giving and receiving, rather than being undermined by it.

Zimbabwean HIV-positive women with insecure immigration status were recruited opportunistically and purposively through a Zimbabwean women's community organisation. Women were notified in advance of participation that their travel and childcare costs, if any were incurred, would be reimbursed to them, but in practice, for the reasons outlined in the Methods section, all women were given £20 on completion of the interview. Some of the results of this research suggest that within this sample, and despite substantial isolation, women did have contact with other Zimbabweans and Africans, where 'street wisdom' often prevailed, and could affect individuals' perceptions of healthcare access. Similarly, knowledge of this research evidently spread rapidly since not all the women were referred to me directly by the community gatekeeper, but rather contacted me themselves, having been given my contact details by a friend, and indicated that they wished to participate in the project. Twelve

women agreed to take part within a ten-day period, and recruitment was thus far more rapid than initially predicted.

By definition, recruiting women through a community organisation meant that all the women who participated were in contact with support services to some extent. In this sense, the research may have been limited in its ability to capture the experiences of women who were more isolated and with no access to support. This is a classic problem of recruitment with hard-to-find populations [235]. However, theoretical sampling did mean that I was able to recruit at least one woman, Jackie, who was less 'networked' than many of the others. This strategy of recruitment through a Zimbabwean community group rather than a peer support organisation may have helped with identifying less 'networked' women. Some women, though known to the organisation, were not necessarily regular attendees of services provided by it, particularly since the organisation provided services to clients on the basis of nationality rather than current geographical location.

Although the community organisation did not limit its clients by where they lived, inevitably most of its clients, and all of the women I recruited lived in Greater London. In this sense, the research findings are not generalisable for those Zimbabwean migrant women living outside the capital, and certainly not for those who might be in dispersal.

Similarly, the failure to recruit any men to the research meant that it was not possible to provide a fully gendered analysis of women's experiences by comparison with those of HIV positive Zimbabwean men.

A further effect of identifying women through a gatekeeper at the community organisation may have been that she identified women that she thought were particularly suitable, either because they were sufficiently robust or because they had more extreme health/immigration experiences. She may have inadvertently contributed to the theoretical approach to sampling (i.e. by identifying women she identified as having experiences particularly pertinent to the study). In addition, the Zimbabwe women's network had collaborated with other organisations for research purposes in the past, and the women I interviewed may therefore have participated in studies before. This throws up the possibility of respondents' research fatigue or of women anticipating particular questions and/or responses.

A second constellation of limitations may have resulted from the research method employed, semi-structured interviewing, which has several documented limitations. Previous researchers have highlighted that interviewees can be affected by the characteristics of the interviewer such as appearance and race [228]. It has been recommended that matching respondents with an interviewer from the same ethnicity or nationality group should be undertaken to ensure

success of the research; however this was not feasible for this study, as resources meant that I was unable to hire Zimbabwean field-workers. Moreover, staff at the community organisation stressed that my 'difference' from participants may have positively influenced their willingness to participate and share their experiences. However, my 'difference' may equally have led some women to be cautious in the responses they provided. Women were often keen to emphasise that despite the many problems they faced in the UK, they were nevertheless 'grateful' for the services that they had received. This positivity might have been influenced by my status as an outsider relative to the respondents, but an insider (in their eyes) in British society. In addition, my ethnic/national/cultural distance from interviewees also raises the problem of meaning, where the interviewer and interviewee have a different understanding of terms, and loss of context can occur when transcripts are read. Although all the women interviewed spoke English very comfortably, it was not their first language, and there were occasional misunderstandings. However, the use of a topic guide meant that there was substantial homogeneity across interviews in terms of the questions asked. Had the terminology been wildly inappropriate or given rise to misunderstandings, this would have created problems of meaning with many interviewees and therefore been clearly apparent. I sought to clarify any misunderstandings that did occur during the interview and the iterative approach to topic guide development helped to keep these misunderstandings to a minimum. For example, if I identified that a particular phraseology or term was unclear with one participant, I adjusted the language in subsequent interviews. Finally, carrying out the interviews myself, rather than using community interviewers, enabled me to become immersed in the data, making subsequent analysis easier, not least because of non-verbal cues that I was able to associate with women's transcribed accounts.

There are also potential limitations with the (1) reliability and (2) validity of the qualitative data collected. Firstly, in terms of the reliability of the data, the length and depth of interviews varied. Overall, those women whose interviews lasted longest were those who were very 'connected' to support organisations and expert patient programmes and therefore had strong views about their situations and their access to care. This may have provided an uneven and potentially biased overall 'picture' in ensuring that more data were sourced from women with better experiences. Furthermore, although standard questions were asked about women's immigration situations, some women talked in much more detail about their personal situations than others. Therefore the quality of data regarding immigration and asylum application histories varied considerably. This may have been exacerbated by the complicated nature of immigration status and law for Zimbabweans in particular, and therefore the limited understanding that women may have had about the specifics of their own situations.

In terms of the validity of the data, despite reassurances about confidentiality and anonymity, and clear information about how the data would be used, women may nonetheless have been worried about disclosing very sensitive information. This may have affected how willing they were to talk in-depth and with honesty. For example, some women may have been reluctant to discuss how they perceived Britain or their treatment within the asylum system for fear it could impact on their applications. Despite stressing the need for privacy throughout the duration of interviews, most interviews took place at the community organisations. These were subject to multiple intrusions, and this interrupted the 'flow' of interviews, and may have affected the responses that women were willing to give in the face of limited privacy. Alternatively, some women may have exaggerated or embellished aspects of their accounts in order to provide the response they thought I wished to hear. This is a phenomenon called 'acquiescence', whereby the interviewee responds with a fixed set of answers or socially desirable responses [317]. This may have been a particular issue when participants discussed more sensitive issues, such as their entitlement experiences or immigration status. This was avoided by probing and reconfirming earlier responses, which was facilitated by the semi-structured interviewing research tool. Further, key informants such as clinicians and advocates were also asked about their perceptions of access to healthcare for this population, and triangulation in this way does help to increase confidence in the validity of the findings.

However, women's accounts of their experiences could not be objectively verified, and this highlights the problem of identifying 'truth' or facts in qualitative research. Given the epistemological approach of this research, one might question the extent to which objectively verifiable 'facts' are necessary. However, the difficulty with ascertaining and understanding women's asylum histories and current legal status in particular, did make understanding other aspects of their experiences, especially those that flowed from or were related to insecure immigration status, more difficult. Stewart points out that since asylum status itself is dynamic, it should be treated as such by researchers since individuals' situations can change very rapidly [263].

A further limitation may have been that validity was reduced as a result of the presumption that declared Zimbabwean nationality meant the sample was relatively homogenous, thus leading me to reduce my own alertness to differences between the women. Conducting research on immigration with one national or ethnic group was intended to improve the internal validity of results, by maintaining as much homogeneity within the sample as possible. Women self-identified as Zimbabwean, which limits some of the concerns that other authors have voiced about ethnic classification and validity in health research [318]. However, I did

explore deviant or negative cases with some care, and this ought to have helped to overcome the potential problems outlined above.

The absence of previously published research on the healthcare access experiences of migrants meant that the research questions, topic guides and research design were largely informed by concepts drawn from advocacy-based studies. These often had a very general focus either on migrants in general, or HIV experiences. Therefore this literature may not have been appropriate for this specific population. This use of advocacy studies for tool development may have biased the research through contributing towards tools that may have had an advocate's interpretation of the evidence. However, the iterative approach to data collection and topic guide development should have helped to minimise any pre-existing biases, particularly since women were given the opportunity to comment on the scope and approach of the interviews.

9.2.4   Limitations Common to Both Study Components

Qualitative data that are analysed using approaches that borrow from grounded theory are highly instructive for generating theoretical insights and for identifying priorities for further research. However, neither the Zimbabwean women interviewed nor key informants are representative of all Zimbabwean HIV-positive women in the UK, or of all those with a potential 'stake' in the issues with which this study was concerned. The findings may not therefore be generalisable.

As the sole analyst in this research, I was able to be fully immersed in all the data for both components of the research, from data collection, through transcription and analysis. However, this also meant that there was no scope for coding comparisons, which would have been preferable in terms of checking reliability of codes and improving the validity of the data.

A grounded theory approach to data collection and analysis has a number of limitations. It has been questioned whether researchers can suspend their awareness of relevant theories or concepts until a late stage in the process of analysis [228]. Grounded theory requires the individual conducting the analysis to put aside all previous knowledge of relevant theories and concepts in order to rely solely on the data collected. I attempted to 'bracket' myself from my own preconceived ideas to prevent me from over-riding the participants' account of their own experience [312]. However, pure theory-neutral observation is difficult to achieve. There are also a number of practical difficulties with grounded theory [228]. For this study, data were collected and analysed simultaneously, thereby facilitating theoretical sampling and the iterative approach of grounded theory. However, it was not always possible to transcribe or analyse interviews before the next interview took place. I had to rely on my field notes to

generate additional questions for the subsequent participant in order to expand on particularly interesting themes or follow up on new areas. Nonetheless, grounded theory was the most appropriate method of data collection and analysis for this study, since it asked "How does access to healthcare happen in the context of insecure immigration status?", and was therefore concerned with developing an exploratory theory of the process of healthcare access [312].

9.3 Conceptualising Access to Health within Insecure Immigration Status – Theoretical Approaches

Despite these challenges, these data provide a unique opportunity to go beyond the policy formulation concepts and healthcare access theories described in Chapter 2 and outline a *wider theory of immigration policy processes, and of how vulnerable migrants access healthcare services in the UK*. This theory also considers how healthcare access is likely to be affected by policy, and by structural, cultural and internal identity processes. This section begins by building this theory and discussing how it relates to the theoretical frameworks outlined in Chapter 3. The implications of this study for further research, policy, and practice are then discussed.

9.3.1 Access to Healthcare as a Tool of Immigration Control

The HO and DH are perceived by key informants to have been in conflict over the development of the 2004 amendment and primary care proposals, and their respective influence over policy development may vary. While the HO would seem to exert more political power than the DH, the latter may have greater influence over practical and procedural components of what is technically health policy. The Government used its high political power to enact immigration policy in a low political arena, and the use of secondary legislation limited the scope for formal opposition to the 2004 amendments. However, advocacy networks may have had some influence over the failure to implement the primary care proposals, especially through collaboration with Parliamentary Committees, and powerful members of advocacy networks, such as clinicians.

Since the policies under consideration in this thesis have utilised the 'low' politics of health for the 'high' political gain of immigration control, they offer an unusual case-study for a consideration of power in immigration policy-making. **Results from this study suggest that recent UK government policies bringing migration and health together (e.g., the 2004 amendments and primary care proposals) were developed as part of a politically defensive strategy intended to bolster the administration at the time against policy failure[81]. As such,**

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[81] The term 'policy failure' is used here, following Castles, normatively. Although "policy failure could be said to occur when a policy does not achieve its stated objectives", evaluation would be reliant on policy

an analysis of the results presented in this thesis (discussed in more detail below) that utilises Kingdon's 'Multiple Streams' model [214, see Chapter 2] suggests that the process of 'window opening' in immigration policy-making can initiate a socially constructed feedback loop. This pushes public opinion further to the right, potentially creating a new 'problem' stream, and a cycle of restrictive immigration policy development.

The stated aim of policy restricting access to healthcare for insecure immigrations has undergone a substantial shift. Resource protection and a concern about health tourism have given way to a punitive discourse where access to healthcare is deliberately restricted in order to make life uncomfortable for those individuals who remain in the UK outside the immigration rules. This punitive approach is encapsulated by three immigration strategies that broadly correspond to the stages of the migration process as defined by Gushulak and MacPherson: deterrence (i.e. home country); internal controls (i.e. destination); and enforced discomfort (i.e. transit, through encouraging migrants to return home) [320]. Freeman argues that much of asylum policy is purely regulatory in its efforts to deter potential applicants, encourage 'unfounded' applicants to leave, and control those within the asylum system (through, for example, restricting access to healthcare). Regulatory policies entail the explicit choice of who will be "indulged and who deprived" [321, p.229] and ensure that distributional consequences will confer general benefits in society, at a cost to only a very small segment of society (in this case, individuals with insecure immigration status). Under these conditions, entrepreneurial politics are to be expected in immigration policy development [321], although in Western Europe these are dominated by state officials, often employing a securitised migration discourse. In this context, the use of healthcare access policy as a tool for immigration control bears strongly on theories of power in the modern state.

There are multiple theories of the influence of power on the policy process, but pluralism and elitism (which encompasses Marxist and professionalist accounts [217]) are commonly discussed [215, 322]. A compromise theory of power, 'bounded pluralism' was suggested by Hall [274] in which issues of high politics are decided by elites, while issues of low politics may take a more pluralist framework, with the participation of different groups during the policy process. Freeman argues that the asylum crisis in Europe following the collapse of the Berlin Wall moved immigration into the stakes of high politics [323], and the conflation of asylum with security issues exacerbated this transformation [143, 324].

Like Hall, Lindblom views pluralism as relatively common in liberal democracies in the secondary policy decisions that actually make it onto the agenda, but almost invisible in

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objectives' transparency. Policy objectives may not always be stated openly, and therefore it is necessary to question "ostensible goals and look for hidden agendas" [319, p.207].

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decision-making on 'grand' issues that rarely appear to come onto the agenda. These 'grand' issues are dominated by a homogeneity of opinion and a dearth of competition of ideas [325]. If elites are able to dominate on issues of high politics (and therefore immigration policy), then according to Ham & Hill, they can use that power to control the agenda and confine discussion to 'safe' issues [322]. By using health as a tool of immigration control, and deflecting attention away from the Department traditionally associated with the development of immigration policy (the Home Office), the Government was able to shore up immigration control strategies while maintaining a politically defensive stance. In this way, the Home Office was able to protect itself from, or lower the political costs of, possible policy failure, thus limiting the discourse on this particular approach to immigration control[82]. Further, by interpreting opposing responses to the 2003 consultation as evidence of a failure to understand the proposals being made, rather than as simple opposition to the proposals, government may have been engaging in 'nondecision-making' [322]. This is an exercise of power whereby the scope of decision-making is limited to safe issues and where grievances are kept covert through the manipulation of, amongst other things, procedures [217]. Interpreting oppositional responses to consultation as a failure to understand constitutes a manipulation of procedure. It also enabled the issues raised by those opposed to the amendment of the Charging Regulations to be dismissed, leaving only 'safe issues' on the agenda. The use of secondary legislation to amend the Charging Regulations made a plural influence on policy change very unlikely.

Similarly, there is a contradiction in developing integration policies that emphasise social cohesion, in conjunction with policies on access to healthcare that allow for integration only after asylum has been determined. It suggests that integration policies enable the portrayal of asylum policy overall as balanced and not wholly restrictive, and constitutes a kind of 'symbolic policy-making' [213]. Thus integration policies are another means of exercising power ('as thought control') in immigration policy by shaping voters' perceptions and preferences [217]. Moreover, Lahav and Guiraudon point out that integration policy was used as an extension of immigration control in the 1990s. At this time, rights for migrants were rolled back and welfare benefits were increasingly restricted to 'ordinary residents', to deter would-be migrants, thus entailing a 'rebordering' of the welfare state [324]. Indeed, these uses of power suggest that elites dominate immigration policy. The failure to further extend restrictions in healthcare, and the temporary 'roll-back' of restrictions through judicial review suggest a more plural influence

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[82] Indeed, this approach extended into the response of Home Office staff approached about participating in this research. The policy came under the auspices of the Department of Health, and therefore they were the more appropriate Department for participation in the research. However, HO did later acknowledge that this was a joint area of interest; and many key informants reported the perception that the Charging Regulations' amendment was driven by the Home Office.

on those aspects of immigration control policies that can be seen to come under the rubric of 'health policy'. It could be argued that a government able to exercise elitist power for policy development would be able to ensure that restrictive policies were always successful, and that therefore the formulation 'failures' described above (e.g., the primary care proposals and judicial review) would not have occurred. However, Boswell points out that immigration has become politically imperative precisely because it cleaves a line through states' claims to legitimacy, which can be assessed through four criteria: fairness, accumulation, security, and institutional legitimacy. Immigration policy highlights "profound tensions between, on the one hand, the imperatives of economic accumulation and institutional legitimacy, which militate in favour of more liberal policies; and, on the other, popular pressures for closure, which encourage the state to implement a protectionist pattern of distribution and robust security measures." [326, p.92].

The state attempts to deal with contradictions between these different interests and goals through the deliberate fudging of policy. This may provide an explanation for the contradictory policies reviewed in this thesis: the conflict between a commitment to Universal Access and limitations on ARV provision in the UK; the delayed 'starting point' for integration policy; and the fact that while the Foreign Office has been vocal in its criticism of Zimbabwe's (and especially Mugabe's) treatment of its citizens, the Home Office has gone to great pains to portray the opposite in order to minimise the scope for asylum applications [47]. These contradictions, sometimes dubbed the 'liberal constraint' (i.e., the liberal institutions and procedures that constrain restrictionist policy-making [326, 327]) in immigration policy, can be understood in terms of Boswell's thesis of the need for state legitimacy. That is, the British state, faced with multiple conflicts of interest among groups in the UK has found it necessary to develop policies that are deliberately 'malintegrated'. Each policy approach can "mobilise consent among its particular constituencies by pursuing policies which, even if never fully implemented, appear to address the needs of these groups... this strategy prevents any one group from claiming that the state has come down on the side of its opponents" [Hall, cited in 326]. This theory might at first glance appear to suggest substantial plural influence over British policy-making. However, Boswell's argument is that the government acts entirely in its own self-interest in 'vote-maximising' [323], even when this means that the development of contradictory policies renders them *all* ineffective. And if it is true that the British state is concerned with immigration policy primarily insofar as its own apparent legitimacy is concerned, then that policy may itself be a component of the agenda-setting process.

Kingdon's multiple streams model of the policy process provides a useful means for examining agenda-setting in policy formulation. This model is concerned with policy 'entrepreneurs' who

take advantage of agenda-setting opportunities, and with policy making that takes place within conditions of ambiguity (when there are many ways of viewing the same circumstances or phenomena [216] that may not be reconcilable). The existence of the liberal constraint and the liberal democratic state's requirement for legitimacy gives rise to this ambiguity in immigration policy-making, and in these circumstances, political manipulation can be seen as the effort to provide clarity.

I will now discuss the way in which the Kingdon model can be applied to restrictions on access in healthcare and the agenda-setting for this issue. *The problem stream* would appear originally to have been perceptions of health tourism, or more generally a concern with the consumption of resources by those not entitled to them[83]. Since policy makers require problems to be identified to be able to act, policy makers learn about them through statistical indicators, focusing events, or other feedback. Greer differentiates between problems and conditions in terms of their malleability to change, and notes that problems are usually identified through media attention [214]. In terms of the Charging Regulations, the UK Government seemed to have interpreted media reporting on health tourism as representative of the views of the UK public. In this sense, the problem (a public concern with the consumption of NHS resources by migrants) was identified at a particular moment in time by the media (although Freeman sees public fears about immigration as being deliberately exploited by political 'entrepreneurs' [323]). Feedback from previous policy decisions can also be important in highlighting what does and does not work [216]. It may be that feedback in the form of negative responses to the 2004 amendment from clinicians and the migrant health interest network contributed to the apparent withdrawal of the primary care proposals.

The politics stream is harder to gauge objectively, but key informants in this research did see public opinion as having contributed to policy development. In this sense, the 'national mood' lent itself to the development of policies that restricted access to healthcare for migrants (although since media reporting in the UK is often taken as a proxy for the 'national mood', it is hard to see how separable the politics stream is from the problem stream in this instance). John Hutton, David Blunkett and John Reid were identified[84] as having used their positions as Ministers or Secretaries of State for Health or the Home Office (at the time of the 2003 consultations and the 2004 amendment) to influence the political discourse on health tourism. This contributed to the coming together of the 'problem' and 'politics' streams; Kingdon identifies legislative or administrative change as a component of the politics stream [216]. *The politics stream* is affected by the many factors that can contribute to a government's political

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[83] However, given the contested aims of the 2004 amendment (discussed in section 4.1.2), it is difficult to identify the problem stream for this policy decision with certainty.

[84] Through the document analysis and key informant interviews.

success or failure, including reshuffles, elections, polls and individual ministers' decisions. These are all capable of changing the direction of the national mood [214]. It is therefore possible to see how the multiple streams model can be tied to Walt's 'triangular' model, and Leichter's accounting framework, through their emphasis on the importance of context for policy development.

The policy stream in this case can be viewed as the proposals (the solutions) put forward in the 2003 consultation, and the evident consideration by policy makers of alternatives within those proposals. For example, the existence of the easement clause came about through policy makers' apparent realisation that the policy would not be feasible (a criterion for a proposed solution to "make it to the surface" [217, p.69]) without its addition. These three streams evidently converged at a given moment, and with help from policy entrepreneurs in the form of civil servants. These entrepreneurs acted to identify the problems and solutions for policy makers (in this case, the Minister of State for Health), giving rise to a policy window that made it possible for policy to change.

However, Zahariadis points out that policies run into trouble when entrepreneurs use the 'wrong window' to pursue their goals [216]. By defining the prevention of NHS use by migrants as a resource consumption issue (rather than an immigration control issue), government opened itself up to attack on the grounds of badly formed health policy. There was little evidence for substantial consumption of NHS resources by migrants, and advocates began to identify public and individual health risks associated with the 2004 amendment. The lack of evidence for the 'problem' is not surprising in this framework[85], since the multiple streams approach to agenda-setting suggests that evidence-based policy making makes appeals for technocratic expertise, and these will not have an easy ride: policy formulation in this model is seen as fundamentally political and unsystematic. And the change in the stated aims of the policy, from a means of dealing with resource consumption, to a punitive response to unauthorised migration is also not altogether surprising. The entrepreneurial element lends itself to precisely this phenomenon, where 'policy entrepreneurs' appear to 'sell' their ideas as a response to any number of problems. This leads to policies that are overloaded with rationalisations, or as Greer puts it "answers adorned with questions they are supposed to answer" [214, p.110]. Equally, Kingdon argued that technical feasibility (including in terms of personnel constraints) was a key criterion for solutions identified in the policy stream [217]. This research would suggest that many clinicians required to implement the policy do not consider it to be 'feasible' given their other constraints and responsibilities. The multiple

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[85] Although it does imply a limited understanding of the causes for and consequences of the proposals and subsequent policy.

streams model provides a useful framework for an examination of agenda-setting in the policy process. However, since this thesis has indicated that policy seems to have an effect on politics and also on problem definition (and that these latter two streams are not clearly separable), the independence of the streams is questionable. Some authors have suggested that they may be more usefully thought of as interdependent [Mucciaroni, in 216]. If it is the case that policy can affect the 'problem' [328] (in this case, public perceptions that NHS resources were being depleted by migrants), then the policy itself may have signalled to the public that marginalising insecure immigrants was an appropriate response to problems of social cohesion. It may have exacerbated the perception that this group was 'socially excludable' [158]. Indeed, Zahariadis argues that in the Multiple Streams approach "decision making may, in many ways, be better conceived as a meaning factory than as an action factory" [216, p.69]. In this sense, is not altogether dissimilar from social constructionist approaches to policy design. Zahariadis views the two approaches as distinct (since in his view constructionists perceive the generation of 'facts' to persuade or change people's minds, while multiple streams theory assumes that policy-makers have yet to make up their minds). However, it is hard to see how policy entrepreneurs do not socially construct when it is they who define problems and distinguish them from 'conditions'. By helping to construct individuals with insecure immigration status as abusive or fraudulent, policy entrepreneurs contribute to a perception among citizens that there are negative consequences associated with migration, leading the public to call for greater restriction [329]. Thus, in a context where much of immigration policy-making results from Governments' need to preserve their legitimacy in the eyes of voters, the process of 'window opening' in immigration policy-making can initiate a socially constructed feedback loop. This pushes public opinion further to the right, potentially creating a new 'problem' stream, requiring additional policy responses.

9.3.2   The Importance of Perceptions for Policy Outcomes

In this research, 'users' perceptions also mediated the effects of policy at all stages of implementation: the way in which those required to implement the policy interpreted both the Guidance and their roles within implementation affected policy 'in practice'; and the way in which Zimbabwean women interpreted the existence of the Charging Regulations and immigration control policies more generally also affected their perceptions of their place in UK society and their responses to care. Most Zimbabwean women interviewed for this research had not been refused treatment, but were aware of this possibility and were consequently fearful that the treatment available to them in the UK could be curtailed. Therefore perceptions of policy and the potential effects of policy on perceptions of access to treatment were almost more important than policy itself in this research. In this sense, women did not necessarily experience direct policy obstacles to care, but responded more to a policy

'spectre', where individuals' (both women's and service providers) perceptions of policy were central to health behaviour.

Enacting 'high' politics through 'low' politics has also been dubbed 'shifting down', where the implementation of immigration policy has been shifted away from the principal (the state) and towards decentralised agents (such as the healthcare or other welfare sectors) [330]. Lahav notes that co-opting non-state actors such as public sector workers into immigration control roles shifts liabilities away from central state actors [324]. In this way, 'shifting down' can be seen as an extension of the policy approach discussed above (that used access to healthcare as a means of buffering the state against policy failure) into implementation as well as formulation. Having considered the role of power in the policy process, and shown that policy itself may have an effect on perceptions of migrants and on further policy expectations, it is also important to consider the effect that perceptions have on policy outcomes. Policies that marginalise immigrants are likely to reinforce their social construction as deviant [146].

a   *Street Level Bureaucracy and Value-Systems*

Despite differing levels of influence on implementation, clinicians, hospital managers and advocates all found ways to interpret the Guidance to suit their agendas.

The notion of a policy 'gap' in immigration policy research is not new, but normally refers to the gap perceived by researchers between restrictive goals and liberal or expansive outcomes that was discussed above in relation to the concept of a 'liberal constraint'. However, previous research has usually focused on the failure of immigration policy to control migration itself, rather than the ways in which immigration control policies might be mediated by those who implement them [324]. In this research, a 'gap' between restrictive aims and relatively liberal outcomes for many in the intended target population was observed, and this might be attributed, in large part, to those clinical staff implementing the policy in hospitals and GUM clinics.

Street-level bureaucrats (SLBs) are the front-line implementers or workers in public sector organisations. They interact directly with service-users, and often exercise considerable discretion, although their behaviour is also constrained by, for example, the resources available for implementation, and the clarity of the policy being implemented [331]. Although the Charging Regulations and Guidance allow for some degree of clinician discretion in terms of defining clinical need to determine whether care is 'immediately necessary', 'urgent', and so on, they do not allow for variations in implementation. However, this research suggested - through interviews with clinicians and managers ('implementers' or SLBs), with other key informants, and with Zimbabwean women - that substantial variation does occur. This must be

related, at least in part, to differences in implementation behaviour by those in "front-line positions and [who] interact directly with citizens [sic] in the course of their jobs" [331].

An absence of sanctions against clinicians who chose to 'circumvent the rules' meant that in practice, they were able to interpret or ignore the Charging Regulations to avoid having to de-prioritise their duty of care. However, they were *able* to exercise this discretion, according to Van der Leun, because of the autonomy clinicians have as a result of their professionalization. In this view, professional autonomy is related to institutionalised trust in the professional, which is affected by the extent of the professional's relevant knowledge that cannot be easily acquired by society at large [332]. In Van der Leun's Dutch research with public-sector workers required to implement a new policy withholding public sector services from "illegal immigrants", professionals with lower status were less able to ignore these policy directives than clinicians [332]. This may go some way towards explaining the difference in approach to care provision for migrants seen in this research, between clinicians and managers. Both the literature available and the data collected for this research suggested that NHS managers were more likely to implement the Charging Regulations than clinicians. Further, they were also more likely to engage in what Sorg has called 'excessive behaviour', where implementers intend to comply with the goal of the policy, but add something to its implementation, such that the outcome is 'unintentional non-compliance' [331]. For example, the Overseas Visitors' Manager interviewed for this research engaged in this 'excessive behaviour' when he approached chargeable patients with a portable chip and pin device in order to extract payments at the bedside: nowhere in the Charging Regulations or Guidance is this recommended, and it is this kind of behaviour by some SLBs that has attracted criticism from concerned NGOs and advocates [182, 201, 333].

Sorg also typologises behaviours engaged in by SLBs who do *not* intend to comply with policy goals, many of whom figured in this research. For example, implementers might engage in 'ritualistic behaviour' when they ignore a policy change altogether and behave as though they are implementing the policy as it was before the change. Behaving as though the 2004 amendment never happened would qualify. Alternatively, they might engage in what Sorg calls 'voice', when attempts are made to get the policy changed; when a set of individuals together engage in 'voice' behaviours, Sorg calls this 'massive resistance'. Clinicians in this research were active, both as individuals and through collective action, in trying to change policy and acting as political advocates for migrants. However, these two behaviours are overt, and Sorg also describes strategies used for deliberate non-compliance that are more covert, or could be dubbed 'passive resistance' (in contrast to the massive resistance of 'voice'). 'Bluffing' is the attempt to give an appearance of conforming to policy goals, while actually not carrying out

their implementation. The hospital debt collector interviewed for this research was 'bluffing' when he found that by efficiently collecting non-overseas debt, he could escape the observation of those who might wish him specifically to collect charges from overseas visitors.

Explanations for these differences in approach go beyond the professionalisation, and therefore the power, of clinicians discussed above. Van der Leun found that attitudes towards migration control among SLBs was related to their degree of professionalization [332]. However, other research has also suggested that professional ethos, and values with regard to immigration are affected by an individual's sense of identity (professional, personal, and national). Duvell & Jordan's research with 'immigration bureaucrats' (staff of various immigration agencies and departments) in the UK found that identity was central to the way in which staff framed the discourses they encountered to provide a 'morally adequate' version of their work [134]. Further, the organisational culture of the agencies affected the professional identities of respondents, and therefore the way they framed these discourses.

Similarly, clinicians and managers in this research came from very different organisational cultures and insofar as professional identity contributes to perceptions of self overall, it was not surprising that their approach to implementation differed. Greer notes that the managerialism that is commonplace in contemporary health policy is a source of friction between clinicians and managers; clinicians interpret 'top-down' reorganisation as an attempt to turn them into "'good corporate citizens' at the expense of their professional ethos" [214, p.106].

Lipsky argues that one way in which workers experience street-level bureaucracy is through the conflicts they encounter in wanting their professional life to be more consistent with their own preferences and commitments. and that people often enter public service positions in order to be socially useful [220]. Therefore, for clinicians, the desire to contribute both to a reduction in health inequalities and to a population-wide improvement in health is likely to have been their main reason for entering the NHS. Thus, implementing a policy which not only conflicts with their formal duty of care, but also with broader principles that rest on a humanitarian approach to the distribution of medical goods in order to reduce health inequalities, may jar for many doctors. Correspondingly, it is unsurprising that managers approach the implementation of the policy with a more resource-protective approach, since preventing hospitals from incurring budget deficits is part of *their* job-description. A behavioural approach to policy implementation also suggests that while clinicians are more likely to be interested in 'processing work consistent with their own preferences', managers are more interested in 'achieving results consistent with agency objectives' [220]. In this view, where personal and professional identities affect perceptions of policy implementation,

clinician/manager conflict over the implementation of the Charging Regulations is almost inevitable. If patients' direct experience of government and policy is via SLBs, then the individual perceptions of implementers become policy in practice, where they are able to exercise discretion regarding the nature and extent of implementation.

b   Zimbabwean Women's Perceptions of Policy and Identity Processes

The Zimbabwean women interviewed for this research were, by and large, receiving HIV treatment. The Charging Regulations seemed to have little impact on women's access to HIV care. However, women's awareness of the existence of the policy contributed to their identities as marginalised and excluded from UK society, and this had repercussions for the way they responded to other obstacles to healthcare (such as difficult trust relations in the doctor-patient dyad).

In research on integration with refugees in Europe, Mestheneos found that refugees who had experienced protracted asylum determination processes and had therefore spent long periods as asylum-applicants prior to being given refugee status, often emphasised how this negative period in their lives had scarred them and affected their subsequent integration [334]. However, the personality of the individual refugee was significant in determining their responses. Some had the agency to strategise socially and to overcome the perceived widespread discrimination that they encountered, especially in terms of institutionalised racism. In this thesis too, the personalities of individual women and their self-efficacy affected how they responded to obstacles: hence the variability in the way that policy is implemented is exacerbated even further. Individual perceptions of self are contained within personality and cognition, as well as being socially constructed [335]. In this sense the way women perceive policies may have influenced their perceptions of self, which in turn may affect their self efficacy and ability to overcome obstacles to healthcare access.

A survey of HIV care providers identified a lack of social support for vulnerable migrants as a key barrier to the provision of HIV care [336]. In this context, the exclusion that women perceived as a result of their awareness of policies designed to restrict their access to care, is likely to have affected the care that they were able to receive, regardless of clinicians' attempts to provide care 'outside the rules'.

Moreover, although few women were refused treatment outright, some had experienced their immigration status encroaching into their health, such as when hospitals contacted the Home Office before providing care. Experiences such as these, and outright treatment refusal were shared among women, and added to a 'street wisdom' [43] among other insecure immigrants. This contributed to a perception of a collective identity [337] as outsiders. It is worth noting

that it was impossible to verify the veracity of these reports, but that to some extent, hearsay within migrant communities could be a powerful agent of (mis)information dissemination[86].The involvement of immigration agencies with health services convinced women in this situation that their healthcare was on a knife-edge, and could be withdrawn precipitately. One woman who had been refused care became very scared that she would be asked to pay for her ART, and subsequently attempted to avoid most contact with services[87]. Johnson notes that Othering in the healthcare context can deter patients from continued healthcare-seeking behaviour [338]. From this perspective, the policy (the use of health for immigration control) could be said to be effective: as a component of a broader immigration strategy of 'enforced discomfort', women's perceptions of the policies and their meaning for their lives in the UK, marginalised them further.

Figure 10 The Contextual Model of Access to Health Services for Populations with Insecure Immigration Status
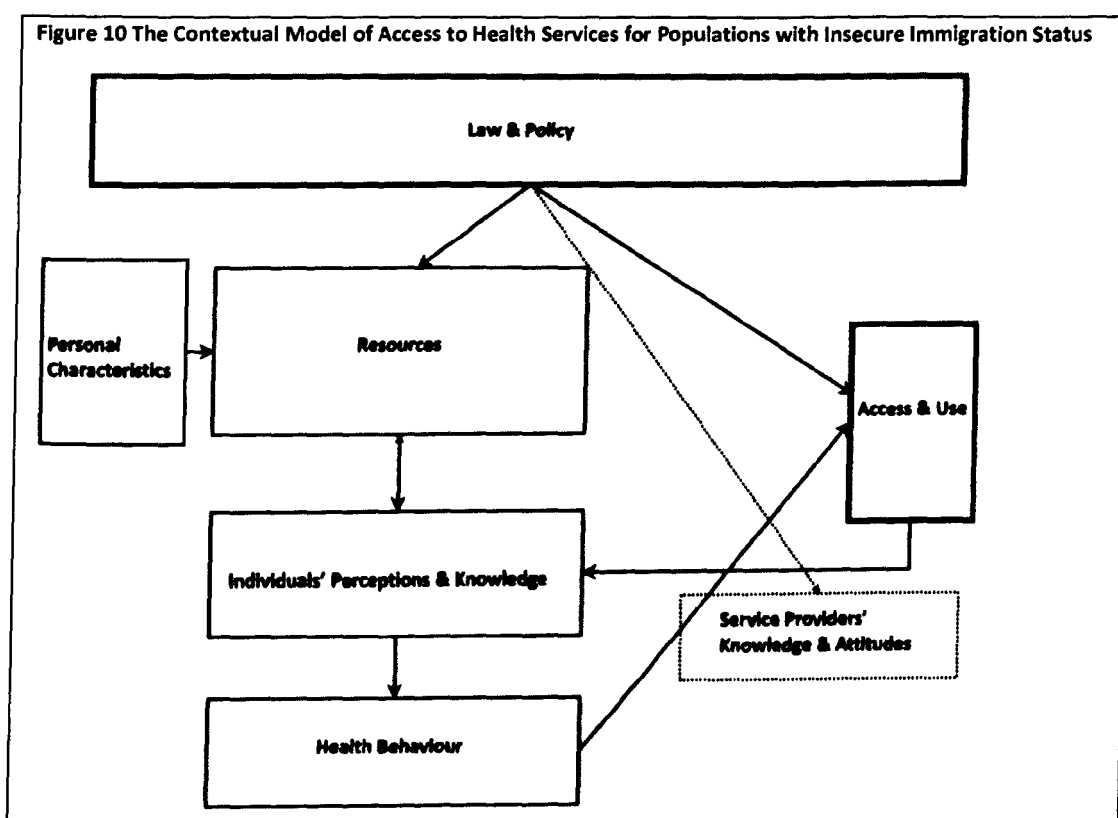
The theoretical framework that informed this research ("The Contextual Model of Access to Health Services for Populations with Insecure Immigration Status", shown above) viewed both clinicians' knowledge and attitudes and the patient's perceptions and knowledge as likely to be important to healthcare access. However, it did not consider the way in which clinicians' identity processes might influence perceptions of policy implementation. It also did not

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[86] Kang discusses the notion of 'community misperceptions' of HIV [107] and the National AIDS Trust have expressed concerns regarding community-wide misunderstandings of the Charging Regulations [178].
[87] This phenomenon (where migrants have avoided contact with health services because of a fear of being charged or reported to the immigration authorities) has also been reported by some third sector organisations [31, 182].

consider clinicians as co-implementers of policy who might operate in conflict with other staff. For that reason, the framework should be adapted to reflect the role of both clinical and non-clinical staff in obstructing or facilitating access to care, and of the dynamics that occur between those who wish to comply with the goals of policy versus those who engage in non-compliance, or even 'massive resistance'. In addition, experiences of healthcare access seem to be mediated by the agency of those implementing policy to a far greater degree than predicted by the framework, and women's *perceptions* of policy and self-efficacy in overcoming barriers are as important as policy itself. Policy is not irrelevant, of course, as it shapes expectations, not least in the effect that we have seen policy can have on perceptions of the 'target population' (in this case, by legitimising the social exclusion of migrants). It also provides some of the parameters for (implementer) behaviour. The original theoretical framework overstated the significance of law and policy itself, especially in the absence of sanctions for non-compliance. It is further reduced by the presence of a powerfully autonomous professional group required to implement policy, and where 'street wisdom' among insecure immigrants can contribute to an understanding of policy that alters collective identities. A revised framework, taking these findings into consideration, is shown below.
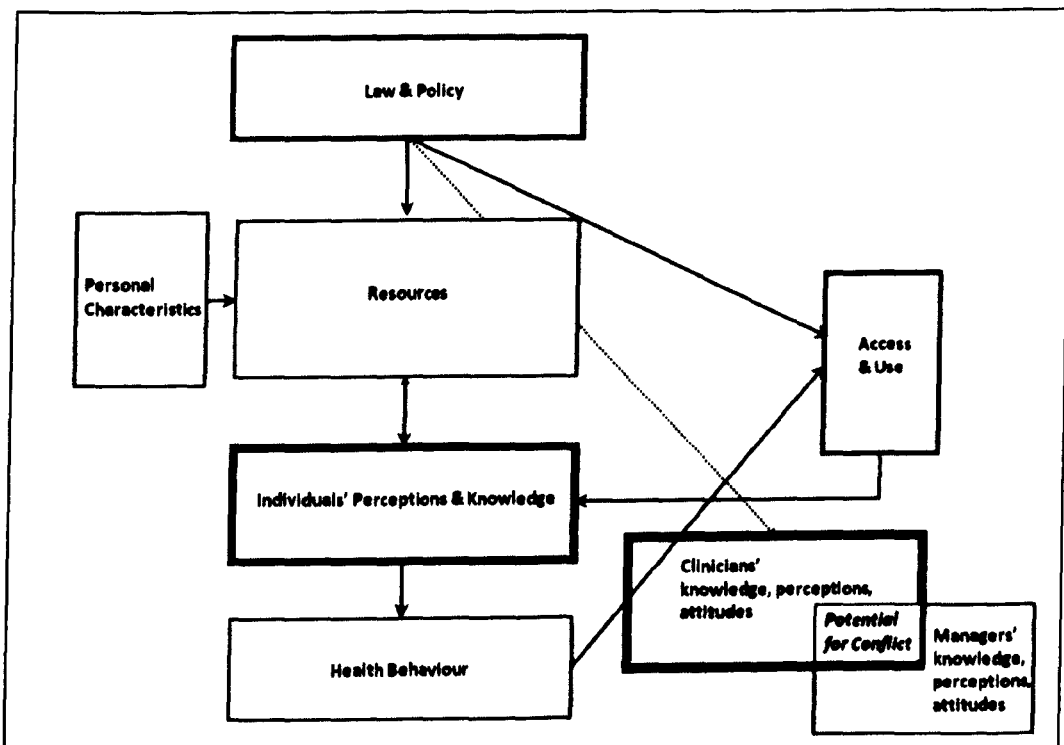

Figure 11 The Contextual Model, Revised

9.3.3 Structural Violence and Access to Healthcare

The women who participated in this research experienced the tripartite 'peripheral' status of being marginalised as a result of their HIV diagnosis, their immigration status, and their low status in society. In this sense, behavioural accounts, including behavioural accounts that emphasise the contextual components of access to healthcare, ignore the effects of structure. The theoretical framework utilised for this study (the 'Contextual Model') needs to be adapted in light of the findings of this research to reflect a structuralist account of access to healthcare (see figure 3).

Galtung defined structural violence as an avoidable disparity between the potential ability to fulfil basic needs, and their actual fulfilment [339]. Structural violence does not necessarily imply intent, but instead exists as a result of an uneven distribution of the power to decide on the distribution of resources. Thus both individuals and (large) groups of people can be the victims of structural violence [339], because structural causes are responsible for constrained agency [340]. Agency is here seen in terms of self-efficacy, which is determined by "the conviction that one can successfully execute the behaviour required to produce the outcomes" [341, p.193].

Structural violence can also be conceived as similar to social injustice (or conversely, social justice may also be equivalent to 'structural peace') [339], and is not dissimilar to concepts of social exclusion, which view disadvantage as being imposed on individuals by society [263]. The Charging Regulations themselves appeared to have a limited impact on these women's access to HIV care. However, their experiences as migrants and the insecurity associated with their immigration status affected many aspects of their lives, not least in terms of the degree of control they were able to exercise, and the choices available to them. By definition, making an asylum application subjects the individual to governmental power as their status is defined and determined by the state [263].

The next section discusses the way in which structural violence limited women's choices at each component of the theoretical framework (see Section 2.3) underpinning this research. Those components were: law and policy, women's personal characteristics, the resources available to them, their own perceptions and knowledge, their health behaviour, the perceptions of their clinicians – and their access to healthcare.

a   *Structural Violence and The Contextual Model of Access to Healthcare*

Women's HIV status as well as their immigration status and *lack of status* in society contributed to their sense of marginalisation and pushed their **individual identities and perceptions** into the background, against a foreground of these triple statuses. Galtung viewed

structural violence as a relationship between "Centres" and "Peripheries", both globally, and within individual nation-states [342], and women's marginalisation can be viewed as an extension of their peripheral status.

Structural violence has been identified as a contributor to increased risk of contracting HIV for marginalised (or peripheral) groups [343], and may help explain the extent of late diagnosis seen among African migrants [84, 95, 162], and among the women interviewed for this research. It can therefore be seen as having contributed to these women's acquisition of HIV, since within Galtung's definition they occupied a peripheral status first globally (as citizens of a developing nation), and within their own society (as women), [344] as a result of their **personal characteristics**.

Once in the UK, their insecure immigration status and ethnic minority status relegated them to the *periphery* of UK society, making them less able to command access to **resources** or exercise their own agency to ensure a good quality of life for themselves and their families. Their immigration status and associated limbo contributed to anxieties about their future wellbeing as well as day-to-day survival, and identity may have been 'suspended' in this liminal state [263]. Contributing to this peripheral state were their experiences of HIV stigma (felt or enacted) from within their own communities and sometimes from their families, marginalising them or pushing them to the periphery even within their own communities.

Being an insecure immigrant limited women's access to many services outside the health sector that also affected their wellbeing. For example, the lack of support that Beatrice experienced from the police as a victim of domestic violence exemplifies a structuralist account of violence. In this sense, Beatrice's inability to access a domestic violence refuge emanated solely from her immigration status: any other woman in UK society would have had the potential to receive this support. Ho views the racial inequality and poverty that is experienced by African Americans as an institutionalised social structure that lowers the level of actual fulfilment of one's fundamental needs below the potential, where the potential is defined by the availability and access that other American citizens enjoy [340].

Similarly, being barred from taking up formal employment was central for many of the women's perception of exclusion and many reported that this was a key factor in the deterioration of their mental health. Ndirangu's research with HIV-positive African immigrant women in the UK also identified the bar on working as reinforcing feelings of uselessness, and that work was central to their identities as providers [114]. In this research, women's inability to command access to resources often left them reliant on charity or family, which itself created feelings of simultaneous gratitude and shame, and undermined their identities as self-

sufficient and independent providers. Stewart also found that the very act of making an asylum application was viewed by some applicants as seeking charity, and that this too could result in feelings of shame that made individuals try to 'hide' their 'asylum identities' [263]. For Galtung, marginalisation was a means of keeping those on the periphery on the outside, and a subtype of structural violence. He noted that violence could be so considered when it left "marks not only on the human body but also on the mind and the spirit" [345, p. 294]. For the women in this study, being prevented from working excluded them and contributed, in their view, to poor mental health outcomes, and as such can be viewed as a type of violence that left "marks on the mind and spirit".

Other research has shown that low social status is an independent risk factor for poor health, as distinct from low socioeconomic position [346]. Women's lack of status in society was exemplified by the lack of control that they expressed about their (often otherwise varied) housing situations. This epitomises the lack of agency that Galtung saw as emanating from the imbalance in power giving rise to structural violence, since housing was an area in which even those women who were assertive (with regard to overcoming the other difficulties they faced) were conspicuously passive in their language. They often seemed to need to express gratitude, implying that women perceived that they were less entitled to this support, and therefore lower down a hierarchy of status. For Galtung, structural violence creates need deficits (such as poor housing), and this causes trauma [345]. When this happens to a group, it becomes collective trauma [345], which may (through a collective understanding of their housing experiences) explain that startling homogeneity in women's accounts of their accommodation experiences. Similarly, it also may explain the 'street wisdom' or rumour mills that both contributed to and emanated from perceptions of immigration and health policies, as this seemed to form part of a collective response to policies that were perceived to ignore the individual.

This 'street wisdom' appeared to be particularly present at or through attendance of support groups, which, while being enormously valuable to many women, may also have helped to reinforce their expectations of prejudice and hardship in the 'outside world'. Advice that women received from in support groups that conflicted with messages received in clinics may have undermined the women's trust in their treating clinician. This was especially the case when perceptions of stigmatising **clinician perceptions** in primary care settings had been shared among women at support groups. Reduced trust for clinicians has been shown in research from the USA to affect levels of unmet need, especially among disadvantaged groups or those who have structural obstacles to healthcare [347].

Trust has been viewed as related to health and wellbeing [348], and likely to improve adherence to treatment regimens [347]. Therefore reduced trust may also have affected women's willingness to tolerate some of the side-effects associated with their ART; some women had considered discontinuing treatment as a result of a lack of trust in their clinicians. In this way the need deficits that arise from structural violence indirectly contributed to their sustained health, or viewed through a structuralist perspective, to their ability to align their actual with their potential health, through their **health behaviour**. A collective awareness of possible contra-indications of particular anti-retroviral drugs (Efavirenz) [309-311] for sub-Saharan African women (neuropsychiatric side-effects are thought to be more common among sub-Saharan Africans prescribed this ARV) exacerbated these anxieties for women who had been prescribed them. It was difficult to identify to what extent the mental health problems they reported (especially symptoms associated with anxiety and depression) could be ascribed to the drugs themselves, or to the anxiety resulting from the difficulties they faced in their day-to-day lives.

The ways in which behavioural or intrapersonal components of the Contextual Model can be affected by structure has been discussed above. However, much of this is underpinned by 'cultural violence'. Cultural violence is the symbolic 'prop' that legitimises or justifies structural violence. One of the six domains of cultural violence is ideology, including the self/other dichotomisation associated with maintenance of the nation-state [345], and therefore it is the symbolism associated with Othering 'the migrant' that enables structural violence. The bi-directional relationship between restrictive immigration **law and policy** and perspectives on migrants was discussed above. In this sense, policies that reinforce a view of migrants as excludable contribute to this symbolism and sanction structural violence. This self/other dichotomy also lends itself to a characterisation of the other as responsible for any direct violence the other experiences. If we view the risk of HIV infection as increased by structural violence and the acquisition of HIV as the direct violence stemming from this risk, then HIV stigma itself can be partially explained by this view of the other as the 'dangerous it' that can be held accountable for its own misfortune. Stigma constituted a substantial barrier to access to HIV services for the women who participated in this research. Discriminatory treatment from families, fears of rejection from their communities, and felt stigma as well as reports of overt discrimination in primary care settings acted together to make women feel vulnerable and isolated. Women often sought to distance themselves from what they saw as stigmatised modes of transmission of HIV, thus inadvertently contributing to HIV stereotypes. Given that Galtung identified 'fragmentation' as another means of enacting structural violence, where those on the periphery are kept away from each other [345], this further diminishes the periphery's capacity to resist structural violence. Experiencing discrimination from family

members (who otherwise might have provided a valuable source of support) 'fragmented' women from their communities and peers. This fragmentation was also visible in the reduction in funding to peer support services and legal aid for asylum-applicants. For the women in this study, access to support services was one of the few means they had of diminishing their sense of isolation and marginalisation, and reduced legal aid funding undermined their capacity to make viable asylum applications and therefore to improve their situations.

According to Galtung, it is the political power that resides in the hands of a few, in the 'Centre', that gives rise to the central inequality responsible for structural violence [340]. South-North migration could be viewed as an attempt to increase one's agency by placing oneself closer to the 'Centre', however since most migrants find themselves marginalised and within the host society's periphery, this is not likely to be a successful strategy. The women who participated in this research exemplified the grey area between forced and voluntary migration, especially given the constantly changing political situation in Zimbabwe and their fluctuating legal status in the UK following from the various court cases aimed at determining the repercussions for deported Zimbabwean asylum-applicants. While these women did not, by and large, qualify as Refugee Convention defined refugees, it was legal precedent that had determined that an absence of ART in a migrant's country of origin did not qualify them for a viable human rights-based asylum claim. Legal precedent is not in itself sufficient to prove a fundamental moral distinction between the individual who has migrated with total personal choice (and therefore an absence of structural violence influencing their decision) and the individual with a human rights need and therefore an imperative to seek asylum.

Similarly, Cole argues that where national borders fall is morally arbitrary [349]. Since most healthcare systems aim to ensure good population health according to individual need, rather than social position, gender, race or ethnicity [346], these characteristics should not determine an individual's welfare or moral status [349]. For Cole, and Galtung, ideally only free choice and not fate should influence life chances, implying a universalist perspective, or a requirement for social justice. In order to maintain a welfare state (or a health system) where sustenance is not provided to outsiders, a philosophical perspective of 'liberal realism' (that liberal institutions such as welfare systems need to be protected with illiberal practices) must be accepted. However, Cole points out that to do so fundamentally undermines the ethical basis of the NHS itself, since it is premised on principles of universalism, human rights and social justice [349]. Therefore using the NHS as a means of maintaining a 'liberal realist' perspective towards the nation-state and its obligations, fundamentally contributes to its erosion as an organisation committed to treatment 'free at the point of need'.

Equity of access to health has been described as synonymous with social justice [350]. If the absence of social justice can be structural violence, then the presence of structural violence fundamentally undermines access to health. From this perspective, simple behavioural (or contextual) frameworks for access to healthcare do not provide a full explanation of access to health for vulnerable or marginalised populations without taking structural violence, or social injustice, into consideration. Every aspect of women's lives was affected by their 'peripheral' statuses, and this affected their capacity for agency and free choice. This is not to say that women were *without agency* – many successfully used strategies and the choices available to them to assert themselves and overcome structural obstacles – rather that individual agency was exercised within the constraints of structural limitations. Thus the healthcare access framework used in this thesis is encapsulated within an understanding of the limitations that being a victim of structural violence may place on access to health, through its impact on, in particular, the 'law and policy' and 'resource' components of the model (see Figure 12). For this reason, greater emphasis has now been placed on structure (as opposed to context) and its importance for healthcare access.

Structural violence could theoretically be applied to any marginalised group as an explanation for limited access to healthcare. However, two aspects of Galtung's theory that apply to these women are not necessarily present for all individuals who experience social inequality or injustice. First, he emphasised the links between structural violence and Imperialism [342], as well as the effects of structural violence on individuals. This former aspect of his theory helps to distinguish it from the concept of social injustice. The women in this research experience *structural violence* not only because of their peripheral existence in the UK, but also because of their status as migrants *from the periphery*. For this reason, the effects of structure on personal characteristics have been emphasised in the adapted model, since it is women's migrant status that establishes this. Second, Galtung discussed the phenomenon of 'fragmentation', whereby individuals in the periphery are kept apart from one another, thus diminishing their capacity to resist the effects of structural violence. The women in this study were 'fragmented' from one another, their communities, and sometimes their families by discrimination and by limited support services that could reasonably have offset this aspect of their exposure to structural violence. Hence the effect of structure on resources has been emphasised in the model below, to take account of the limiting effect of structural violence on most resources that could offset some of the wider effects of structural violence. Any individual experiencing social inequalities and marginalisation could reasonably be argued to experience social injustice; not all individuals experiencing social injustice are 'twice' peripheral and fragmented by stigma and explicitly diminishing support. It is for this reason that only these two components of the model have been emphasised – structural violence as a

phenomenon could reasonably be said to touch all aspects of the model below. However the way in which women's personal characteristics and the resources available to them are the product of a structurally violent world are uniquely affected by their status as migrants and by their HIV-positivity.

This final figure (Figure 12) has gone beyond a purely behavioural or structural account of healthcare access, in placing a substantial emphasis on the perceptions and values of individuals (both service users and providers), and the relationships between individuals.

Figure 12 The Structural Model of Access to Health Services for Populations with Insecure Immigration Status
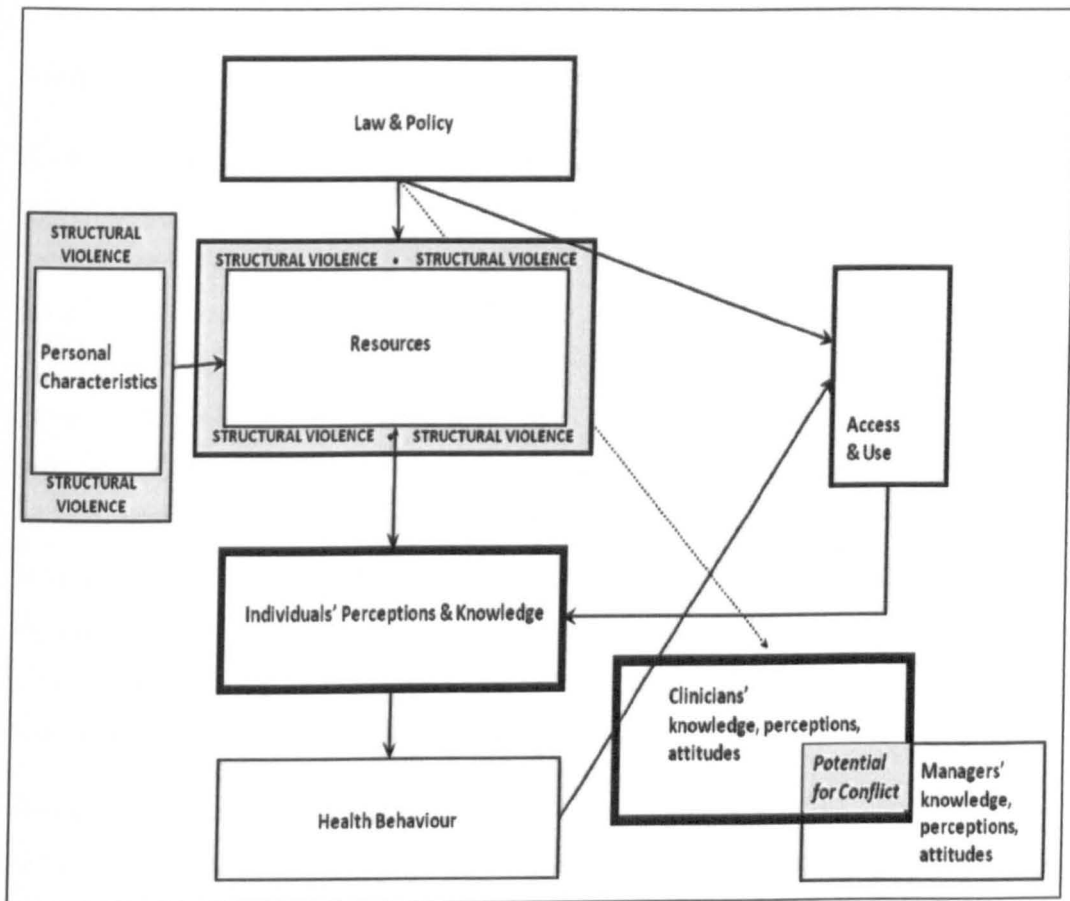
9.4   Implications for policy, practice and further research

Drawing on the findings of the policy analysis and qualitative research with Zimbabwean women, and the theory advanced above, this thesis concludes with a discussion of the:

- implications for UK health and immigration policies;
- potential of increased support to offset the effects of structural violence on access and use of health services for HIV-positive Zimbabwean women;
- scope for further research examining the relative contributions of pharmacological and social effects on the mental health of HIV-positive women with insecure immigration status.

Political Leadership in Immigration Policy-Making

The apparent lack of evidence behind the development of the 2004 amendments undermined their implementation and the Government's stated commitment to evidence-based policy making. The results of the 2004 consultation on extending healthcare access restrictions into the primary care sector have not been published, nor has an explanation been provided for the delay. This contradicts Cabinet Office rules on accountability and transparency in policy consultation and development processes [266]. The use of secondary legislation limits the opportunities for plural engagement in policy development, and a seemingly fickle approach to the aims of the policies by government implies (in a multiple streams approach) an attempt to fit prior solutions to subsequent problems [214]. Immigration is an issue that cleaves a particular line through a government's legitimacy [326], and this opaque and fickle approach to immigration policy-making had undermined many key informants' perceptions of the Government's legitimacy.

Although the policies on access to healthcare fit into New Labour's 'rights and responsibilities' paradigm [131, 133, 142, 144, 157], rather than into a framework for integration policy, they and other policies that restrict access to services and thus socially exclude asylum-applicants do undermine integration [130]. Many asylum-applicants can remain in the UK for years before their asylum is determined [165], and refusal does not necessarily entail deportation [26]. In this context, systematically excluding these groups undermines the social inclusion approach [130] to integration. Policies such as these may be effective in terms of deterrence and encouraging migrants to leave the UK, but they ought to be reconsidered in light of these other effects, especially given current concerns about social cohesion and threats to national security [138]. Border controls/deportation responsibilities need to be kept separate from the treatment that asylum-applicants and unauthorised migrants face while in the UK, if the quest for integration and social cohesion is to be maintained.

'Multiple streams' analysis [216] of agenda-setting suggests that where access to healthcare for insecure immigrants is concerned, development of policy solutions and problems were intertwined, contributing to a cycle of public opinion and policy development feedback loops. There has been a glut of new immigration legislation under New Labour [130], and this glut had itself undermined the Home Office institutionally in key informants' eyes. Improving political leadership on immigration policy such that public perception of an issue is no longer identified as the 'problem stream' might improve the quality of immigration policy as well as public and stakeholder trust in the Home Office and government.

The politically defensive approach to immigration policy implied by the use of 'low politics' has backfired. Substantial advocacy has coalesced around the restrictions on access to healthcare and other similar welfare access policies (such as the extent of Section 4 support and the bar on working) in the form of anti-destitution coalitions and campaigns. The involvement of clinicians and other powerful advocates in these campaigns may have contributed to their success in the apparent withdrawal of the proposals to extend health restrictions into the primary care sector. Similarly, the 'shifting down' [330] of the implementation of immigration policy appears to be less effective where those (such as clinicians) required to implement policies have a high degree of professionalization, autonomy, and consider themselves bound by other duties that trump their responsibilities as a public sector employee [332]. Under these conditions, the Charging Regulations can serve as an exemplar of the organisational conflicts developing in the NHS between clinicians and managers [214] and may have implications for future institutional development and organisation of the NHS.

In addition, policies that aim to restrict access to healthcare for vulnerable populations do raise concerns about individual and public health [178, 199-203]. Despite the marketisation of the NHS facilitating the development of the Charging Regulations, policy on access to healthcare needs to be separated from market issues, especially since restricting access could have implications for public health [178, 199-203].

Trust and Support for Patients with Insecure Immigration Status

Direct experiences of or hearsay about treatment refusal may lead migrants to believe that they are considered worthless by UK clinicians. When these concerns are coupled with perceptions of a possibility of discriminatory treatment in primary care settings, trust in clinicians can be significantly undermined. Late diagnosis of HIV is prevalent among African migrants in the UK [84, 95, 162], and although research has shown that Africans prefer to use primary care services [70, 94], women in this research felt GP knowledge of HIV was poor.

Similarly, altering women's negative perceptions of clinicians and of likely experiences in HIV care would facilitate earlier testing and improve individual and public health.

In this research, those women who expressed satisfaction with their clinical care often did so because they thought that they were receiving clear and honest information from their clinicians. Conversely, a lack of trust [347] was a key factor for those women who said they might stop taking their ART. Women who felt supported in their clinics and through peer support were better empowered to take advantage of the services that were available to them. As discussed above, this is a population with substantial structural limitations on their access to healthcare. As a group and as individuals they are likely to face exclusion and marginalisation in many spheres of their lives that can affect their agency and wellbeing. Peer support groups were a significant source of succour for women and provided a good opportunity to 'offset' the structural obstacles that women may experience. Information received in this setting was trusted (often in contrast to the information received in clinical settings), because of the sense of safety and inclusion provided there. However many women felt that their access to these services was also becoming more limited, because of a decrease in funding. Key informants' reports of the extent of support group availability supported this view, while implying that the problem was not funding cuts per se, but rather that the increasing cost of providing HIV treatment was limiting funds for support groups. These funds had traditionally come from PCTs who were no longer obliged to ring-fence sexual health monies [303].

Healthcare access could therefore be improved through a reintroduction of ring-fencing of central government funding for sexual health. This would ensure that funds were not diverted away from sexual health and HIV care, and could facilitate a resurgence in PCT funding of support groups. In the clinical setting, enhancing the level of trust in doctor-patient interactions, and in patients' perceptions of clinicians is needed to substantially lower women's levels of anxiety in this context as well as to improve treatment adherence [347]. Trust has been identified in facilitating collective action, between groups and institutions as well as individuals [122]. A priority for enhancing trust in this setting will be establishing better links between support groups and GUM clinics and clinicians, facilitating a bi-directional exchange of information in both settings to improve women's access to and experiences of both support groups and clinics.

In addition, further research is needed into the role of trust in clinician-patient interactions, whether trust is itself always positive, and the way that these phenomena are themselves affected by relationships with third parties, such as patient support organisations [348].

Neuropsychiatric Adverse Drug Reactions (ADRs) and Efavirenz – understanding the contribution of stress

For people living with HIV, quality of life may be seriously affected by taking anti-retrovirals, especially where they were previously asymptomatic [351]. Some of the women who participated in this research interpreted their side-effects with resentment, since they were the only unpleasant physical experiences they had perceived as a result of their HIV diagnoses. HIV-positive women with insecure immigration status may be at greater risk of developing mental health problems because of: the trauma (both individual and collective) associated with the needs deficits arising from structural violence [345]; and because of the pharmacoepidemiologic profile of particular ART that may be contraindicated for African women [308, 309].

In this research, many of the women taking Efavirenz expressed concerns that they were or they might experience CNS ADRs associated with the drug, and some reported symptoms such as anxiety, depression, and vivid dreams. Previous studies have suggested that Africans taking Efavirenz are more at risk of neuropsychiatric adverse events than Caucasians [308, 309] taking the drug, because they are more likely to have a hepatic mutation on the CYP2B6 allele that would slow down their metabolism of the drug [352]. Neuropsychiatric or Central Nervous System (CNS) effects associated with Efavirenz can include anxiety, depression, and suicidal ideation [353]. Gender may also affect plasma concentrations of Efavirenz, meaning that women might be more prone to higher drug exposure and therefore different clinical outcomes [354].

However, studies have shown that significant anxiety is associated with the uncertainty of being an insecure immigrant, which can aggravate existing health conditions and affect health behaviour [44]. The women in this research had experienced substantial exposure to social stressors that might themselves increase the risk of mental health problems [116]. In this context it may be hard for clinicians working with African migrant women to gauge the relative contributions of pharmacoepidemiology versus a vulnerable populations' response to numerous social stressors. This may be particularly so since 'street wisdom' has contributed to women's perceptions of their own responses to the drug. In the post-HAART era quality of life is now a key measure of treatment success [351]. The need to understand how pharmacoepidemiology, psychiatry, neuropsychiatry, and social stress interact to reduce quality of life in a migrant population with an arguably low (structural) quality of life means that: *further research is required that examines the relative contributions of gender, race, and social stressors in determining risk of developing neuropsychiatric ADRs in response to Efavirenz.*

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10. Appendices

10.1 Appendix 1 – Additional Migration and Refugee Data

Refugees residing outside Europe number 3.2 million in Africa, and 3.5 million in Asia [16]. Of those seeking asylum in Europe, Asia was the source region for the majority of asylum applicants in 2005, followed by Europe, and then Africa[88] [18]. Of those worldwide who had been granted refugee status up to 2006, the majority settled in Asia, followed by Africa, and then Europe[89] [355]. The top five asylum producing countries at the end of 2006 were, in descending order: Iraq, the Democratic Republic of the Congo, Myanmar, Colombia, Serbia, and the Russian Federation [355]. It is interesting to note that the dynamics of asylum can change rapidly year on year - at the beginning of 2005, the top five asylum producing countries were, again in descending order: El Salvador, Guatemala, DRC, Iraq, and Afghanistan [18]. These annual differences highlight the value of a brief overview of recent refugee/asylum and migration trends.

Forced Migration Trends

Although the global number of migrants has increased substantially over the last 40 years, the number of refugees has fallen, from over 18 million in 1992 [16], to just under 16 million by the end of 2007 [356]. Much of this change can be ascribed to the end of a number of protracted armed conflicts that arose out of the end of the Cold War [16]. However, some have argued that the changing nature of conflict and 'push factors' in a post Cold-War climate (e.g. from a bi-polar world order to multiple ethnically-motivated civil wars [8]) means that forced migration has not decreased as significantly as these figures would suggest, but that instead migrants may be less likely to cross international boundaries.

UNHCR data have been used here to provide a brief overview of forced migration trends 1997-2007. Figure 13 demonstrates that refugee numbers have declined overall since 1997, as have the numbers of those seeking asylum. However, the global number of internally displaced persons (IDPs) has increased substantially over the same period, contributing to a total 'population of concern to UNHCR' of over 20 million by 2007. It is interesting to note that despite the fact that IDP numbers only equalled those of refugees between 2005-2006 (before substantially overtaking them by the end of 2006), the absolute numbers of IDPs in the period since then have been so high that they are clearly the main group contributing to UNHCR's

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[88] 94,582 of asylum applicants in Europe came from Asia, while Europe and Africa produced 71,275 and 67,492 European asylum applicants respectively (UNHCR Statistical Online Database, 2005).
[89] Asia had a population of 3,502,500 refugees in 2005, Africa had 2,767,600, while Europe had 1,747,400 refugees (UNHCR Statistical Online Database 2006).

total population of concern in this period. In 2007, UNHCR's mandate only enabled the provision of assistance to around 50% of the world's IDPs [19].

Figure 13 Populations of concern to UNHCR, trends 1998-2007
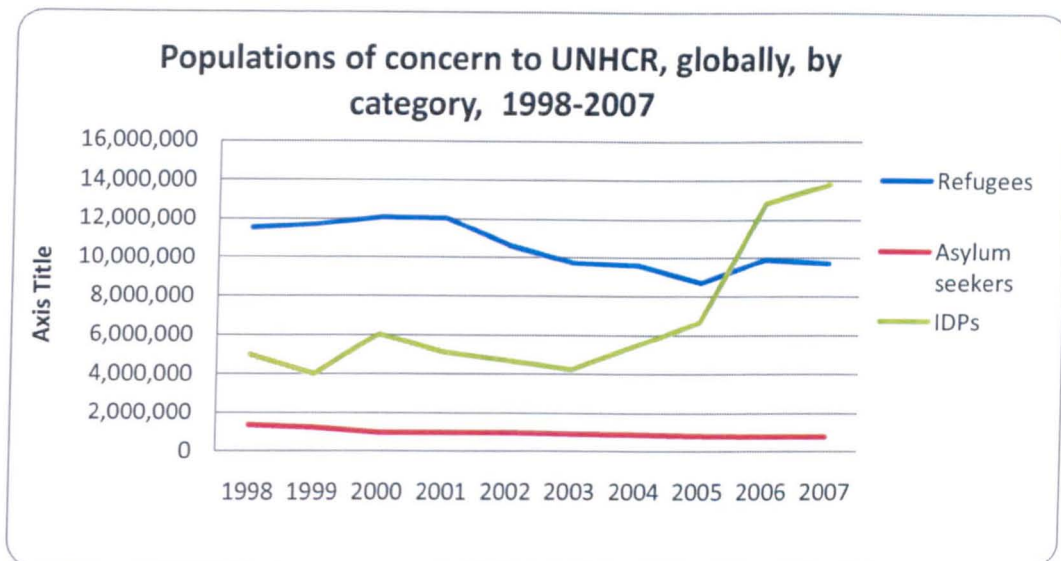
10.2 Appendix 2 – Zimbabwe Deportations

In November 2004, however, amid concerns about exploitation of the policy by some Zimbabweans (asylum applications from Zimbabweans increased 3.5 times between 2001 and 2002 [3]), the HO announced that enforced removal would be resumed, despite continuing disquiet about the situation in Zimbabwe. This policy of sending individuals back to a location where they might experience persecution and torture was challenged in July 2005 over the case of 'AA' [357]. The defence for AA argued that merely the act of claiming asylum in the UK would be prejudicial to AA's treatment on arrival back in Zimbabwe, and forced removals were again suspended, pending the outcome of this case. In October 2005 the Asylum and Immigration Tribunal (AIT) upheld AA's position. However, the Government appealed against the AIT's decision and the case became a Country Guideline case, meaning that the decision would be followed in all future cases. At appeal in August 2006, the AIT reversed their original decision. However, although the act of claiming asylum was no longer held to place returned individuals at risk, the AIT did identify three types of claimant where there may be a risk of persecution and therefore a need for protection [357]. This broadened the groups thought to be at risk on return to Zimbabwe, and the Court of Appeal ordered the AIT to consider the case of AA once again. In May 2007 the AIT dropped the case of AA as a test case, in favour of the case of HS to determine country guidance for Zimbabwean removal policy. This case would enable the AIT to consider issues beyond the removal risk for asylum-applicants, and also to consider the risk of ill-treatment on return, humanitarian conditions in the country and what deterioration had occurred in Zimbabwe since the AA case was first heard.

The case of HS was first heard in November 2007 and the AIT decided that some asylum-applicants could be safely returned. However, much as in the case of AA, it again concluded that the categories of individual at risk on return were broader than it had initially considered [358]. A request for appeal in HS was brought in June 2008, and in November 2008 the AIT published a new determination on Zimbabwe country guidance. It found that "additional categories of Zimbabweans would be at risk on return; notably that a person not able to demonstrate loyalty to Zanu-PF or with the regime in some form or other will be at real risk having returned to Zimbabwe from the United Kingdom having made an unsuccessful asylum claim." The Borders Agency undertook to maintain the suspension of removals to Zimbabwe until the HS case had been resolved [359].

10.3 Appendix 3 – List of Documents for Policy Analysis

- UK Borders Act 2007

- Transcripts from Strasbourg Case of N

- Revised BMA Guidance on Implementing the Overseas Visitors Charging Regulations

- Nationality Immigration and Asylum Act 2002

- NASS Policy Instruction – Dispersing Asylum Seekers with Health Care Needs

- Transcript from Mitting Judicial Review

- John Reid Speech "I Stand with the Public"

- Joint Committee on Human Rights – Report from Hearing on The Treatment of Asylum Seekers

- Joint Committee on Human Rights – Uncorrected Oral Evidence from Hearing on Immigration and Human Rights

- Joint Committee on Human Rights – Uncorrected Oral Evidence from Hearing on The Treatment of Asylum Seekers

- Immigration Asylum and Nationality Act 2006

- Immigration and Asylum Act 1999

- Transcript from the House of Lords, Case of N

- Transcript from the House of Lords, M vs Slough

- White Paper *Secure borders, safe haven: Integration with diversity in modern Britain,* 2002

- Home Office document "Public performance target: removing more failed asylum seekers than new anticipated unfounded applications"

- Home Office Guidance on Section 4 of the Immigration and Asylum Act 1999

- Five-year plan on Immigration and Asylum "Controlling our borders: Making migration work for Britain" 2005

- Home Office review of the Immigration and Nationality Directorate - "Fair, effective, transparent and trusted - Rebuilding confidence in our immigration system" 2006

- Immigration White Paper - Fairer, faster and firmer: a modern approach to immigration and asylum

- House of Commons Health Committee - New Developments in Sexual Health and HIV/AIDS Policy - Third Report of Session 2004–05

- Government Response to the JCHR Hearing Report "The Treatment of Asylum Seekers"

- Government response to the Health Select Committee's Session on "New Developments in Sexual Health and HIV/AIDS Policy"

- Immigration Strategy Document - Enforcing the rules - A strategy to ensure and enforce compliance with our immigration laws

- Department of Health Consultation - Proposals to Exclude Overseas Visitors from Eligibility to Free NHS Primary Medical Services 2003
- Department of Health Guidance on Failed Asylum Seekers and Ordinary residence
- Department of Health document Consultation – Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 2989
- Department of Health document Consultation – Summary of Outcome – Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989
- Department of Health – National Strategy for Sexual Health and HIV
- Department of Health report on Overseas Visitors
- Statutory Instrument 1989 No. 306 National Health Service, England and Wales The National Health Service (Charges to Overseas Visitors) Regulations 1989
- National Health Service - Implementing The Overseas Visitors Hospital Charging Regulations Guidance For NHS Trust Hospitals In England 2007
- Health Service Circular - Overseas Visitors' Eligibility to Receive Free Primary Care, 2002
- Asylum and Immigration Act 2004
- Court of Appeal – Judgment in the Case of YA

10.4 Appendix 4 – Freedom of Information Approach

In February 2008 I contacted both the DH and HO requesting: "information not currently in the public domain, including internal communications, relating to the process by which the change to the Charging Regulations came to be made, if appropriate". The HO responded that they did not hold any documents relevant to the request. The DH turned the request down under Section 35(1) (a), (b), and (c) of the FOIA. This section provides an exemption relating to the formulation of government policy, and holds that:

Information held by a government department or by the National Assembly for Wales is exempt information if it relates to-

- o **(a)** the formulation or development of government policy,

- o **(b)** Ministerial communications,

- o **(c)** the provision of advice by any of the Law Officers or any request for the provision of such advice.

However, this is a 'qualified exemption', which means that even if information is exempt under Section 35, the public interest must be considered, and "a public authority must consider whether there is an equal or greater interest in disclosure" [360]. I therefore made an internal request for a review of the decision, but was told that the DH maintained its original decision, and was given no new reasons other than that the lapse of time had not altered the balance of the public interest test. I submitted a complaint to the Information Commissioner's Office (ICO) in May 2008 (See Appendix 5). In July 2009, I was informed that the DH had decided in consultation with the ICO to release the documents, although the documents released appeared to be limited in scope. I am therefore in ongoing discussions with the ICO about the DH releasing further documents, although I do not anticipate they will arrive in time to be included in this thesis.

Documentation relating to the FOI request made for this research, including the documents released, see following Appendices.

10.5 Appendix 5 – Department of Health Response to Request for Internal Review of FOI Processes

(DH) Department of Health

334B Skipton House 80 London Road London SE1 6LH Telephone: 020 7972 2000
Direct Line: 020 7972 6045
Email: t@dh.gsi.gov.uk

Our ref: 279818R

Ms Hana Rohan
Hana.Rohan@lshtm.ac.uk

23 April 2008

Dear Ms Rohan,

OUTCOME OF A REQUEST UNDER FREEDOM OF INFORMATION [FOI] ACT 2000 FOR INTERNAL REVIEW

Thank you for your email of 25 February 2008 requesting an internal review of the decision taken to withhold, pursuant to section 35(1)(a),(b) and (c) of the FOI Act, documents regarding policy decisions which led to the change to Regulation 4(b) in the *NHS (Charges to Overseas Visitors) (Amendment) Regulations 2004.*

I apologise for the delay in responding to your review request, which has been subject to extensive discussions within the Department.

We have considered all the relevant issues and concluded that the Act was correctly applied and that the reasons for the decision were appropriate to the circumstances of the case. We have also considered where the public interest lies in this case and have again concluded that it is in the public interest to withhold the information.

Having investigated further, we are satisfied that all of the information you requested was covered by the exemption cited and that the lapse of time has not altered the balance of the public interest.

However, whilst I am unable to release the documentation requested, I hope that it will help if I explain some of the background to the change to Regulation 4(b).

The 2004 amendments were largely in response to a growing recognition that the *NHS (Charges to Overseas Visitors) Regulations 1989* were no longer able to maintain the principle that access to free NHS hospital treatment should be based primarily on appropriate residence in the UK. The NHS itself informed the Government regularly of loopholes in the law which meant that people who should not be able to access free treatment were legally able to do so. This had been exacerbated by changes in migration patterns and the incidence of international travel over the intervening years.

The change to Regulation 4(b) was to clarify what had always been intended by that regulation – the fact that it should be only those people who accumulate twelve months of lawful residence in the UK who become exempt from charges, not those who are in the UK unlawfully and merely manage to remain here for twelve months

without being identified and deported. This is borne out by the fact that some of the other 2004 amendments also sought to clarify that residence must mean lawful residence for the exemption categories to apply.

It has often been reported that the amendment to Regulation 4(b) was made in relation to failed asylum seekers, so that that specific group of people could no longer receive free treatment. This is not the case. The clarification of Regulation 4(b) was meant to exclude all those who are in the country unlawfully – including illegal immigrants and those who overstay their visas – and it was certainly not the intention to target failed asylum seekers with the amendment.

Whilst the Government was clear that only those who are living lawfully in the UK should be entitled to free NHS hospital treatment, it was mindful of the humanitarian and public health consequences of that. That is why an "easement" clause was inserted into the Regulations in 2004 so that any course of treatment which begins free of charge must remain free of charge until it is complete or until the person leaves the country. Therefore, a person whose immigration status changes after the point that they begin a course of treatment free of charge will not have to begin paying for that course of treatment or have it withdrawn. Guidance to the NHS is also clear that immediately necessary or urgent treatment must never be withheld because of doubts about a person's entitlement, or if they will have the resources to pay for their treatment if it is established that they are not entitled to it free of charge.

I hope that this further information is useful to you.

The review is now complete. The Department is satisfied that section 35(1)(a), (b) and (c) of the FOI Act was correctly applied to your original request.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Once again, I apologise for the delay in replying and I appreciate your patience.

Yours sincerely,

Section Head, Freedom of Information Unit

10.6 Appendix 6 – FOI Complaint to the Information Commissioner
THE INFORMATION COMMISSIONER

HANA ROHAN

<u>Complainant</u>

and

THE DEPARTMENT OF HEALTH

<u>Respondent</u>

_____

GROUNDS OF COMPLAINT

_____

Introduction

1. This document sets out Ms Hana Rohan's grounds for a complaint against the Department of Health ('the Department') pursuant to s 50 of the Freedom of Information Act 2000 ('the Act'). Ms Rohan requests the Information Commissioner's determination of whether the Department has handled her request for information in accordance with the requirements of Part I of the Act.

2. In outline, Ms Rohan requested that the Department provide her with copies of documents illuminating the reasoning behind an amendment made in 2004 to the regulations governing the eligibility of failed asylum-seekers to free National Health Service ('NHS') hospital treatment. The Department refused her request, citing s 35(1)(a), (b) and (c) of the Act. At its internal review the Department upheld its original decision. She appeals against the Department's refusal.

3. Page references in square brackets in this document are to the hand-numbered pages of the attached bundle of supporting documents.

Facts

4. Ms Rohan is researcher and doctoral student at the London School of Hygiene and Tropical Medicine, which is part of the University of London. She is a member of her institution's Health Policy Unit. She conducts research into health policy relating to access to health services of people seeking asylum, including those whose claims for asylum have failed. Her research covers policy-making, the implementation of policy, and the experiences of those affected by policy.

5. In 2003, the effect of regulation 4(b) of the National Health Service (Charges to Overseas Visitors) Regulations 1989, SI 1989/306 was that those who had spent the previous twelve months in the UK were entitled to free NHS hospital treatment. The relevant wording at that time was:

Overseas visitors exempt from charges

4. No charge shall be made in respect of any services forming part of the health service provided for an overseas visitor, being a person, or the spouse or child of a person –

[...]

(b) who has resided in the United Kingdom for the period of not less than one year immediately preceding the time when the services are provided, whether or not immediately prior to the completion of one year's residence as aforesaid, charges under these Regulations may have been made in respect of services provided as part of the same course of treatment; or

[...]

6. On 29 July 2003 the Department of Health published a document entitled *Proposed Amendments to the National Health Service (Charges to Overseas Visitors) Regulations 1989: a Consultation* (full document: http://snipurl.com/2epse). The document sought responses to government proposals to reduce or remove the entitlement to free NHS hospital treatment of certain groups of overseas visitors in England and Wales.

7. One such group consisted, expressly, of those who had sought asylum and whose asylum applications had been rejected. The government proposed to exclude anyone who was identified as being in the UK without proper authority from the twelve month residency exemption. The consultation document asked whether this amendment should be made, how far hospitals should be expected to go in checking whether patients have a legal right to be in the UK, and to what extent there is a duty of confidentiality to a patient who is discovered to be in the UK without lawful authority.

8. The government indicated that it was 'keen to obtain the views of anyone with an interest in the issues set out in this consultation document' (paragraph 7.1, page 24 of that document). Responses were requested by 31 October 2003.

9. In December 2003 the Department of Health published a document summarising the results of the consultation exercise (full document: http://snipurl.com/2epsz). This indicated that 141 replies had been received, of which it considered 124 to be relevant. The document provided a qualitative and quantitative synthesis of the results of the exercise, and a list of respondents.

10. On 11 March 2004 the Secretary of State for Health laid before Parliament the National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2004, SI 2004/614. These amended the relevant parts of regulation 4 thus:

Overseas visitors exempt from charges

4 (1) No charge shall be made in respect of any services forming part of the health service provided for an overseas visitor, ~~being a person, or the spouse or child of a person~~ –

[...]

(b) who has resided <u>lawfully</u> in the United Kingdom for the period of not less than one year immediately preceding the time when the services are provided ~~whether or not immediately prior to the completion of one year's residence as aforesaid, charges under these~~

~~Regulations may have been made in respect of services provided as part of the same course of treatment~~ unless this period of residence followed the grant of leave to enter the United Kingdom for the purpose of undergoing private medical treatment or a determination under regulation 6A; or

[...]

11. The material change for the purposes of this complaint is the insertion of the word 'lawfully'.

12. This amendment came into effect in England on 1 April 2004.

13. Immediately prior to this the Rt Hon John Hutton, then Minister of State for Health, issued guidance for the benefit of NHS trusts on the implementation of the regulations (full document: http://snipurl.com/2epqa; extract at page 10 of the attached bundle). The guidance advised (at paragraph 6.24 [page 10]) that asylum-seekers whose claims have finally been rejected are ineligible for free NHS treatment, whether or not they had completed a year's residence in the United Kingdom.

14. Identical changes came into effect in Wales two months later by virtue of the National Health Service (Charges to Overseas Visitors) (Amendment) (Wales) Regulations 2004, SI 2004/1433. To date there have been no further relevant amendments to the quoted regulations.

15. On 14 February 2008 Ms Rohan contacted the Department of Health by email, requesting information not currently in the public domain, including internal communications if appropriate, held by the Department of Health relating to the process by which the change to the regulation came to be made [page 1]. She explained that she was seeking information to help her understand what factors led ministers to make the decision they made, what weight was given to those factors, and why.

16. Ms Rohan indicated that the focus of her request was upon the development of policy, not upon the preceding consultation exercise. She further indicated that she would be pleased to clarify her request, to receive the information in any convenient form, and to receive information redacted to the limited extent necessary. She indicated that she was not seeking any individuals' names.

17. On the same date Ms Rohan made a request in essentially identical terms to the Home Office. As the Department of Health led on this matter, this complaint is restricted to her request to the Department of Health.

18. Eight days later, on 22 February 2008, David Winks of the Department's Customer Service Centre replied by email, declining Ms Rohan's request on s 35(1)(a), (b) and (c) grounds [page 2].

19. On 26 February 2008 Ms Rohan requested an internal review. (The original of this email has not been retained.) The Department acknowledged this request by email on 4 March 2008 [page 3].

20. 11 April 2008, before the Department's review was complete, Mitting J had handed down judgment in the High Court on the legality of Department of Health's guidance on the regulations: R (A) v West Middlesex University Hospital NHS Trust [2008] EWHC 855 (Admin) [pages 12-26]. Mitting J held that the guidance was, with regard to regulation 4(1), unlawful. Specifically, Mitting J established that failed asylum-seekers for whom removal directions have yet to be set remain, for the purposes of regulation 4(1), lawfully in the United Kingdom.

21. On 23 April 2008, a fortnight after the judgment in *R (A)* and some 58 days after Ms Rohan's request for a review, ‾ ‾ ‾ ‾ ‾ ‾ t of the Department's Freedom of Information Unit replied by email [pages 4-5]. The Department maintained its original decision, giving no new reasons other than that the lapse of time had not altered the balance of the public interest test. Ms Wyatt provided Ms Rohan with some commentary on the background to the change to the Regulation.

The test

22. It is not disputed that s 35(1)(a) of the Act (the formulation or development of government policy) is engaged by Ms Rohan's request.

23. Mr Winks expressly asserts, for the Department, that the material requested includes communications with ministers and law officers [page 2, paragraph 2]. Ms ‾ ‾ ‾ ‾ impliedly asserts the same thing [page 5, paragraph beginning 'The review is now complete']. On the basis of these assertions s 35(1)(b) and (c) are also engaged.

24. The test to be applied to the s 35(1) exemptions is the s 2(2)(b) balancing test: whether, in all the circumstances, the public interest in maintaining the exemption outweighs the public interest in disclosing the information.

The public interest in maintaining the exemption

The starting position

25. The Act creates, in effect, a presumption in favour of disclosure: *Office of Government Commerce v Information Commissioner* [2008] EWHC 774 (Admin) *per* Stanley Burnton J at [69]-[71]; *Department for Education and Skills v the Information Commissioner and the Evening Standard* (2007) UKIT EA/2006/0006 at [60-66]; *Secretary of State for Work and Pensions* (2007) UKIT EA/2006/0040 at [25]-[32]. Even absent any special public interest in disclosure, the Department must identify some particular reason or reasons with sufficient weight to displace this presumption if it wishes to rely upon the s 35(1) exemptions.

26. The Department is, by s 17(3) of the Act, required to state its reasons. In the reasons it has provided the Department has simply said, in its initial response [page 3, paragraph 3]:

> 'It is important that officials and Law Officers can provide frank advice to Ministers, and that this is as free as possible from potential public controversy arising around issues on which strong opinions are held, such as regulation 4(b).'

27. The Department's letter reporting the outcome of its internal review [page 4, paragraph 4] adds only that the lapse of time had not altered the balance of the public interest test.

28. The reason the Department has given for considering that the public interest in maintaining the exemption is a reason that applies to all internal information relating to the formulation of government policy. There is nothing particular or special about the reason as it applies to Ms Rohan's application.

29. The Department has, therefore, failed to displace the presumption in favour of disclosure.

The chilling effect of disclosure

30. The Department seems to assert that the public interest in maintaining the exemption is stronger in policy areas about which strong opinions are held. There are two problems with this reasoning.

31. First, one would be hard-pressed to identify any area of government policy-making on which strong opinions are not held. This is not a consideration that applies to any special extent to this policy change. The Department's point, even if correct, is insufficient to displace the presumption in favour of disclosure.

32. Secondly, even if the mere existence of strong opinions were sufficient to displace the presumption in favour of disclosure, the existence of those strong opinions must, in this and virtually every imaginable case in an open and democratic society, weigh more heavily in favour of disclosure than in favour of maintaining the exemption.

33. In any event the Commissioner is reminded of Deputy Chairman Mr Farrer QC's findings in *The Department for Education and Skills v Information Commissioner and The Evening Standard* EA/2006/0006 at [75] that:

(vii)   In judging the likely consequences of disclosure on officials' future conduct, we are entitled to expect of them the courage and independence that has been the hallmark of our civil servants since the Northcote-Trevelyan reforms. These are highly-educated and politically sophisticated public servants who well understand the importance of their impartial role as counsellors to ministers of conflicting convictions. The most senior officials are frequently identified before select committees, putting forward their department's position, whether or not it is their own.

(viii)   On the other hand, there may be good reason in some cases for withholding the names of more junior civil servants who would never expect their roles to be exposed to the public gaze. These are questions to be decided on the particular facts, not by blanket policy.

34. In the context of sub-paragraph (viii) immediately above, it is material that, in her initial request [page 1, paragraph 5], Ms Rohan indicated that 'I am happy to receive material that has been redacted to the minimum extent necessary to entitle me to receive it. I am not seeking any individuals' names.'

35. Finally, any 'chilling effect' on the development of policy must be most weighty during the process of policy formulation. Once this is complete (and, *a fortiori*, some years after the policy has been implemented) this consideration is, if it applies at all, very different and, in this case, much weaker: see the *Evening Standard* case at [75] sub-paragraphs (iv) and (v).

36. The Department cannot rationally conclude in this application that 'strong opinions' weigh in favour of maintaining the exemption in any special sense.

Policy development, ministerial communications and law officers' advice

37. The Department gives no particular reasons weighing in favour of the exemptions contained in s 35(1)(b) (ministerial communications) and (c) (legal advice) over and above those that are already caught within the s 35(1)(a) exemption (formulation or development of government policy). Nothing, therefore, is added by considering the s 35(1)(b) and (c) exemptions separately. The Department impliedly does not do so in the reasons it gives.

38. For the complainant it is submitted that there are, indeed, no new reasons weighing in favour of the s 35(1)(b) and (c) exemptions over and above those that are dealt with elsewhere in this document in relation to s 35(1) generally and s 35(1)(a) specifically.

39. In this context the Commissioner's attention is drawn to the observation in Philip Coppel *Information Rights* 2nd ed (Sweet & Maxwell, 2007) at paragraph 22-013 that, other than in Cabinet-related deliberations, 'the public interest in maintaining the exemption is not readily divined'.

40. Any legal advice was presumably given in connection with policy development rather than possible litigation and it is, similarly, difficult in the context of this request to conceive of any special considerations under s 35(1)(c) that are not already caught by s 35(1)(a).

The public interest in maintaining the exemption

41. In summary, there are no special reasons weighing in favour of maintaining the exemption and so the presumption in favour of disclosure is not displaced. Alternatively if, which is denied, there are special reasons favouring maintaining the exemption, they are of insufficient strength to permit the maintenance of the exemption.

The public interest in disclosure

Open policy development: general considerations

42. The Department recognises, in its response to Ms Rohan, the 'benefit in demonstrating a transparent policy making process' [page 2, paragraph 3]. This is, as a general principle, significant: *Office of Government Commerce v Information Commissioner* [2008] All ER (D) 169 (Apr) *per* Stanley Burnton J at [71]; *Secretary of State for Work and Pensions v the Information Commissioner* (2007) UKIT EA/2006/0040 at [29].

43. Further, the government has a specific, public commitment to the development of policy in a manner that is rational and, particularly, based upon evidence: Cabinet Office *Better Policy-Making* (2001) (available from: http://snipurl.com/2etlk); chapter 2 of the *Modernising Government* White Paper (1999) (available from: http://snipurl.com/2etln). The Cabinet Office's document *Professional policy making for the twenty first century* (September 1999) (available from: http://snipurl.com/2etlr) describes as 'core competencies' policy-making that is 'forward looking – takes a long term view, based on statistical trends and informed predictions, of the likely impact of policy' and policy-making that involves 'using evidence – uses best available evidence from a wide range of sources and involves key stakeholders at an early stage'.

44. In the government's *Guidelines on scientific analysis in policy making* (October 2005, available from: http://snipurl.com/2epz3) the Government Chief Scientific Advisor indicates at paragraph 2 that:

'...we must ensure that:

- key decision makers can be confident that evidence is robust and stands up to challenges of credibility, reliability and objectivity

- key decision makers can be confident that the advice derived from the analysis of evidence also stands up to these challenges

- *the public are aware, and are in turn confident, that such steps are being taken'* [Emphasis added.]

45. The same document states at paragraph 25 that 'there should be a presumption at every stage towards openness and transparency in the publication of expert advice. Departments should also ensure that procedures for obtaining advice are open and transparent. It is good practice to publish the underpinning evidence for a new policy decision, particularly as part of an accompanying press release.'

46. As well as the general public interest in transparency in the development of policy, this commitment to rational, evidence-based policy development weighs in favour of disclosure for at least three reasons.

   (i) This approach is uncontroversially proper, and disclosure allows the public, and others, to ensure that the government is indeed adopting this approach.

   (ii) Disclosure of the processes of policy development is likely to encourage future policy development to be more consistently rational and evidence-based, as it heralds the likelihood of continuing public scrutiny.

   (iii) This commitment to rational, evidence-based policy making it is a standard the government has publicly set itself, and disclosure allows the public to measure the performance of the government against the standards it sets itself.

Open policy development: Ms Rohan's application

47. The public interest in open policy development is engaged by Ms Rohan's request in at least three ways. The first is general. The other two are specific to Ms Rohan's request.

48. First, as submitted above, if this is, as the Department asserts, an area of policy in which strong opinions are held, this will normally, in an open and democratic society, weigh more heavily in favour of disclosure than in favour of maintaining the exemption.

49. Secondly, the Department's summary of responses to the consultation exercise indicates that respondents, including both the Commission for Racial Equality and the Royal Society for the Promotion of Health, criticised the consultation document for its lack of quantitative data and substantive evidence to support the proposals [page 9, fourth paragraph from the bottom]. This is of particular and legitimate concern in the context of the government's commitment, outlined above, to rational, evidence-based policy-making. One might expect the government to have considered, for example, evidence on whether removing the right of a group of vulnerable people to free health care would have consequences for public health, infectious disease control, or costs incurred by other public services. Evidence of the concerns about lack of evidence expressed by the Commission for Racial Equality and the Royal Society for the Promotion of Health, two reputable independent national bodies, weighs heavily in favour of the specific disclosure sought by Ms Rohan.

50. Thirdly, the Department's own conduct gives rise to some legitimate interest in the reasoning underlying this change of policy.

   (i) In reporting to Ms Rohan the outcome of the internal review, the Department said [page 5, first full paragraph]:

      'It has often been reported that the amendment to Regulation 4(b) was made in relation to failed asylum seekers, so that that specific group of people could no longer receive free treatment. This is not the case [...]

it was certainly not the intention to target failed asylum seekers with the amendment.'

This is, to put it at its most charitable, untrue. The consultation document spoke expressly [pages 6-7, paragraph 1.4] of the

'aim to stop the following abuses:

[...]

- free hospital care for **failed** asylum seekers (ie those whose applications and any subsequent appeals have been finally rejected) [...]' [Emphasis in the original.]

This inconsistency raises questions about the approach the government took towards reaching this policy decision.

(ii) The Department's summary of responses to the consultation exercise seeks, unusually, to marginalise some of the responses to the relevant question: 'There seems to be a lot of misunderstanding over what the proposals actually mean' [page 8, first paragraph under 'Comments']. A dispassionate reader might legitimately wonder whether those respondents opposed to the change understood the proposals perfectly well but simply expressed views inconvenient to the government. In this context the Commissioner may wish to note that the Department has failed to publish even a summary of responses to a similar consultation exercise regarding eligibility to free primary care for, *inter alia*, failed asylum seekers carried out in 2004 (*Proposals to exclude overseas visitors from eligibility to free NHS primary medical services: a consultation*). This is despite the Department having committed itself, in the consultation document, to publishing a summary of the outcome of the consultation by 12 November 2004. It is currently resisting a Freedom of Information Act request in relation to this. All of this does little to allay concerns about the approach the government took towards reaching this policy decision.

51. In summary it is submitted that the general public interest in open and transparent policy making favours disclosure unusually strongly in this application.

Unlawful guidance

52. As outlined above, the High Court held, on 11 April 2008, that the government's guidance on regulation 4(1) was unlawful: *R (A) v West Middlesex University Hospital NHS Trust* [2008] EWHC 855 (Admin) [pages 12-26].

53. This creates a further public interest in disclosure for at least three reasons.

(i) It provides further evidence of (at best) confusion within the government about the reasoning behind this policy change. The public interest in transparency in policy development therefore shines particularly strongly upon this decision.

(ii) It reveals a significant (sufficient for judicial review to have succeeded) violation of the intentions of the legislature, which enacted the parent Act and approved the Regulations, and the executive, which implements the Regulations. This represents a failure of good government, and there is a public interest in illuminating how this came about.

(iii) There is, as a result of the High Court judgment in *Re A*, now some cause for interest in establishing exactly what the government was intending in introducing this change. This is of particular and legitimate interest to those who are personally affected by it, as well as those obliged to implement it.

Disclosure may assist those individuals affected, the National Health Service, and the public generally, to understand what the government's purpose was.

54. The consequence of *Re A* is that the guidance was unlawful from the moment it was made. The s 2(2) test should be determined with reference to the moment the request was received: *Bellamy v Information Commissioner* (2006) UKIT EA/2005/0023 at [6].

55. Further, the s 2(2) test can, and here, it is submitted, should take into account matters coming to light after the date of a request where they shed light on the public interest at the time it fell to be decided: *Department of Trade and Industry v Information Commissioner* (2006) UKIT EA/2006/0007 at [46]. The judgment in *Re A* was handed down twelve days before the Department determined the outcome of Ms Rohan's request for review.

The public interest in disclosure

56. There is, in summary, a range of reasons weighing particularly strongly in favour of disclosure in the particular circumstances of Ms Rohan's request.

The application of the s 2(2)(b) balancing test

The requirements of s 2(2)(b)

57. In approaching the s 2(2)(b) balancing test, '[t]he weighing exercise begins with both pans empty and therefore level. Disclosure follows if that remains the position': *Department for Education and Skills v the Information Commissioner and the Evening Standard* (2007) UKIT EA/2006/0006 at [65].

58. The Department has, in its reasons for refusing to disclose the information requested, merely provided standard, generic reasons that may sometimes be relevant to the s 35(1) qualified exemption [page 2]. It has not, in the reasons it has given, given any evidence of having considered the specific application of the exemption in this case, nor of its reasons for reaching the conclusion it reached on the s 2(2)(b) test. It appears, in effect, to have treated the s 35(1) exemptions as absolute.

59. Moreover s 2(2) of the Act requires the Department to carry out the weighing test for each item of information in relation to which it relies upon a s 35(1) exemption. The Department's reasons, as given to Ms Rohan [pages 2 and 4], do not suggest that it has done so.

60. To quote from the Information Commissioner's *Practice Recommendation* of 31 March 2008, relating to the Department of Health (available from: http://snipurl.com/2eq1q and extracted at page 11 of the attached bundle):

> 'The Department repeatedly applies blanket exemptions to requested information with the effect of withholding entire documents from release. This suggests that rather than considering requests on their own merits, exemptions have been applied on a general principle. The Commissioner is concerned that the application of exemptions in this way may have the effect of suppressing non-exempt information from release.' [Page 11, first bullet point.]

The Department concluded its internal review into Ms Rohan's application a little over three weeks after receiving that Practice Recommendation.

61. It is, simply, highly implausible that a s 35(1) exemption applies to every single piece of information caught by Ms Rohan's carefully circumscribed request.

62. The Department has misdirected itself in law in its approach to the s 2(2)(b) balancing test.

Lapse of time

63. The Department suggested, in its letter of 23 April 2008, that 'the lapse of time has not altered the balance of the public interest' [page 4, paragraph 4]. The Department does not make it clear what lapse of time it is referring to. But, whether it is the lapse of time since the government's decision, or the lapse of time between Ms Rohan making her request and the Department completing its review, this assertion must be wrong.

64. The general public interest in transparent policy-making has not diminished in any way. The specific public increase in openness in this case has recently increased significantly, for several of the reasons given above, including the decision of the High Court in *Re A*, and the somewhat unusual circumstances, outlined above, surrounding the way in which the government has made, implemented and described this policy change.

65. Meanwhile, the public interest in maintaining the exemption can only have diminished, if period of time being considered is from the making of the decision to the moment of Ms Rohan's request. Sub-paragraphs (iv) and (v) of paragraph [75] of the decision of Deputy Chairman Mr Farrer QC in the *Evening Standard* case makes it clear that the s 35(1) exemptions apply particularly while policy is in the process of formulation, but that the situation may be very different some time after the formulation or development of a particular policy is complete. In this context, '[t]he timing of a request is of paramount importance to the decision': *ibid.*

66. The public interest in maintaining the exemption does not, for these reasons, apply anything like as strongly as it may arguably have done while the policy was being formulated.

67. The lapse of time is, therefore, material. A rational and properly-directed application of the s 2(2)(b) test at the time of Ms Rohan's request must trigger disclosure.

The correct application of the s 2(2)(b) test

68. It is suggested above that there are no special factors weighing in favour of maintaining the s 35(1) exemption. The presumption in favour of disclosure is, therefore, not displaced. Consequently the s 2(2)(b) test must, necessarily, produce the result that the public interest in disclosure outweighs the public interest in maintaining the exemption.

69. Even if there are some particular reasons weighing in favour of maintaining the exemption, it is submitted, for the reasons identified above, that there are, in the circumstances of this request, very much more weighty reasons favouring disclosure.

Conclusions

70. The Commissioner is respectfully invited to issue a s 52 enforcement notice requiring the Department to disclose the information requested by Ms Rohan.

10.7 Appendix 7 – Department of Health Response to Complaint to the Information Commissioner

(DH) Department of Health

3 July 2009

Room 317
Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 2705
Email: lynwen.paddy@dh.gsi.gov.uk

Our Ref: 279818ICO

Dear

**OUTCOME OF A REQUEST UNDER FREEDOM OF INFORMATION [FOI]
ACT 2000: CASE REF: 279818ICO**

I understand you are acting on behalf of Hana Rohan in relation to her appeal to the Information Commissioner concerning our handling of her FOI request, 279818.

Her original request, received on 14 February 2008, was as follows:

"My request relates to the 2004 amendments to the eligibility to free NHS secondary care as they affect people whose claim for asylum has failed. Specifically it relates to regulation 4(d) of the National Health Services (Charges to Overseas Visitors) (Amendment) Regulations 2004 (SI number 614).

I am seeking information, including internal communications if appropriate, held by your Department relating to the process by which that change came to be made. To be more precise, I am seeking any information that would assist me to understand what factors led to ministers making the decision they made, what weight was given to each of those factors, and why. My request relates to the development of the policy, rather than details of the preceding consultation exercise."

The Department replied on 22 February 2008 withholding the information requested under section 35 (1a, b, c) of the FOI Act.

The applicant requested an internal review of the case on 25 February 2008. She further complained to the ICO and we received a letter from them dated 18 July explaining that the case was deemed eligible for formal consideration under the Act.

As a result of on-going discussions with the ICO we have now decided to release the documents previously withheld. In addition, although the applicant

specifically stated that she was not interested in details of the preceding consultation exercise, we do feel that the consultation responses report is relevant as it led policy officials to consider the changes that were submitted to the minister. The consultation exercise and summary of responses was therefore part of the process that led to the submission being made which resulted in changes to the regulations. We are not providing a copy of this report as it is already publicly available on our website at the address below and therefore exempt from disclosure under Section 21 of the Act.

http://www.dh.gov.uk/en/Consultations/Responsestoconsultations/DH_4068337

We are disclosing the following documents with this letter:

- The submission made to the minister.
  Various paragraphs have been redacted from this document where they are considered to be out of scope for the purposes of this request. Details of these redactions can be found within the document itself.

- Two e-mails to and from the ministers private office concerning the submission document.
  We have redacted individual's names from these e-mails and replaced the key personnel with job titles only. This is in line with the applicants request that she is "not seeking any individuals' names".

- The explanatory memorandum. Unredacted.

In addition, there should be some further information which we can release that relates to the drafting of the NHS (Charges to Overseas Visitors) (Amendment) Regulations 2004 but we are currently finalising a search for this material. The explanatory memorandum which we have released to you today accompanied the final draft of those regulations.

We hope to send you any additional material, in a separate disclosure, in the near future.

We hope that you are happy with this reply.

Yours sincerely

~~~~~~~~~~~~~~~~
Freedom of Information Unit

Email address: _   _)dh.gsi.gov.uk

10.8 Appendix 8 – Documentation received from Department of Health following Decision to Disclose Documentation

Ministerial Submission

MS(H)

From: DH policy lead, Overseas visitors

Date: 3 March 2004

cc: as e-mail address list

OVERSEAS VISITORS – AMENDED CHARGING REGULATIONS

Issue

1. This submission seeks your approval of the draft National Health Service (Charges to Overseas Visitors) Regulations 2004 and the accompanying explanatory memorandum for the House of Lords SI Merits Committee. Both documents are attached.

Timing

2. Urgent. We are committed to ensuring that these regulations come into force on 1 April. For them to be laid on 10 March, the latest date for achieving this, they must be cleared and finalised by Monday 8 March.

Recommendation

3. That you approve the attached draft regulations and explanatory memorandum.

Discussion

Draft Regulations

4. The attached draft regulations put into effect changes to the hospital charging regime set out in the NHS (Charges to Overseas Visitors) Regulations 1989. This is a near-final draft still subject to final clearance by Solicitors Branch, but the substance is not expected to change.

5. The changes the regulations make are those you announced on 30 December, designed to close loopholes and tighten up the operation of the hospital charging regime, together with three others which were agreed subsequently. They cover:

    - Re-dacted as out of scope. Concerns regulation 4(4) eligibility of spouses and dependent children of exempt persons
    - Re-dacted as out of scope. Concerns regulation 4(1)(c)(ii) employment exemption
    - Re-dacted as out of scope. Concerns regulation 4(1)(e) working abroad exemption
    - changing the 12 month residency exemption so that it only applies to those living in the UK lawfully (safeguards are written into the regulations to ensure there is no risk of treatment already under way at

the time it is realised that the patient is not here lawfully being withdrawn) (reg 4(1)(d));

- changing the 12 months residency exemption so that it does not apply to anyone who was originally granted leave to enter the UK in order to receive private medical treatment (reg 4(1)(d));
- Re-dacted as out of scope. Concerns regulation 4(c)(iii) overseas students
- Re-dacted as out of scope. Concerns regulation 5 British state pensioners
- Re-dacted as out of scope. Concerns regulation 4 NHS Walk-in Centres
- Re-dacted as out of scope. Concerns regulation 7 exceptional humanitarian grounds
- Re-dacted as out of scope. Concerns regulation 8 SARS and the lists of communicable diseases.

Explanatory Memorandum

6. Under new arrangements introduced in February, all Statutory Instruments must be accompanied by an explanatory memorandum covering specific matters for the benefit of the [new] House of Lords SI Merits Committee. A draft of the memorandum to go with these regulations is also attached for your approval.

Conclusion

7. You are asked to confirm that you are content with the draft regulations and explanatory memorandum as soon as possible.

DH Policy Lead, Overseas Visitors

Departmental Emails

Here, at last, is the submission on the outcome of the overseas visitors charging regs consultation that you have been expecting, together with the draft summary of outcome. My apologies that we didn't quite manage to hit the original deadline of last Friday.

You will see that para 2 warns that there will be another sumbission in time for MS(H)'s last box before Christmas on the other issues which have arisen on the regs but which are not connected to the consultation. When we spoke last Thursday I had been considering rolling it all up into one submission, but it has proved too complicated and it would have made the paper far too long, so I have decided to keep them separate.

Let me know if you need anything further.

Policy Lead
NHS Income Generation/Overseas Visitors
4W26 Quarry House
Quarry Hill, Leeds LS2 7UE
Tel 0113-2

Attachments :
Summary outcome submission 101203.doc
Annex A - Draft summary of outcome 10-12.doc

Thank you very much for this submission. MS(H) is happy with your proposals, and would like the announcement to go ahead on 30 December. He has asked Brad to work on the media aspects, to make sure the announcement is positioned in the right way.

Because we are going for the 30th, I would be very grateful to receive the follow-up note for Thursday rather than Friday, just to be sure that it goes into MS(H)'s Christmas box.

Please give me a call if you'd like to discuss any of this,
Many thanks,

RH

**EXPLANATORY MEMORANDUM FOR
HOUSE OF LORDS SI MERITS COMMITTEE**

Title of SI

1.   The Statutory Instrument will be known as "The National Health Service
      (Charges to Overseas Visitors) (Amendment) Regulations 2004".

ECHR compatibility

2.   The Minister of State for Health has confirmed that this Statutory Instrument
      is compatible with Convention Rights.

Powers under which SI is made

3.   This SI is made using powers conferred on the Secretary of State for Health by
      section 121 and section 126(4) of the National Health Service Act 1977. These
      powers allow the Secretary of State to make regulations to charge anyone who
      is not ordinarily resident in Great Britain for the provision of NHS services.

Policy background

4.   The section 121 powers have been used only in relation to hospital services.
      The principal regulations define an overseas visitor as anyone who is not
      ordinarily resident in the United Kingdom. They place a duty on the NHS
      body providing the treatment to establish whether a patient is an overseas
      visitor and if so whether they meet any of a number of exemptions from
      charges set out in the regulations. If none of the exemptions apply, the NHS
      body is required to make and recover a charge for any hospital treatment
      provided. However, the principal regulations do not give the Secretary of State
      or NHS body powers to refuse treatment, only to charge those who are not
      eligible for free treatment.

5.   Over time, as patterns of migration and employment have changed, and
      international travel has become more common, certain elements of the
      exemption criteria have become outdated. Loopholes have appeared in the
      principal regulations which have allowed overseas visitors to access free
      hospital treatment in ways that were never intended. For example, the spouse
      and dependent children of an exempt person are also entitled to free hospital
      treatment, even if they are simply visiting the exempt person for a few weeks
      and have no intention of residing here. This Statutory Instrument makes
      changes to the principal regulations to close this and other identified
      loopholes, and to make the operation of the charging regime clearer.

6.   The overseas visitor charging arrangements have long been a matter of
      considerable public interest, particularly in terms of media coverage of so-
      called "health tourism" – overseas visitors coming to the UK deliberately to
      obtain free NHS treatment to which they are not entitled. With two exceptions,
      the changes contained in this SI were the subject of a full public consultation

exercise carried out between 29 July and 31 October 2003. Responses were received from a wide range of interested parties, including other Government Departments, voluntary bodies and individual members of the public. Whilst some responses were opposed to the changes proposed, this was often because the true implications had not been properly understood. Overall, the outcome of the consultation was broadly in favour of making the changes.

7.   Two revisions were made to the original proposals as a result of the consultation process, one in relation to the 12 months residency exemption where treatment is already under way, and the other in relation to the new exemption for overseas students where the course is funded wholly or substantially by Her Majesty's Government but is of less than 6 months duration.

8.   The two changes which were not subject to consultation are as follows:

- regulation 3, which makes treatment provided at a Walk-in Centre associated with an NHS Accident and Emergency Department free of charge for all. This is merely an administrative change to bring such Walk-in Centres into line with Accident and Emergency Departments, where treatment has always been free. The fact that Walk-in Centres are not specifically mentioned in the charging regulations is causing organisational difficulties which this change will resolve;
- regulation 7, which introduces a new exemption on exceptional humanitarian grounds. This is being introduced in order to allow HMG to continue in its practice of occasionally accepting patients from abroad (often children) where the circumstances of their injuries represent an humanitarian imperative to provide help. In the past there have been difficulties in that such patients were technically chargeable for any treatment received, even though they had been invited to the UK to receive that treatment. It is envisaged that the exemption would need to be invoked only very rarely.

Regulatory impacts

9.   The changes to the principal regulations contained in this SI have effect only in relation to charging overseas visitors for hospital treatment. They do not affect any other regulations. Patients themselves are liable to pay any charges due, so there are no impacts on businesses, voluntary bodies or others. They do not place any new obligations on NHS bodies.

Costs to the public

10.   There will be some costs to the public in that in some cases individuals who were not liable to pay for NHS hospital treatment previously (eg visiting spouses) will become chargeable and will be asked to pay. In other cases, however, eg where the new exemption for students comes into play, there will potentially be a reduction in costs as overseas students who were previously chargeable become exempt.

Costs to the Exchequer

11. There are no identifiable costs to the Exchequer arising from this SI.

Wales

12. This SI is not applicable to Wales. The Welsh Assembly Government is planning to introduce its own regulations to make the same changes as those contained in this SI.

Department of Health
March 2004.

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Variable print quality

23rd January 2003

Date: 23 January 03

Ref: 24842 IMMIGRATION AND ACCESS TO BENEFITS AND SERVICES

Issue

1. SofS has commented on Annex A & B of the departments response to the Cabinet Office paper on Immigration and Access to Benefits and Services and a full response addressing those concerns is attached as Annex A for MS(H)'s consideration.

Recommendation

2. That MS(H) writes to SofS covering the attached response to his questions and recommending that we await the outcome of the Cabinet Office review before issuing revised guidance to the NHS or amending regulations.

Illegal Entrants

3. There is a clear distinction between asylum seekers (who are able to access free primary care as they are considered ordinarily resident in the UK, and secondary/tertiary care as they are exempt from being charged by the Charging Regulations); and people who are here illegally.

5. We have no knowledge of the scale of the access but although we are aware of trusts that have identified people here without appropriate authority - this is not an everyday occurrence in every hospital. Currently there is no clear policy on how to deal with these patients. ▓▓▓▓▓▓▓▓ ▓▓ ▓▓ ▓▓

6. The legal position is not clear because if trusts were correctly applying the system of identifying those not ordinarily resident to the letter of the current guidance then it is unlikely that they would discover a patient's immigration details. Current DH advice is that all enquiries should be answered on an individual basis and in the full light of their medical and personal circumstances. Where it is thought that breaching the patient's confidentiality is in the public interest then the immigration authorities can be informed. However before doing so trusts are urged to take advise from their Caldicott guardian and legal advisers. We are aware of cases where the immigration authorities have been informed only to take no action.

10. [redacted] of the proposed amendments, subject to consultation, to the charging regulations is to include specific provision for people who are in the UK illegally.

What decisions can be made now on 'health tourism' and those who are here without proper authority?

1.1. There are regulations in place for identifying and charging those not ordinarily resident in the UK and following the Cabinet Office cross government review on 'health tourism' these regulations will be strengthened.

12. We are aware that the current system can allow those who are in the UK without proper authority to slipping through the screening process.

13. MS(H) is asked to consider the following options:

- Do not pre-empt the outcome of the review on 'health tourism' but wait until the results are published and produce a robust plan of action. Once the plan has been implemented new guidance will be roll out to the NHS in a series of roadshows.

- Distribute the revised guidance to the NHS, this has been drafted (missing a chapter on reciprocal healthcare agreements) but on hold pending the outcome of the review. This can easily be updated to take account of any policy revision.

- Go ahead with the amendments, you have already agreed, to the existing charging regulations without going to public consultation. - However the department could be criticised for not consulting on the amendments. Also if the outcome of the review requires further amendments we would be criticised for making too many amendments to secondary legislation in a such a short period of time.

1. Although we believe that this is not an everyday occurrence in every hospital,
anecdotal evidence is being reported to DH via both requests for advice from trust overseas managers who come across these people and the Overseas Visitors Support Action Group (OSVAG). ████████████████████
████████████████████ This issue is always raised at these meetings.

2. Currently there is no clear policy on how to deal with these patients. There is
no legislation restricting access to the NHS by any person, there is however legislation which allows NHS trusts to charge certain people for secondary health care. The exact status of people who are in the country illegally and the charging regulations is not clear. The regulations make no provision for people found to be here without proper authority.

3. The legal position is not clear because if trusts were correctly applying the system of identifying those not ordinarily resident to the letter of the current guidance then it is unlikely that they would discover a patient's immigration details. However, the fact remains that some trusts are identifying these patients and we believe such patients are not entitled to NHS treatment without charge as they are not legally living in the UK. They are also not chargeable under the overseas regulations. In theory they should be treated as private patients.

4. Recent discussions with the BMA and GMC at official level resulted in them agreeing to DH advice that all enquires should be answered on an individual basis and in the full light of their medical and personal circumstances. Where it is thought that breaching the patient's confidentiality is in the public interest them the immigration authorities can be informed. However before doing so trusts are urged to take advise from their Caldicott guardian and legal advisers.

Action

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• Following the review of 'health tourism' the charging regulations will be amended to make provision for people who are here illegally.

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████████████████████

Asylum Seekers (Para 4 and aspects of S of S's comments on Annex B)

1. Although we believe that this is not an everyday occurrence in every hospital, anecdotal evidence is being reported to DH via both requests for advice from trust overseas managers who come across these people and the Overseas Visitors Support Action Group (OSVAG). ███████████ This issue is always raised at these meetings.

2. Currently there is no clear policy on how to deal with these patients. There is no legislation restricting access to the NHS by any person, there is however legislation which allows NHS trusts to charge certain people for secondary health care. The exact status of people who are in the country illegally and the charging regulations is not clear. The regulations make no provision for people found to be here without proper authority.

3. The legal position is not clear because if trusts were correctly applying the system of identifying those not ordinarily resident to the letter of the current guidance then it is unlikely that they would discover a patient's immigration details. However, the fact remains that some trusts are identifying these patients and we believe such patients are not entitled to NHS treatment without charge as they are not legally living in the UK. They are also not chargeable under the overseas regulations. In theory they should be treated as private patients.

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Action

███████████████████████

- Following the review of 'health tourism' the charging regulations will be amended to make provision for people who are here illegally.

███████████████████████

Asylum Seekers (Para 4 and aspects of S of S's comments on Annex B)

5.   There is a distinction between asylum seekers and people who are here illegally and not made themselves known to the authorities. Although the 1951 UN Convention on the Status of Refugees does not specify the minimum level of healthcare to be afforded to asylum seekers, historically however the UK has provided healthcare to those seeking asylum on the same basis as UK nationals. As the numbers of asylum seekers has increased, DH's has been proactive in trying to ensure that those who have specific health and social care needs are able to access health services to meet these and to protect public health.

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7.   Asylum Seekers are able to access free primary care as they are considered as ordinary resident, and secondary /tertiary care as they are exempt from being charged by the Charging Regulations, including assessment for organ transplants and IVF treatment (subject to local provision). They do not get preferential treatment and they do not queue jump. It is currently left to local Trusts to take legal advice when faced with people who have been refused asylum, but appealed against this decision citing Article 3 of the Human Rights Act in relation to a lack of HIV availability services in their home country. This is currently a strong focus of the Cross Government Study.

Action

- Are Ministers content with the current policy approach towards asylum seekers, noting the remit of the Cross Government Study and refused asylum seekers/HIV services?

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██

[REDACTED] PS/SoS   From: [REDACTED] FID-RPA

Date: 28 January 03

Copy: [REDACTED] APS/MS(H)
[REDACTED] PS/SofS
[REDACTED] PS/PS(PH)
[REDACTED] FID
[REDACTED] FID-RPA
[REDACTED] SHSPB
[REDACTED] SHSPB
[REDACTED] SHSPH
[REDACTED] PO
[REDACTED] IPU

Ref: 24642 IMMIGRATION AND ACCESS TO BENEFITS AND SERVICES

Issue

1. SofS has commented on [REDACTED] paper of 17 January on Immigration and Access to Benefits and Services and this submission responds to those comments. Officials had a meeting with MS(H) this morning and this response takes his comments into account.

What anecdotal evidence is there of people here without appropriate authority accessing NHS hospital treatment?

2. [REDACTED]

3. [REDACTED]

4. [REDACTED]

5. The legal position is not clear because T trusts were correctly applying the system of identifying those not ordinarily resident to the letter of the current guidance then it is unlikely that they would discover a patient's immigration details. ██ ██ ██ In theory they should be treated as private patients.

6. Recent discussions with the BMA and GMC at official level resulted in them agreeing to DH advice that all enquires should be answered on an individual basis and in the full light of their medical and personal circumstances. Where it is thought that breaching the patient's confidentiality is in the public interest then the immigration authorities can be informed. However before doing so trusts are urged to take advise from their Caldicott guardian and legal advisers.

Action

- ██ ██ ████████████

- This issue is being revisited as part of the Cabinet Office review being carried out by the Cabinet Office's Economic and Diplomatic Secretariat due to report at the end of March, and will include options on general checks on entitlement to services.

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Asylum Seekers (Para 4 and aspects of S of S's comments on Annex B)

7. There is a distinction between asylum seekers and people who are here illegally and have not made themselves known to the authorities. Although the 1951 UN Convention on the Status of Refugees does not specify the minimum level of healthcare to be afforded to asylum seekers, historically the UK has provided healthcare to those seeking asylum on the same basis as UK nationals. As the numbers of asylum seekers has increased, DH has been proactive in trying to ensure that those who have specific health and social care needs are able to access health services to meet these and to protect public health.

8. Although the issues raised in the Cabinet Office paper went beyond just asylum seekers, it concluded that overall access to healthcare is likely to be trivial as a pull factor to the UK, ██ ██ ██

9. Asylum Seekers are able to access free primary care as they are considered as ordinarily resident, and secondary /tertiary care as they are exempt from being charged by the Charging Regulations, (including assessment for organ transplants and IVF treatment subject to local provision). They do not get

preferential treatment and they do not queue jump. It is currently left to local Trusts to take legal advice when faced with people who have been refused asylum, but appealed against this decision citing Article 3 of the Human Rights Act in relation to a lack of HIV services in their home country. This is currently a strong focus of the Cabinet Office review.

Action

- MS(H) has supported existing policy at today's meeting that those who sought asylum should have access to healthcare whilst their cases are pending. Is SofS content with the current policy approach towards asylum seekers, taking into consideration the remit of the Cabinet Office review and the issues around refused asylum seekers/HIV services?

Action

SofS has also asked -

What decisions can we take independently as a Department on asylum seekers ?

Confusion, though, is being caused in the NHS by the uncertain status, and the entitlement to services (including healthcare), of people who have failed in their asylum applications but who are not being removed from the country. SofS may wish to make this point to the Home Secretary. Current DH policy towards asylum seekers is set out at Annex A (para 5 – 7). does SofS want to move away from the basic approach outlined?

FID-RPA

302

31. 01. 2003
14. 45

Subject: FOLLOW UP COMMENTS TO REF:24842 AND DRAFT
SPEAKING NOTE MISC 20

RESTRICTED - Policy

Please find attached:

1. Follow up note on Immigration and Access to Benefits ansd Services addressing

SoS comments. solenote dcc

2. Draft speaking note for MISC 20 on 3 Feb including 6 point plan as requested
yesterday.

speaking note misc 20.dcc

Regards

Ref: 24642 IMMIGRATION AND ACCESS TO BENEFITS AND SERVICES

You say that the 1951 UN convention on the status of refugees doesn't specify the minimum level of healthcare to be afforded to asylum seekers. So could we within the bounds of the convention restrict entitlement to a level less than ordinary residents?

7. Solicitors are currently considering this issue, along with other related European legislation such as the European Social Charter and other relevant international obligations, such as the International Covenant on Economic, Social and Cultural Rights which commits signatories, including the UK to the creation of conditions which would assure to all medical service and medical attention in the event of sickness. S of S will be updated next week.

8. It would be difficult within the NHS to restrict entitlement for this part of our community to say emergency care only. Frontline doctors and nurses would have to make a decision on what was emergency treatment and there would be resentment and resistance in doing so.

9. The Department's current approach to asylum seekers has been to achieve a proportionate response:

- to met the needs of asylum seekers;
- to meet public health concerns;
- and to ensure that a level of provision is being put in place that will act as a pull factor.

FID-RPA

SPEAKING NOTE FOR S OF S – MISC20 ON 3 FEBRUARY

[redacted]

Cabinet Office Review

- Since our last meeting the Cabinet Office paper on Immigration and Access to Benefits and Services, which was originally prepared for the Prime Minister's Asylum Group, was circulated. This has been helpful in distilling thinking around a number of issues to do with asylum seekers and [redacted]

- Although that paper concluded that overall access to healthcare is likely to be trivial as a pull factor to the UK, I agree with a point that the Home Secretary made in relation to the paper – that access might be expected to change in the future if there is a risk that the UK might become a place to try and get to because it provides easy and free access to particular treatments which are not available in other countries.

- [redacted] is expected to take two months.

- [redacted]

- [redacted]

Further Work

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  ███
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  ████████████████████████████████████

These options will include:

3. ████████████████ Changing Regulations ████████████████████████████
   ████ the eligibility criteria ██████████████████████
   ███
   ███
   ███

4. ███
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   ███

5. ██████████████████████████████████

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- But the NHS needs help. Planning and providing appropriate healthcare provision
  for immigrant populations is problematic due to the difficulty in establishing
  patients' immigration status and identifying failed asylum applicants or those not
  being supported by NASS. ████████████████████████████
  ██████████████████████████████

- However, those falling into other categories prove more difficult. For example,
  large numbers of asylum seekers have their asylum applications turned down
  every year but are not removed from the UK. ████████████████
  ██████████████████████████████

- There are other grey areas - for example, asylum applicants that have not applied
  for NASS accommodation. ████████████████████████████████
  ██████████████████████████████████████

Restricted - Policy

From: ▮▮▮▮▮▮ Policy&Planning

2. Secretary of State

Date: 21 February 2003

Copies : MS (H)

(full copy list at end)

Cabinet Office Review of Imported Infections and Immigration

Issue

1. Briefing for your meeting with the Home Secretary, Chief Secretary and Foreign Secretary about the report on Imported Infections and Immigration, also covering 'health tourism'.

Timing

2. The Ministerial meeting is 9 am Thursday 27 February.

Summary

3. The Cabinet Office paper (to be sent separately) reflects substantial work across DH and by other departments to describe the problem of imported infection, in terms of public health risk and cost to the NHS, to explain current controls and recommend some proposals for consideration by Ministers. This submission comments briefly on the recommendations and gives further briefing on the most significant for DH, a review of the overseas patient regulations to see whether (even if fully implemented) they give the desired effect in terms of entitlement to free health care.

Recommendation

4. Lines to take on each recommendation are set out below. In addition, a steer is needed on whether to plan for early action on changes to the overseas patient regulations already agreed, or to defer this until a wider review is complete.

Argument

5. The Cabinet Office paper is now almost complete. The notes below are based on the latest draft; final text may vary.

Submission or IIIWG Paper 21 Feb

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310

Asylum Seekers' Entitlement to Services

33. In summary, there would be severe difficulties in reducing asylum seekers' access to health care below the level of 'necessary healthcare which shall include at least emergency care and essential treatment of illness', and 'necessary medical or other assistance to applicants who have special needs' which are proposed as minimum standards in a European Directive. But it would be possible to consider restricting access to elective treatments (including fertility) – though decisions would have to be made case by case.

Decisions Required

5. You are asked to:

- Agree the timetable attached as Annex A;

- Agree to distribute temporary guidance to the NHS based on the current regulations;

- Agree to the recommendation that the charging regulations be amended to provide that people who are in the UK without proper authority are not exempt from charges for NHS hospital treatment irrespective of how long they have been living in the UK.

Timing

6. Officials are beginning work on the consultation document as indicated in the timetable. Confirmation asap that you are content for us to proceed along the lines indicated would be helpful.

Current Situation

7. Anyone who is considered to be "ordinarily resident" in this country (defined by the House of Lords in 1982 as meaning a person lawfully living in the United Kingdom voluntarily and for settled purposes as part of the regular order of his life for the time being. He should have an identifiable purpose for his residence here and that purpose should have a sufficient degree of continuity to be properly described as 'settled") is entitled to NHS treatment without charge. If they are not 'ordinary resident', then they are subject to the charging regulations. These provide that anyone who has been living in the UK for twelve months or more immediately preceding their treatment is exempt from charges for any hospital treatment they may need. There is no provision to exclude people who have been living in the UK for twelve months but who are in the country without proper authority. Both SoS and yourself have indicated that this situation is not satisfactory and asked that the regulations be amended to provide that those people who are in the country without proper authority be charged for NHS hospital treatment regardless of how long they have been living in the UK.

These people will fall into three categories:

Failed Asylum Seekers (FAS)

8. People who make a formal application to the Home Office for asylum but the application is refused. They will have exhausted all the appeal processes but the Home Office will not yet have removed them from the country. The majority of these people will have been in the country for over twelve months and some may be undergoing ongoing treatment.

Overstayers

9. People who have exceeded the term for which they were granted leave to enter or leave to remain, and do not have valid entitlement to remain. They may have been in the country for twelve months or may have previously been

2

exempt from hospital charges and therefore may be undergoing ongoing treatment. For example, students who have completed a course of study and people who came to the UK for the purpose of employment but have exceeded the term of their work permit or other immigration entitlement.

Illegal Entrants

10. The main categories of illegal entrants include those who have entered the UK without leave i.e. clandestinely, and those who have used verbal or documentary deception on arrival. Many subsequently disappear into the general population. They are unlikely to readily identify themselves to trusts in these terms and may obtain treatment by saying they have lived in the country for twelve months or more. However, we are aware of occasions where trusts have identified that a person is in the country illegally.

Issues to be considered

Implementation

11. We think it is important to have a clear legal position, and that it should be based on limiting NHS entitlement to those lawfully in the country. We have never provided written advice on what trusts should do if they come across a person who is in the country without the proper authority. This has allowed trusts to exercise discretion but the lack of written policy also leaves them exposed and unsure of the legal position. Overseas visitors managers have expressed their frustration at this lack and on numerous occasions have asked for clarity on this issue.

12. It is clear, however, that this amendment to the regulations could place a legal obligation on trusts, in certain cases, to establish a person's immigration status and may leave trust overseas managers equally exposed. You have indicated that you do not want overseas visitors managers to act as though they were immigration officers and SofS has recently indicated that realistically trusts cannot be expected to check on the entitlement of every patient for every healthcare episode without a system such as universal entitlement cards, as proposed by the Home Secretary. This is particularly the case for those who had legitimately established exemption from charges at an earlier stage of continuing treatment. There are also discrimination issues to be considered – it would not be acceptable in human rights terms to introduce procedures that require trusts to deal with some patients differently from others purely in terms of what they have to do to establish entitlement to free treatment. We are currently consulting with health bodies and Immigration and Nationality Directorate on how all this will work in practice. Subject to your approval, however, our intention would be to amend the regulations in such a way as to ensure that trusts are not placed under any greater obligation to establish immigration status than they are now. Rather, if they become aware that an individual is not entitled to free treatment, either during the normal course of baseline screening or subsequently, the regulations will allow that individual to be charged, irrespective of how long they have been in the UK.

13. Revised guidance could be used to encourage trusts to note relevant dates on the documentation of a patient exempt from charges for a 'time limited' reason such as study, and to make periodic further enquiries. Trusts can also be advised to check at intervals on the current status of asylum seekers,

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with the agreement of the Home Office. But current administrative procedures will not easily support such processes and SofS's comments above apply equally here.

14. A change to the regulations will not affect genuine cases of clinical need because the NHS will always provide immediately necessary treatment to safe life. It will, however, give greater leverage in resolving problems of entitlement to ongoing health care for continuing conditions such as HIV and renal dialysis.

Status Change

15. Some people may be undergoing ongoing treatment at the point their status changes. It is essential to ensure that this transitional period is handled carefully and that any moral and ethical issues are taken into account. Clinical judgement is needed on whether treatment should be stopped or should continue, but the patient (once their status is known) should be advised that charges will be levied for continued treatment from the date their status changed. The general rule that treatment, which in a clinical opinion, is immediately necessary to save life will always apply in all cases. We will ensure that the new guidance fully addresses all of these issues.

16. People who are identified as being in the country illegally will not have been exempt from charge at any stage in their treatment. As with FAS and overstayers they may be undergoing ongoing treatment and therefore the same rules will apply with the exception that people who have entered the country illegally will be liable for the full cost of all their treatment.

17. As part of the IIWG work we are exploring ways in which communication between the NHS and the Immigration and Nationality Directorate could be improved where necessary, e.g. to make it easier to check on current legal status.

Article 3

18. You are aware of the issue of people suffering from HIV/AIDS who access treatment as visitors or students and then apply for asylum or for exceptional leave to remain on the grounds that removal from the UK (and the treatment they are receiving) will breach their rights under Article 3 of ECHR. We are currently visiting a number of trusts to talk to HIV/AIDS consultants and scope the problem and will cover this issue in a separate submission.

Conclusion

19. You are asked to:

- Agree the timetable attached as Annex A;

- Agree to distribute temporary guidance to the NHS based on the current regulations;

4

- Agree to the recommendation that the charging regulations be amended to provide that people who are in the UK without proper authority are not exempt from charges irrespective of how long they have been living in the UK.

Overseas Policy Manager

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(12)

02·04·2003
17·02·

cc: ████████████████████

Subject: MSS/M: Access to NHS treatment by non-UK residents - FIN/15/0026

████████

Many thanks for your submission. MS(H) has seen it and made the following comments:

████████████████████████████████████

In relation to amending the regulations, MS(H) has asked whether this will make a difference in practice when it will still be difficult or undesirable to ascertain the status of a patient. How will their status come to light, if staff are not going to ask questions about it?

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Ministerial

From:

To:
cc:

Subject: NHS/S; Access to NHS treatment by non-UK residents - FIN/15/0327

student submission 4-4.do REVISED TIMETABLE FOR AMENDMENTS TO CHARGING REG

Mr Hutton

From: ▮▮▮▮▮▮▮▮▮▮▮▮▮

Date: 4 April 03

Copy: ▮▮▮▮▮▮▮▮▮▮▮▮

PROPOSED AMENDMENTS TO THE NHS (CHARGES TO OVERSEAS VISITORS) REGULATIONS 1989 – OVERSEAS STUDENTS

Overseas Policy Manager

Response to MS(H)s questions following the submission of 2nd April

In relation to amending the regulations - will this make a difference in practice when it will still be difficult or undesirable to ascertain the status of a patient? How will their status come to light if staff are not going to ask questions about it?

It is our intention to change the baseline question to ask ' Have you lawfully lived in the UK for the past twelve months?' If a patient answers yes then they will be given the benefit of the doubt, as is the case now, so that the NHS cannot be accused of inappropriate discrimination. However if it should come to light at a later date, as it often does, that a person is in the country illegally then there will be a provision for the trust to apply charges. This will also apply in cases where people are acting out of the entry conditions of their visa entry. For example, if a student is given entry to study for 3 years but drops out of their course after 18 months.

Are all people regardless of status entitled to free emergency treatment?

Yes. Treatment that is provided in an accident and emergency department is free of charge to all. However, once a patient is admitted onto a ward or intensive care unit or given an outpatient appointment charges will apply. Treatment that, in a clinical opinion, is immediately necessary to save life will never be withheld because the patient cannot pay and irrespective of whether it is provided free in an A&E department or at a charge elsewhere in the hospital. Where the patient is not entitled to NHS treatment free of charge, charges will apply and will be pursued subsequently.

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PROPOSED TIMETABLE FOR AMENDMENTS TO CHARGING REGS

DATE	ACTION	TIMESCALE
	Policy decisions on amendments and guidance to be made by Ministers.	1 month
2 April	- Submission on those in country without proper authorisation	
4 April	- Submission on students	
16 April	- Submission other issues – repatriation, EEA pensioners, unaccompanied minors, Article 3	
25 April 03		
30 April 03	- Finalise guidance on existing regulations	
April/May	Draft consultation document, Obtain gateway approval, contact COMMS re funding for publication of document	1 month
9 May	Submission – draft consultation document and DA approval letter (allow 14 days for DA to respond)	3 weeks
19 May	Print consultation document	2 weeks
26 May	Issue consultation document.	12 weeks
June	Draft and issue instructions to solicitors on agreed amendments to regulations	8 weeks
21 July	Receive draft regulations back from Sol	
18 Aug	Enter consultation responses on database Submission - summary of outcome of consultation	2 weeks
1 Sept	Issue instructions to Sol based on outcome of consultation	2 weeks
12 Sept	Receive draft amended regulations back from Sol	
15 Sept	Ministers to approve final draft regulations	1 week
22 Sept	Amend guidance and leaflets based on agreed regulations	On going
22 Sept	Send regulations to Parliamentary to be made & Ministers signature	2 weeks
6 Oct	Lay regulations in parliament	21 days
End Oct	Regulations agreed	
Nov 03	Roll out new guidance and leaflets to NHS	

(15)

Ministerial ⬛⬛⬛⬛⬛

From: ⬛⬛⬛⬛ 14/04/2003 16:41:40

To: ⬛⬛⬛⬛
cc.

Subject: MSS/M: Access to NHS treatment by non-UK residents - FIN/15/0027

In relation to the 12 months residence exemption, he has commented that 12 months residence should not automatically guarantee free NHS care. ✓ He would be grateful for advice as to whether this can be amended.

(12)

28/05/2003 13:47

To:
cc:
bcc:
Subject: current guidance to be issued and update on amended regs

I have agreed with ████████████ that the revised - interim guidance - will be sent up by next Wed at the latest. Therefore grateful if I could have your comments by Mon at the latest.

Thanks

22/05/2003 13:46

To:
cc:
bcc:
Subject: current guidance to be issued and update on amended regs

Update on amended Regs

MS(H) has already agreed that those who have applied for permanent residence should not be exempt from charges during the application process. The latest submission on the amendments to the regs is with MS(H) and seeks his agreement that the regs be further amended to provide that having any claim for leave to remain should not exempt a person from charges and that this should include claims under Article 3.

Mr Hutton

NHS (CHARGES TO OVERSEAS VISITORS) REGULATIONS 1989 – MISCELLANEOUS AMENDMENTS

Issue

1. This is the third and final submission regarding amendments to the overseas visitors charging regulations. It covers the following issues:

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iii)   people who have made an application for leave to remain in the UK on medical grounds under Article 3 of the ECHR.

Discussion

Leave to Remain Under Article 3 of the ECHR

2. Currently, the regulations give an exemption to anyone "taking up permanent residence in the UK". Current guidance advises that anyone who has made an application for permanent residence be treated as exempt from the date they apply, pending the outcome of the application. You have already agreed, however, that an application to take up permanent residence is not sufficient grounds to exempt a person from charges and that the exemption should only apply once the right to remain has been granted (assuming that no other exemptions apply). This will include people who have applied for extended leave to remain, and exceptional leave to remain in the UK.

3. Similarly, you have already agreed that the 12 months residency exemption should not apply to someone who is in the UK without proper authority.

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30/06/2003 10:35

To:

cc:

bcc:

Subject: Re: MSS/S: Revisions to NHS (Charges to Overseas Visitors) Regulations 1989 - Consultation Exercise - FIN/S4/0185

Many thanks for this submission. MS(H) had a few questions and comments:

On the consultation document itself:

- fourth para, fourth bullet: MS(H) has asked at what point do we start charging failed asylum seekers. Is it when the appeals process has been exhausted, and they are waiting to be removed from the country?

Thank you again,

10.9 Appendix 9 – Key Informants Breakdown

- 2 Migrant Community Representatives
- 3 HIV Organisation Representatives
- 1 Resource Protective Thinktank representative
- 3 HIV clinicians
- 4 Refugee Sector representatives
- 3 Non-clinical NHS staff
- 1 Academic
- 2 MPs
- 1 Lawyer
- 3 Civil Servants
- 1 Journalist
- 1 GP

10.10 Appendix 10 – Topic Guide Stakeholders

Topic Guide Stakeholders

– the questions shown in this topic guide are for illustrative purposes; the actual questions asked are liable to change subject to data that emerge from other interviews. Topic guides for stakeholder interviews will not be finalised until the document analysis and interviews with the affected population have been carried out, and will be strongly informed by the data that emerge from these components of the research.

Thanks for agreeing to meet me. My name is Hana. I am a researcher at the University of London.

My research is about immigration and access to HIV and health services for people with insecure immigration status. This component of the research is interested in what you perceive the facilitators and obstacles to access of HIV services to be, and how you perceive UK policy to have influenced access to services for this population.

The interview today should take about an hour. Everything we talk about will be **confidential. You will not be identified at any point and what you say will be private.** Also, if you don't want to answer a particular question, you don't have to.

Have you got any questions before we start?

#	Question	Potential probes	Rationale
Background characteristics *Providers/Civil*		*For All: Policy Makers/Service Society/Zimbabwean Women*	
1	What is your name?		
2a	What is your position within your organisation?		
2b	How long have you held this position?		To explore each actor's experience of the relevant policy area, and relationship with the stakeholding organisation.
2c	Have you had any other jobs here or elsewhere that were related to this field?		
Health services access and use *Providers/Civil*		*For All: Policy Makers/Service Society/Zimbabwean Women*	

3a	Can you describe to me how you think asylum seekers or failed asylum seekers might access health services? Would this be the same for HIV services?	What steps would an asylum seeker typically need to take to access services?	To explore stakeholder's perceptions of whether women experience obstacles and barriers to health care, and to enable stakeholders to identify areas other than law and policy (examined below).
3b	Do you think there are barriers to access for this population? (If so) What are they? Would this be the same for treatment of HIV?	Do you consider legislation to be a barrier to access? Do service providers' attitudes facilitate or provide obstacles to women's access? To what extent do cultural/linguistic factors obstruct access to health?	To ascertain what stakeholders consider to be important obstacles to access.
3c	Do you think that asylum seekers/failed asylum seekers experience things that help them to access health care/HIV services? Do you think that there might be gender differences in this?	Do women experience things that help them to access health care? What kind of things? In your opinion, what are the main facilitators to access for this population? How much do [any facilitators that you identify] improve their health? Do service providers facilitate women's access? How? Does legislation help women access health care services in any way? To what extent do cultural/linguistic factors facilitate access to health?	To explore stakeholder's perceptions of whether women experience facilitators to health care access/ To ascertain what stakeholders consider to be important facilitators to access.

3d	Do you think funding to HIV services has declined/fallen off in recent years?	Why do you think this is? What do you think the consequences of this are?	

Service providers' knowledge and attitudes
For Service Providers only

4a	Have you ever come into contact with people with insecure immigration status? If so, can you describe any particular issues or problems that you felt affected this population (in terms of accessing services)?	*Probing will then take place according to the flow of he interview, on the topics below:*	
4b	Have you had any particular problems in treating individuals with insecure immigration status (i.e. problems you would not experience with a person who had residency)?	What are these?	To explore difficulties that service providers might face when treating individuals with insecure immigration status
4c	What do you consider were the main cause of these sorts of issues?	I.e. Cultural factors/legislation or policy/societal attitudes/women's attitudes/other	To explore service providers' attitudes/beliefs as to the origin of difficulties for people with insecure immigration status
4d	In your opinion, do service providers communicate appropriately with patients with insecure immigration status?	Are language issues ever a problem? Are there ever problems communicating with patients that are not necessarily linguistic? Can you identify any possible solutions to these problems?	To investigate issues around cultural competence
4e	What would make it easier for you to do your job when you are seeing a patient with immigration issues?	What changes could be made by patients/other services/other clinicians/policy that would help?	To explore service providers' attitudes to the way that people with insecure immigration status might affect their practise
4f	Focussing on the issue of immigration status in particular (i.e. not language/cultural/other issues), how far do you think	Does immigration status matter for health? What else influences treatment for this	To explore the extent to which service providers see having insecure immigration status as affecting care

		population (HIV positive women with insecure immigration status)?	
	that impacts on the treatment an individual might receive?		

Law and policy		*For all stakeholders – not Zimwim*	
5a	Do you know of any specific laws or policies that are pertinent to this population's access to health services/HIV services?	Have you heard of the 2004 changes to the NHS (Charges to overseas visitors) Regulations? If so, what do you understand these changes to mean? Have you heard of 'section 4' of the 1999 Immigration and Nationality Act/'Hard Case' support? If so, what do you understand section 4 or hard case support to be?	To explore knowledge of policy
5b	To what extent do you consider law and policy to be a barrier or facilitator of access to health/HIV care?	Do you think these policies have influenced the way asylum seekers/failed asylum seekers access services? Is law and policy an important determinant of access to health for this population? What else do you think is an important factor?	To ascertain where in a hierarchy of factors law and policy are held (by stakeholders) to determine access to services
5c	Which policies/policy changes do you consider to be most important? Why?	NHS (Charges to overseas visitors) Regulations/Consultation on primary health/Immigration law/Country specific asylum policies/APIs/NASS policy bulletins	To examine which policies are considered to be most important in determining access
5d	Can you describe to me what it was that changed with the 2004 amendments to the NHS (Charges to Overseas Visitors) Regulations ?	Why did these changes occur, in your opinion? *(Financial/political/public opinion/ media pressure/fears*	To explore the perceived motivations for recent policy changes

		over health tourism/other??) (Was interviewee in office at that time?): Can you tell me a bit about this policy's formation?	
5e	In your opinion, which factors are most crucial in affecting immigration legislation/policy in the UK?	Public opinion/media/political ideology/other	To explore what stakeholders consider to be important in the development of immigration legislation in the UK
6a	Are you aware of a Department of Health 2004 consultation on charging failed asylum seekers and undocumented migrants for primary care services?		
6b	If yes, why do you think these changes have been proposed?	Are the reasons for the proposal financial? Is there a political component? Why do you think this might be?	*To explore what stakeholders consider to be the intentions behind the proposal to restrict statutory access to primary services for undocumented migrants and failed asylum seekers*
	How far has the policy halting returns to Zimbabwe affected asylum applications for this group?	To what extent has the ban on deportations been observed by immigration officials (e.g. Malawi passports)? Will the Home Office continue to challenge the judgments made in the case of AA, in your opinion? Would a change of regime in Zimbabwe immediately reverse the ban?	
	What is your understanding of Article 3 claims for asylum made by HIV positive Zimbabwean nationals? What is the stance of the BIA/Home Office regarding Article 3 claims on this basis?	Case of N, European Court. How to accommodate the conflict between human rights (i.e. avoiding inhuman treatment by deporting to drugs vacuum) and	

		'national' character of health service/limited resources?	
	To what extent has New Labour's emphasis on joined up government/working impacted on enforcement?	Is immigration an especially 'joined up' policy area, relatively speaking? I.e. Health charging regulations are an example of immigration enforcement by a non-Home Office department. How do you think other departments feel about their responsibilities to immigration enforcement?	

6c	What are the potential benefits to you and your organisation if the Department of Health were to go ahead with this proposal?	Do you support this proposal/all aspects of this proposal? In what manner would you demonstrate this support (publicly/other)?	To explore how the proposed legislation is perceived by relevant actors
6d	What are the potential disadvantages to you and your organisation if the Department of Health were to go ahead with this proposal?	Do you support this proposal/all aspects of this proposal? In what manner would you demonstrate this support (publicly/other)? If object to proposal: In what manner would you demonstrate this opposition?	To explore how the proposed legislation is perceived by relevant actors
6e	Who are the likely beneficiaries from the proposed policy (if it were to go ahead)?	I.e. can you identify any other actors (other than you/your organisation) who would benefit? In what way?	To explore which actors stakeholders perceive to have an interest in the policy.
6f	Who are the likely losers from the proposed policy (if it were to go ahead)?	I.e. can you identify any other actors (other than you/your organisation) who would lose out? In what way?	To explore which actors stakeholders perceive to have an interest in the policy.

Is there anyone else in your field that you think I should speak to about these issues?

10.11 Appendix 11 – Topic Guide Zimbabwean Women

Topic Guide Zimbabwean Women

– the questions shown in this topic guide are for illustrative purposes; the actual questions asked may change subject to data that emerge from other interviews.

Thanks for agreeing to meet me. My name is Hana. I am a researcher at the University of London. What would you prefer I called you?

I'd like to talk to you today about your experiences of health services since you've been in the UK, and how your life is affected by being HIV positive and having immigration problems.

The interview today should take about 60-90 minutes. Everything we talk about will be **confidential. You will not be identified at any point and what you say will be private.** Also, if you don't want to answer a particular question, you don't have to and if you feel uncomfortable or find it difficult to talk about things **we can stop the interview at any point.**

Have you got any questions before we start?

#	Question	Potential probes	Rationale
	Demographics and background information	*I'm just going to ask you some introductory questions before we start, but please don't worry – no one other than me will ever hear your answers.*	
1a	How old are you?		
1b	What area of the city do you live in?	(Not your actual address)	
1c	What is your religious affiliation?	Protestant/Anglican/Catholic/Islam/Orthodox/None/Other	
1d	What is your highest educational qualification?	None/O-levels or GCSEs or equivalent/A levels or equivalent/University degree or higher/Other, such as professional or vocational qualifications	
	Health services: access and use	*I'm now going to ask you some questions about your experiences of health services in the UK. Please remember that anything you say to me is completely confidential and will not affect your health care.*	

2a	Do you attend an HIV clinic? (if yes, continue with questions. If no, see grid below)	How did you hear about this service? Were you referred to this service? Did you have any difficulties coming to, signing up for this service?	To get information about referral resources, the way women might hear about HIV services
2b	Have you been to any other clinics before that?	If yes, did you experience any problems in the transfer between clinics? Do you feel your health has ever been affected by where you have lived in the UK?	To explore possible dispersal issues/continuity of care
2c	How did you feel the first time you came to this clinic?	Were you nervous, happy, etc? Has the way you feel about the clinic changed over time? If so, why do you think this is?	Tries to identify some of the emotional/cultural barriers that may affect women's access
2d	Do you use any other health services?	E.g. GP, walk-in clinics, other outpatient services. Has communication between these services been effective?	To identify other services that women use/to explore coordination between services
2e	How do you feel about the care that you receive at the clinic?	Do you find it easy to communicate with staff here? Is there anything that would make your experiences at this clinic easier/better?	To explore satisfaction with services
2f	Do you find it easy to understand what clinic staff tell you about your anti-HIV treatments?	Do you ever ask questions when you don't understand what they are saying about anti-HIV treatments/HIV itself?	To explore communication/cultural competence

2g	How would you describe your health at the moment?	Has there been any change in your health since you started coming to this clinic? Is there any aspect of your health you feel is not well cared-for?	To explore perceived/ evaluated health
	Health services: access and use (if not accessing a clinic)		
	Would you like to be attending a clinic regularly?	What prevents you from attending a clinic? (Entitlement/distance/don't want to etc) Have you ever been to an HIV clinic in the UK?	To explore what barriers to access of secondary services might be
	Have you ever received any healthcare in the UK?	Do you have a GP? Have you ever been to an emergency department? Have you ever been to hospital for any reason in the UK?	To explore use of services more generally
	Have you ever received any help with seeing a doctor here in the UK?	Has the Home Office/charities/support groups/GP tried to refer you to an HIV clinic? What happened?	To explore what might facilitate access to any services
	Resources	Life in the UK can be very challenging at times, I would now like to ask you some questions about your lifestyle here.	
3a	How do you support yourself?	Where do you get money to live off? What organisation do you receive that from? Since being in the UK, have you always received support from that organisation? Have you ever been given money under the voucher system? Do you do any paid work?	To identify what financial resources she has available to her
3b	How would you describe your accommodation?	How long have you lived in London? Have you always lived in London, since arriving in the UK? Where else have you lived? Did you choose to live there? How long have you lived in that house/flat/b&b? Is it rented/NASS/a friend's house?	To explore satisfaction with accommodation/home environment/ To investigate whether she has

			been dispersed
3c	Who else lives in your household?	Family/friends/other asylum seekers (male? female?)/children/staff? **Do you have a partner/children who live somewhere else?** Where do they live?	To get information about home life/house hold structure/ whether she has children to care for./ To get information on marital status/pari ty, and whether she has been separated from her family
3d	Do you have anyone outside of your family that you can go to for support?	Friends? Do you go to church/community organisation/peer support group? How do you find this helpful? If church, do friends there know about your HIV diagnosis?	To investigate whether she has any social support networks
3e	Do you get any help local to where you live?	E.g. council support services/support provided within accommodation/Health services resources/Social services resources/Charitable or NGO resources. How helpful do you find these services? (If no): What local support would make managing your illness easier?	To explore community resources
	What made you start coming to the Zimbabwean Women's Network?	How did you hear about it? What help/support do you get from ZimWim that you don't get elsewhere? Do you know of any other similar groups? Would you recommend to a friend who was	To explore the role of informal networks/ NGOs in service delivery and access

		having problems with seeing a doctor/accessing health care to come to ZimWim? Why?	
3f	In thinking about your life in the UK, what do you think most affects your health or your ability to take care of yourself.—good or bad?	E.g. Food or nutrition/transport/having access to a telephone or computer/housing/. How could these things be improved? **What do you do when you feel upset?** *Added on basis of first round of interviews*	To explore how the presence or absence of material resources can affect access or use of health services
3g	What is your current immigration status?	Waiting for decision on application/Going through appeals process/receiving section 4 ('hard case') support/other	
3h	How long have you lived in the UK?	*(Remember that this interview is completely confidential)* Have you lived anywhere other than the UK and Zimbabwe? Do you feel differently about the UK than you did when you first arrived?	To explore acclimatisation/acculturation
	Perceptions and knowledge	Now I am going to ask you some questions about your HIV status and the care you receive.	
4a	Can you explain to me what have you been told about HIV, as a disease?	How it is transmitted, what it does in your body, how the medications work.	To identify her knowledge of HIV, to learn how well she has been informed.
4b	Where/how did you learn this information?	Was there anything that was particularly difficult to understand?	To learn about women's sources of information that may affect their help-seeking patterns.

4c	How do you feel about the medications/treatment you have received in the UK/at this clinic?	Are you happy with the treatment you are receiving? What would you change about your treatment, if you could? How often do you come to clinic? Is that enough/too often?	To explore attitudes towards health services
4d	Who have you told about your HIV diagnosis?	Does anyone other than the clinical team here at Homerton know about your diagnosis? Is there anyone that you would like to be able to tell, but you feel unable to? Why did you choose to tell this person(s)? What do you think would happen if you told friends/family/pastor/church group?	To explore issues around stigma
4e	What have you been told about the types of health services you are entitled to, or may receive in the UK?	What is your current immigration status? Are you allowed to register with a GP? If you felt ill or had a health problem (not related to HIV), where would you go to seek help? As far as you know, what services or treatments must be paid for?	To explore her knowledge of her entitlements
4f	Do you think that men and women have different experiences of living with HIV in the UK?	*Make it clear that I am talking about Zimbabwean men with insecure immigration status.* In terms of e.g. how they access care/how they are received or treated by health services/how HIV affects their lives/how HIV medications affect their lives, etc.	To explore her perception of differences between men and women in terms of access and use of services.
	Health behaviour	Now I am going to ask you some questions about your HIV diagnosis. Please remember that you are free to stop the interview at any time, and that anything you do tell me will be completely confidential.	
5a	Can you talk to me about the medications you take?	What medicines (if any) are you taking at the moment? How often do you have to take them? How long have you been taking them?	To identify the medications, how she might feel about them.

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5b	Do you have any difficulty following the medication regimen prescribed by the doctor/taking this medication?	Remembering to take it, swallowing the pills, side effects, taking with food, social life interferes, working life interferes, refrigerating medicines.	To identify issues affecting compliance
5c	Does anyone/every one else in your household know you are taking these medicines?	If not, is it sometimes difficult to take them without other people finding out? What measures do you take to stop other people finding out?	To explore relationship between disclosure and compliance
5d	Other than taking your HIV medicines, what other things do you do to look after your health?	Food, other health issues, etc	To explore her self-care tactics
5e	Are there ever times when the medication makes you feel unwell? When you do not feel well, what is the first thing that you do?	Look after yourself/ask a friend for advice/go to pharmacy/go to walk-in clinic/make appointment with GP/make appointment with HIV clinic/other outpatient service/go to A&E/other. If that doesn't work, what would you do next?	To explore health seeking behaviours
5f	Do you ever go to anybody else for treatment?	I.e. non-NHS doctors/healers? Do you ever take any herbs when you are unwell? Does the (non-NHS) doctor make you feel better? What does he/she do that helps?	To identify whether she uses any alternative health care/beliefs around alternative healthcare
	Concluding questions		

6a	If you could talk to the health minister here in the UK, what would you say?	How do you think that the way that the UK deals with immigration and immigrants has affected the way that you get care?	To give her the opportunity to give her perspective on UK policy.
6b	Is there anything else that you'd like to tell me that we haven't talked about today?		

Participant Information Sheet

Study Title: HIV and Immigration policies: The experiences of Zimbabweans in the UK

Investigator's Name: Hana Rohan

Investigator's email address: hana.rohan@LSHTM.ac.uk

Investigator's phone number: 07943 368 291

You are being invited to participate in a PhD research study. Before you decide if you would like to take part in the study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

This study is part of a PhD that is looking at how policy relating to access to HIV services for insecure immigrants in the UK has been formulated and implemented, and in particular on the impact of immigration and health policy in the UK on access to HIV services for Zimbabwean HIV positive women with insecure immigration status.

I am particularly interested in your perceptions of access to HIV services for women with insecure immigration status in the UK, and how you think immigration and health policies may have influenced access and health in this population.

You have been chosen to take part because you are considered a key informant for this issue. About twenty other key informants will also be interviewed.

If you agree to take part, we will arrange a time and place convenient to you for the interview to take place.

It up to you to decide whether or not to take part in this research. If you do decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time without having to give a reason why.

The interview will last for around one hour.

With your permission, the interviews will be recorded using a digital dictaphone, and the recording will be transferred onto a computer. Written

notes of your responses in the interview may also be made - again, with your permission.

All information which is collected about you during the course of the research will be kept strictly confidential, and will normally only be seen by me, Hana Rohan. If other people (such as academic supervisors) involved in the research need to see it, any information which could identify you (such as your name or address) will be removed first.

The research will be published next year, as a series of papers and then as a PhD thesis.

Every effort will be made to ensure that you will not be identifiable in the papers or thesis — for example, if any quotes from your interviews are included, they will be attributed only to your professional role e.g. 'Service Provider 1'/'NGO worker 7'. You will have the choice of whether or not you are prepared to be quoted, even anonymously, in any reports on the study.

The information collected about you will be kept for a period of time after the papers and thesis have been published, and will then be securely disposed of.

When the research is finished, if you want to be contacted with results from the study, let the researcher know at the interview's conclusion.

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions.

Provision has been made for insurance or indemnity to cover the liability of the investigator and sponsor which may arise in relation to this research study.

This study is funded by the Economic and Social Research Council, and has been organised by Hana Rohan[90], Dr Jane Anderson[91], Charlotte Watts[1] and Cathy Zimmerman[1].

This was given a favourable opinion for conduct by the Ethics Committee at the London School of Hygiene & Tropical Medicine and the East London and the City Research Ethics Committee

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[90] London School of Hygiene & Tropical Medicine
[91] Homerton University Hospital NHS Foundation Trust

Participant Information Sheet

Study Title: HIV and Immigration policies: The experiences of Zimbabweans in the UK

Investigator's Name: Hana Rohan

Investigator's email address: hana.rohan@LSHTM.ac.uk

Investigator's phone number: 07943 368 291

I would like to invite you to take part in a PhD research study. Please take some time to read this information sheet before you decide to take part. You don't have to decide anything today. Please talk to family or friends about the study if that would help you to make up your mind. If you do agree to take part, you could be interviewed today, or at another time that you can choose.

My name is Hana Rohan, and I am a researcher at the University of London. I am doing a research study as part of my PhD looking at health and access to services for Zimbabwean women who are HIV positive and who have immigration problems. I am interested in how hard it is for women in this position to see doctors and get medical help in London.

I am inviting you to take part in this study because you are a Zimbabwean woman, who is involved with the immigration system and who is HIV-positive. I am particularly interested in your everyday life: how might it be affected by HIV, and by your immigration status?

It is up to you to decide whether or not to take part in this research. If you do decide to take part, I will give you this information sheet to keep and I will ask you to sign a consent form.

You can change your mind and say you do not want to be part of this project at any time without having to give a reason why. **Please do not be afraid that this will affect the treatment you may be receiving, or your immigration situation in any way. It will not.**

If you do decide to take part, I will ask you to meet with me at the Zimbabwean Women's Network offices in Isleworth, or in central London (you can say which place) for an interview.

Interviews will last for around an hour, and we will be talking about your experiences of living with HIV in the UK and about your immigration status. If you find some of these things difficult and upsetting, you don't have to talk about them. And if you don't like my questions, you don't have to answer them. Just tell me you don't want to answer.

If you let me, I will record the interviews with a digital recording device, and the recording will be transferred onto a computer. Nobody but me will see the information that I collect while I am doing my research, and nobody but me will know who you are. If other people (such as academic supervisors) involved in the research need to see it, any information which could identify you (such as your name) will be removed first. The research will be published next year in the university. If I include anything you have said to me in the interviews, I will make sure your name is not mentioned. Nobody will be able to identify you at all. You will have the choice of whether or not you are prepared to be quoted, even anonymously, in any reports on the study.

If it costs you any money to take part in the research, because of travel, or the costs of a meal while you are being interviewed, or paying for childcare, I will pay you back.

When the research is finished, if you would like to know about the results of the study, I will be giving a copy of the report to the Zimbabwean Women's Network for them to make available to clients. If you want one mailed to you, I am happy to take your contact details and send you a copy. The research will be published at the University. If I include any quotes from your interviews, I promise I will not use your name or anything else that could identify you. The information collected about you will be kept for a period of time after the papers and thesis have been published, and will then be destroyed.

I cannot promise the study will help you, but the information I get might help improve the situation for other people in your situation in future.

If anything worries you about this study, please ask me and I will do my best to answer your questions.

This was given a favourable opinion for conduct by the Ethics Committee at the London School of Hygiene & Tropical Medicine

10.13 Appendix 13 – Consent Forms

<u>Consent Form Key Informants</u>

Consent Form

Study Title: Use of, and access to HIV services for Zimbabwean women in the UK with uncertain immigration status.

Investigator's Name: Hana Rohan

Investigator's email address: <u>hana.rohan@LSHTM.ac.uk</u>

Investigator's phone number: 07943 368 291

I have read the information sheet concerning this study [or have understood the verbal explanation] and I understand what will be required of me and what will happen to me if I take part in it

My questions concerning this study have been answered by Hana Rohan.

I understand that the interview will be recorded unless I specifically ask for it not to be.

I understand that at any time I may withdraw from this study without giving a reason.

I am happy to be quoted anonymously in any reports or publications (Yes/No).

I agree to take part in this study

Signed .... Date ....

Consent Form

Study Title: Use of, and access to HIV services for Zimbabwean women in the UK with uncertain immigration status.

Investigator's Name: Hana Rohan

Investigator's email address: hana.rohan@LSHTM.ac.uk

Investigator's phone number: 07943 368 291

I have read the information sheet concerning this study [or have understood the verbal explanation] and I understand what will be required of me and what will happen to me if I take part in it

My questions concerning this study have been answered by Hana Rohan.

I understand that the interview will be tape recorded unless I specifically ask for it not to be.

I understand that at any time I may withdraw from this study without giving a reason and without affecting my normal treatment.

I am happy to be quoted anonymously in any reports or publications (Yes/No).

I agree to take part in this study

Signed .... Date ....