

Healthy-illness representation of HIV
in the UK

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PHD

2013

Abstract

Title: Healthy - Illness Representation of HIV in the UK

The purpose of this research was to explore the interactions between the perceived healthcare needs of people with HIV and the processes involved in their healthcare in order to inform future models of care. A grounded theory approach was adopted utilising semi-structured interviews with 13 HIV patients and 21 healthcare workers in 3 HIV facilities of different size and service specification. Constant comparative analyses of concepts that emerged from the data were undertaken and a dimensional analysis strategy applied to develop conceptual categories and the connections between them.

HIV as a condition was conceptualised in different ways by patients and healthcare workers. Although most patients viewed their condition as stable, previous illness experience, uncertainty and the impact of HIV on social integration influenced their views on the role of HIV services. Patient-provider relationships, feeling accepted and participating in care was central to maintaining high levels of patient engagement within the HIV setting. This was in contrast to the felt or enacted stigma experienced by most patients either in other healthcare settings or in their communities and challenges current theory that advances in treatment have reduced the social stigma of HIV.

The service user illness representations were not necessarily reflective of HIV service provider views on the health status of medically stable patients or of funding mechanisms for HIV healthcare. A theory of illness representation has been developed utilising the principles of Leventhal's model adapted for service planning. While HIV clinics were actively adapting services, the pervasive experience of HIV for some stable patients suggests that representations of HIV span a healthy-illness spectrum comprising a complex range of cognitive and emotional processes. These representations influenced how HIV healthcare services were organised and utilised and may be a useful tool to inform healthcare delivery and sustain quality and public health outcomes.

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Acknowledgements

I am very fortunate in having a lot of people to thank for their contribution and support during the development of this thesis.

Firstly, I would like to thank the patient participants who came forward for the study and for their invaluable contribution to the findings of this research. Many thanks also to the healthcare workers who participated in the interviews and took the time to explore their practice with me. I would also like to thank the research site hosts who gave me a great deal of support in navigating the approval systems and the staff in the research sites for accommodating me and making me feel part of the team.

The research findings were greatly enhanced by the contribution of my Patient Advisory Team; Angelina Namiba; Paul Clift; Robert Fieldhouse and Robert James. I thank each of them for their consistent support throughout the study. Their personal expertise and national perspective of HIV through their advocacy roles were integral to informing the planning, data collection and theory development of this research.

Many thanks to my academic supervisor, Professor Julie Scholes, for her attention to detail, her wisdom and methodological expertise. Many thanks also

to Professor Martin Fisher, my clinical supervisor, for his amazing and extensive expertise in the field of HIV and his ability to spot discrepancies in my argument.

A big thank you to my colleagues and friends who adopted the role of critical friends and who provided invaluable insights into my working hypotheses that helped me to articulate and reflect on my findings. Finally, a huge thank you to my immediate family, extended family and friends for their patience, tolerance and support which sustained me throughout the duration of this research.

Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. This thesis has not been previously submitted to this or any other university for a degree and does not incorporate any material already submitted for a degree.

Signed:

Dated:

Terms and abbreviations

ADHERENCE	Adherence is the term used to describe the ability of patients to stick to their antiretroviral therapy regime and consistently taking the right dose at the right time in the correct way. In order for antiretrovirals to achieve their maximum effect it is estimated that they need to be taken correctly 95% of the time.
AIDS	Acquired Immune Deficiency Syndrome. This commonly occurs when HIV is left untreated and is characterised by serious and often life threatening infections as a result of a compromised immune system.
ARVs or ART	Antiretrovirals or antiretroviral therapy. These are the medications used to control HIV infection.
CD4 CELL	A cell that deals with certain types of immune function. HIV uses these cells to reproduce and then destroys them. A CD4 count of below 350 cells/mm is associated with depleted immune function and in the UK treatment is recommended before the CD4 cells fall below 350 cells/mm. Immune function is more effective the higher the CD4 count.
HIV	Human Immunodeficiency Virus. HIV is transmitted by exposure to the blood or body fluids of an infected person.
HAART	Highly Active Antiretroviral Therapy refers to a combination of at least 3 active antiretroviral viral drugs that are capable of reducing HIV viral replication to below the defined level of detection in the blood.
OPPORTUNISTIC INFECTION	An infection that is associated with immune dysfunction in AIDS.
VIRAL LOAD	A measure of the presence of HIV usually in the blood stream. The goal of HIV treatment is to reduce the viral load to below 40 copies/ml. At this level, the risk of HIV transmission is negligible.

Section 1: Introduction and background to the research

Introduction to the thesis

On 15th June 1981, the first case of Acquired Immune Deficiency Syndrome (AIDS) was reported in the UK (Health Protection Agency 2011d). Three years later the Human Immunodeficiency Virus (HIV) was identified as the virus that caused AIDS and antibody testing for HIV subsequently became available (Ranga 2009). Over the following fifteen years HIV/AIDS was associated with high levels of morbidity and mortality particularly among gay men in the prime of their lives.

The initial response from the UK government included a widespread publicity campaign warning of death and ignorance and promoting condom use and needle exchange programmes (House of Lords 2011b). The media created images of infection and deviance and mainstream society recoiled (Cullen 2003). Ambulance drivers refused to take people with AIDS to hospital and healthcare workers donned fully protective clothing including masks and visors. People with HIV were reliant on finding empathetic healthcare workers with a special interest in order to access treatment for life threatening conditions. The provision of support, counselling and end of life care was largely funded through charitable donations from discrete sectors of society.

Over the past 30 years, HIV has become a more treatable chronic condition (British HIV Association 2012) and healthcare services for people with HIV have evolved in response to this. This thesis is based on the experiences of people with HIV and healthcare workers and presents an academic theory of HIV as a long-term condition in the current UK setting.

The thesis is divided into four sections. This first section will present the background to the HIV epidemic in the UK and the rationale for undertaking the research. Section 2 will examine the theoretical perspective and methodology and demonstrate the application of the study design. The findings and substantive theory will be presented in Section 3 and the thesis will conclude with a discussion and considerations for future HIV services in Section 4.

Chapter 1: Introduction to the research

1.0 Introduction to the chapter

“We have to remember that history will judge us not by our scientific breakthroughs, but how we apply them”

Michel Sidibe, Executive Director of UNAIDS

There have been considerable changes to the management of HIV/AIDS over the past three decades due to the advent of combination antiretroviral treatment in 1996 (Hammer 1996; Palella, Baker, Moorman et al. 2006). This breakthrough in treatment has had a huge impact on reducing mortality and the burden of illness from AIDS related infections worldwide. Since then there have been further scientific advances in the co-formulation of antiretroviral agents (Clotet, Carmena and Pulido et al. 2004; Goicoechea and Best 2007) and in the development of new drugs with new modes of action (Wilkin, Su and Kuritzkes et al. 2007; Steigbigel, Cooper and Kumar et al. 2008). As a result of these technological achievements, the focus of HIV healthcare has dramatically changed from terminal care to chronic disease management (Hammer 1997; Van Sighem, Gras and Reiss et al. 2010; Joint United Nations Programme on AIDS 2011).

In spite of the on-going advances in the treatment of HIV infection, the challenge in applying these lies in delivering and sustaining treatment and care programmes for people with HIV globally within financial and health system constraints (Joint United Nations Programme on AIDS 2012). In the UK, where access to HIV treatment and care is free, disease outcomes have reached a high standard and there are excellent rates of patient retention in care in comparison to many other developed countries (British HIV Association 2012; Health Protection Agency 2012). However, as the epidemic matures in the UK, the needs of people with HIV are changing within a spectrum of chronic disease manifestations (British HIV Association 2007; House of Lords 2011b; National AIDS Trust 2012). There is a scarcity of academic theory on how healthcare services respond to HIV as a long-term condition and what models of care may be required in the future to sustain current disease outcomes within the financial constraints of the current healthcare environment.

The purpose therefore of this research was to generate an academic theory that explains what is involved in receiving and delivering HIV healthcare in order to inform future models of care.

This chapter will commence with an overview of HIV in the UK and present the preliminary literature review. It will conclude with a summary of what is currently known and a review of the gaps in knowledge that are to be addressed by this research.

1.1 Researcher perspective

I have worked as a nurse in the HIV speciality since 1988 and have undertaken a variety of roles in HIV care across a number of different healthcare settings including statutory and voluntary sectors. I therefore have had a close biographical relationship with the HIV epidemic in the UK.

My perspective as a Nurse Consultant in HIV over the past eight years has informed this research from my clinical, educational, professional and service delivery experiences. My clinical work with both medically stable patients and with those who have more complex problems has influenced my perception of the needs across patient groups. As chair of a working group that developed national competencies for HIV nurses, I have been actively involved in defining nursing skills and linking clinical competencies with key HIV policy. My involvement with national HIV nursing issues and international educational partnerships has exposed me to different models of HIV service delivery and the potential contribution of nurses to the multidisciplinary care of people with HIV. I was conscious that I did not know or understand the situated perspectives of others in relation to this.

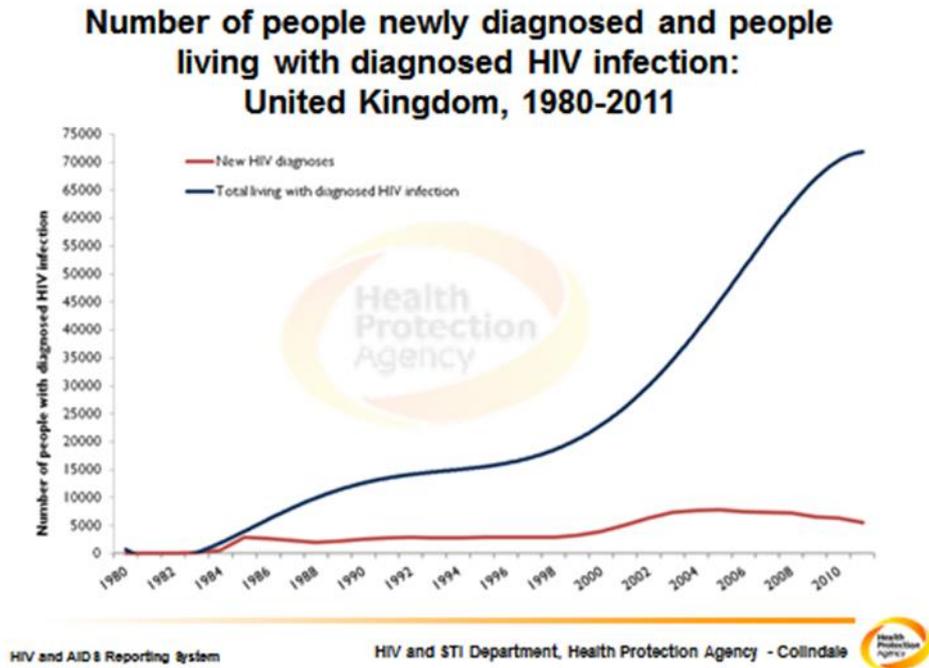
I was therefore sensitised to many of the issues in HIV healthcare that needed to be explored to uncover the main concerns of patients and healthcare workers. This research created an opportunity for me to approach the topic area from multiple perspectives and to utilise these perspectives to build a substantive

theory. The strategies taken to address the potential influence of my experience and views on the research findings will be discussed throughout the thesis and again in the final chapter.

1.2 Overview of HIV infection in the UK

1.2.1 Increasing numbers with HIV infection

There were an estimated 96,000 people in the UK infected with HIV by the end of 2011 (Health Protection Agency 2012) of whom 24% were unaware of their infection. Currently, a total of 73,400 people have been diagnosed with HIV of which 6,280 were newly diagnosed in 2011 (Ibid.). Although the number of new HIV diagnoses has steadily declined over the past seven years, 16% of people newly diagnosed in 2011 had acquired their infection within the previous six months; that indicates on-going transmission of the virus through sexual contact (Ibid.). These figures highlight the continuing rate of HIV infection in the UK and the public health concerns regarding the on-going sexual health transmission of HIV. Figure 1.1 shows the increase in the total numbers of people diagnosed with HIV since 1980.



Source: Health Protection Agency 2012

Figure 1.1: Increase in the numbers of people with HIV infection in the UK

The success of HIV treatment has significantly improved the life expectancy of people with HIV in the UK although it is still below the average life expectancy of the general population (May, Gompels and Delpech 2011). This increase in life expectancy has resulted in 58% more people continuing to access HIV services in 2011 compared with ten years previously (Health Protection Agency 2012). Anonymous surveillance testing indicates that an estimated 22,600 (24%) of people with HIV infection remained undiagnosed in 2011 (Health Protection Agency 2012) in spite of strategies to expand HIV testing in generic healthcare settings (British HIV Association, British Association for Sexual Health and HIV and British Infection Society 2008; Health Protection Agency 2012). Although the focus of this thesis is on people who have been diagnosed with HIV, future HIV service models will also need to accommodate a 24% increase in the current

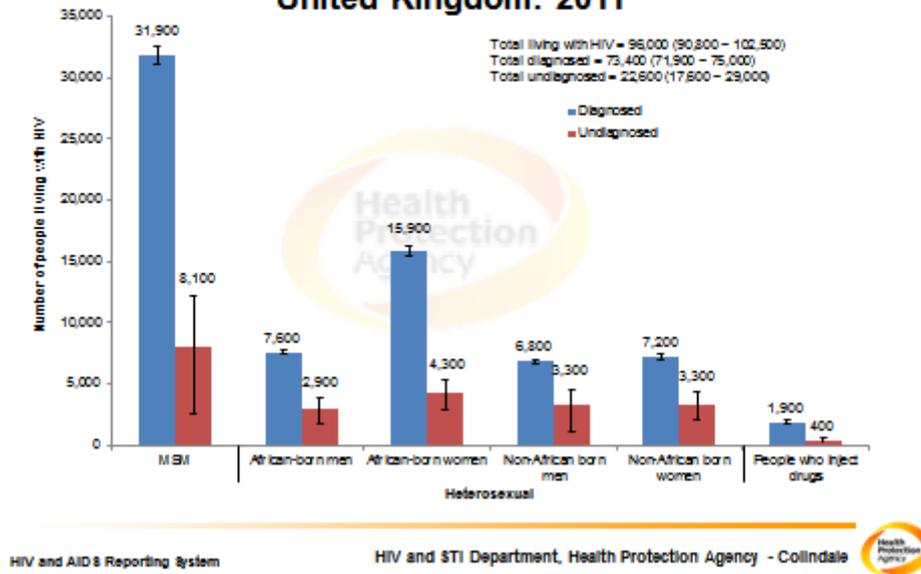
number of patients when those who are presently undiagnosed are tested or present for care.

This combination of new diagnoses, increased survival and estimated numbers of people with undiagnosed HIV is likely to present challenges in managing an increasing volume of patients attending for HIV healthcare.

1.2.2 Diverse risk groups

In the UK, HIV disproportionately affects certain risk groups that include men who have sex with men (MSM) and men and women who were born in Africa. The prevalence of HIV in 2011 among these groups was 47/1,000, 25/1,000 and 50/1,000 respectively (Health Protection Agency 2012). This is in comparison to a background HIV prevalence rate of 2.1/1,000 for men and 1.0/1,000 for women in the UK, although the rate of infection among UK born heterosexuals is increasing (Ibid.). The number of new infections among MSM has continued to increase every year since 2007 but the number of people with HIV who were born in Africa has started to decline. In addition to the main risk groups, HIV also affects intravenous drug users, haemophiliacs and infants born to HIV positive mothers. Figure 1.2 shows the distribution of HIV across MSM, heterosexuals and intravenous drug users.

Estimated number of people living with (both diagnosed and undiagnosed) HIV infection in the United Kingdom: 2011



Source: Health Protection Agency 2012

Figure 1.2: Distribution of HIV across risk groups in the UK

The prevalence of HIV among injecting drug users in the UK rose from 1:400 in the year 2000 to an estimated 1:73 injecting drug users with HIV infection in 2009 (Health Protection Agency 2011a). Although the overall prevalence of HIV remains low in this group, the number of new infections in 2011 suggests there is on-going transmission within this risk group (Health Protection Agency 2012). Conversely, there has been a significant reduction in the number of infants who have acquired HIV from mother to child transmission, with recent estimates being 2% compared to 12% in 1999 (Health Protection Agency 2010; Health Protection Agency 2012). This is due to huge successes in universal antenatal screening for HIV and timely antiretroviral intervention when indicated. There is currently a total of 1,100 children who are HIV positive in the UK with approximately half of this number being born outside of the UK (Children’s HIV

Association 2013). Many of these children have now reached adolescence and are beginning to transition into adult HIV services (Children's HIV Association 2011). In the early 1980s, 1,246 people with haemophilia were infected with HIV through blood products, of which 64% have died (UK Haemophilia Centre Doctors' Organisation 2004; Macfarlane Trust). Following the introduction of routine HIV screening of blood donations in the UK in 1985, the risk of acquiring HIV through blood products is now considered rare (Byrne, Brant and Davison 2011).

What these data demonstrate firstly is the changing prevalence of HIV across the different risk groups and this has informed recent HIV testing strategies across the UK (National Institute for Health and Clinical Excellence 2011a; National Institute of Health and Clinical Excellence 2011b). The diversity of the risk groups infected with HIV also means that there are healthcare needs that are specific to each group and these will need to be considered in the way services are planned in the future. For example, HIV positive men who have sex with men are at increased risk of anal cancer (de Pokomandy, Rouleau and Ghatthas et al. 2011) and require prompt diagnosis and monitoring to maximise treatment options (Reed, Britt and Novosel et al. 2012). Intravenous drug users are more at risk of developing life threatening bacterial infections (Health Protection Agency 2011c) and have also been associated with increased hospital admissions and length of stay (Hsieh, Rothman and Bartlett et al. 2008). Haemophiliac patients with HIV have specific needs in relation to co-morbidities and require a co-ordinated service across specialist healthcare teams (Dolan, Hermans and Klamroth et al. 2009). More than two-thirds of African patients are diagnosed

when their HIV is at an advanced stage (Health Protection Agency 2012) and often require complex medical interventions to stabilise their condition. In addition, many African people in the UK with HIV have complex social and psychological issues that may impact on their health and ability to take antiretroviral therapy (Anderson and Doyal 2004; Flowers, Davis and Hart et al. 2006; Prost, Elford and Imrie et al. 2008).

The distribution of these risk groups across the UK depends on local population demographics and the Health Protection Agency have recently reported higher HIV prevalence in more deprived areas of the country and particularly in London where half of people with HIV reside (Health Protection Agency 2011d; Health Protection Agency 2012). It is not clear what models of care are required in the future to continue to reflect and respond to the needs across these diverse risk groups of people with HIV.

1.2.3 Disease outcomes and quality of care measures

In 2011, 73,660 people with HIV were receiving HIV care within specialist outpatient clinics; that represents a 6% increase from 2010 (Health Protection Agency 2012).¹ However, in spite of this continual increase in the numbers of people accessing HIV care, current quality of care measures remain one of the highest in developed countries (British HIV Association 2012). These measures

¹ The increase in the number of people accessing services is accounted for by the numbers who are newly diagnosed each year and the significant reduction in deaths among people with HIV as referred to in section 1.2.1.

are based on disease markers, such as CD4 cells that measure immune function and viral load that measure the amount of virus in the blood. A higher CD4 count of >350cells/mm indicates a stronger immune system and a viral load of <50 copies/ml is the goal of antiretroviral therapy (see also Terms and Abbreviations). Figure 1.3 below shows an adapted summary of the HIV quality of care indicators and results that are monitored annually by the Health Protection Agency.

Quality of care indicators for adult HIV patients: United Kingdom, 2011

Indicators	Aim	Result
Late diagnosis	CD4 cell count <350 cells/mm ³ within 3 months of diagnosis	47%
Link to care	CD4 cell count taken within 2 weeks of diagnosis	76%
	CD4 cell count taken within 1 month of diagnosis	88%
	CD4 cell count taken within 3 months of diagnosis	97%
Retention in care - new patients	12 months after HIV diagnosis	86%
	24 months after diagnosis	81%
Retention in care - all patients	Adults seen for HIV care in 2010 and also seen in 2011	96%
Viral load outcome	Viral load <50 copies/ml within 12 months of starting ART	87%
ART coverage	CD4 cell count <350 cells/mm ³ prescribed ART	88%
CD4 outcome	CD4 cell count ≥350 cells/mm ³ after at least 12 months in HIV care	83%

HIV and AIDS Reporting System

HIV and STI Department, Health Protection Agency - Colindale



Source: Health Protection Agency 2012

Figure 1.3: Adapted summary of HIV quality of care indicators in the UK, 2011

As well as monitoring disease markers, other quality of care measures include the number of people who require HIV treatment who are actually receiving it

and this was 88% for 2011. In addition, 96% of patients were retained² in care between 2010 and 2011, which indicates high levels of engagement in care³ in comparison to other HIV epidemics (Gardner, McLees and Steiner et al. 2011). Poor retention in HIV care is associated with reduced adherence to HIV medication and to increased transmission of HIV (Mugavero, Davila and Nevin et al. 2010; Mugavero, Norton and Saag 2011; Gardner, McLees and Steiner et al. 2011). This suggests that current secondary care models of service delivery are successful in maintaining HIV patients on treatment in the UK. However, there is no academic theory underpinning what keeps HIV patients retained or engaged in care within the UK model of service delivery and further understanding of this may help with planning how and where care is delivered in the future.

1.2.4 Changing clinical picture of HIV

The high numbers of people with HIV in care who have a CD4 count of >350cells/mm (as shown in Figure 1.3) indicate that large numbers of patients are bio-medically stable from an HIV perspective. The recent development of a national HIV Care Pathway⁴ estimates that around 80% of people with HIV are stable at any one time (Department of Health 2012b). There are guidelines which advise that people who are medically stable on antiretroviral therapy are monitored every three to six months (British HIV Association 2011). There are several approaches to delivering this in practice including face-to-face

² Retention in care reflects a measure of the number of people who are registered for HIV care who have attended in the previous 12 months.

³ Engagement in care reflects the processes involved in linking HIV patients to care and keeping them retained in care.

⁴ The HIV Care Pathway has been developed to inform the financial tariff for the commissioning of HIV services. This is discussed in more detail later in this chapter.

appointments, nurse-led clinics (McPeake 2011) and virtual e-mail results clinics (Coyne, Kerley and Mandalia et al. 2008; Iwuji, Whetham and Churchill et al. 2010). However, it is not known how people with HIV view their stable status or whether this influences the way they view or utilise HIV services.

In spite of this group of bio-medically stable patients, increased life expectancy has changed the spectrum of disease affecting people with HIV infection. This can manifest in a number of ways including non-AIDS defining cancers (Stebbing, Duru and Bower 2009), bone disorders (Triant, Brown and Lee et al. 2008), neurocognitive changes and infectious hepatitis (British HIV Association 2010). Cardiovascular disease is particularly high in people with HIV compared to the general population (Goetz, Brown and Oursler et al. 2011; Freiberg, McGinnis and Butt et al. 2011). In addition, people with HIV have higher rates of tuberculosis and pneumococcal disease (British HIV Association 2010; Health Protection Agency 2011d). Engsig, Hansen and Gerstoft et al. (2009) reported an increase of 175% in the attendances of HIV positive patients at non-HIV specialist outpatient clinics in Denmark. Although this is in a different context, it represents the expanding disease spectrum of people with HIV and is likely to reflect the UK situation. For example, although death rates from AIDS related conditions are still very high among those diagnosed late in the course of their infection (Health Protection Agency 2010), the number of deaths in people with HIV exceeded the number of AIDS diagnoses for the first time in 2010 (Health Protection Agency 2011d). This indicates that people with HIV in the UK are now dying of non-AIDS related conditions. How this will impact on the way that

services are organised for people with HIV or the role of HIV services in managing these complexities is not known.

As well as the evolving epidemiology within the main HIV risk groups as discussed earlier, 22% of people in HIV care in 2011 were over 50 years of age in comparison to 12% in the year 2002 (Health Protection Agency 2012). This is due to both longer survival rates with HIV and the number of people being newly diagnosed at age 50 or over (Ibid.). It is not yet fully understood what the impact of HIV is on the ageing process, but studies over the past 3-4 years have suggested that HIV accelerates the ageing process in those aged 50 years and over and contributes to a range of conditions including cardiac disease, osteoporosis, and liver and kidney disease (Effros, Fletcher and Gebo et al. 2008; Triant, Brown and Lee et al. 2008; Deeks and Phillips 2009; Guaraldi, Zona and Alexopoulos et al. 2009). Fisher and Cooper (2012) have questioned the evidence on the impact of HIV on ageing and raise questions about the absence of control groups, the use of extrapolated data and the role of underlying risk factors in accelerating the ageing process. While this debate continues, preliminary studies that have explored the perceived needs of HIV patients over 50 years of age have identified that new models of care are required to address the future needs of this group of patients in the UK (Perry 2009; Power 2010).

In addition to the changing spectrum of disease and age-related conditions, there continues to be a significant number of people who are diagnosed at an

advanced stage of HIV infection. In 2011, almost half (47%) of those who were newly diagnosed presented with disease markers that were below the recommended level for starting antiretroviral therapy⁵ (Health Protection Agency 2012; British HIV Association 2012). This means that their immune function was already compromised and that this group are more at risk of morbidity and mortality as a result (Strategies for Management of Antiretroviral Therapy Group (SMART) 2006; Obel, Omland and Kronborg 2011). Furthermore, over half of those who were diagnosed late had severe immune dysfunction defined by a CD4 count of <200cells/mm. This group of patients often require intensive medical intervention and monitoring in the initial stages of disease management.

This intricate picture of HIV in the UK is comprised of increasing numbers of patients, diverse risk groups and a mixture of stable and complex patient groups. Quality of care measures indicate that current secondary care models are delivering services that maintain people on antiretroviral therapy and keep them engaged in care. However, further understanding of the processes involved in the current model of care is required to inform the future planning of services in relation to preserving high levels of retention in care.

1.2.5 Current healthcare climate in the UK

The coalition government's Health and Social Care Act (Department of Health 2012a) will result in significant changes to the way that national health services

⁵ This group of patients are known as late diagnoses or late presenters and are defined by those with a CD4 count of >350cells/mm. See also Terms and Abbreviations for further explanation of CD4 counts.

are provided within the UK. The act is intended to focus on keeping patients at the centre of care, health outcomes for patients and clinical innovation (Department of Health 2010a) and the introduction of considerable structural changes to the funding and provision of healthcare that are currently underway (NHS Commissioning Board 2013). At the same time there are substantial cost savings to be made across all health services.

In relation to HIV healthcare, there have already been reductions in social care funding for some time (Weatherburn, Keogh and Dodds et al. 2007). There have also been recent changes to the prescribing guidelines for antiretroviral therapy in London that have been driven by financial pressures on maintaining service delivery (London Specialist Commissioning Group 2011; UK Community Advisory Board (UK-CAB) 2012).

In comparison to other disease areas, the numbers of people with HIV are relatively small. For example there are 2.9 million people with diabetes in the UK (Diabetes UK 2011), and 2.7 million with coronary heart disease that resulted in 18% of male deaths and 12% of female deaths in the UK in 2009 (British Heart Foundation 2011). A total of 309,500 people were diagnosed with cancer in 2008 and increases in incidence of cancer are estimated at 16% in men and 34% in women since the mid to late 1970s (Cancer Research UK 2011). However, HIV remains an expensive health condition as the estimated lifetime cost of treating one person with HIV infection in the UK is between £280,000 and £360,000 (House of Lords 2011b) with an overall annual cost estimated between £858 -

£1,065 million for people with HIV in treatment and care (Mandalia, Mandalia and Lo et al. 2010; Health Protection Agency 2012). In 2009/2010 HIV treatment and care accounted for 40% of the infectious diseases budget of £1.9 billion, not including testing and prevention. Therefore future models of HIV care need to consider long-term costs and explore ways to balance cost with maintaining current disease outcomes.

In 2011, a Health Select Committee on HIV/AIDS was convened to review HIV treatment and care in the UK (House of Lords 2011a; House of Lords 2011b). This committee carried out key informant interviews with 47 representatives from HIV organisations and received a further 108 written evidence reports (Ibid.). The Committee made several recommendations to inform the future of HIV funding and care that included the modernisation of services through virtual results services and nurse-led clinics with an overall strategy to support patient self-management. However, there is a lack of evidence to guide the modernisation of HIV services and what models of care may be appropriate to respond to the needs of medically stable patients or for those who have more complex needs.

1.3 Preliminary literature search

A preliminary literature search was undertaken to situate the research area and to identify gaps in knowledge in relation to HIV as a long-term condition and models of HIV service delivery. A search strategy was designed to identify publications relating to the needs of people with HIV in the UK in the post

antiretroviral therapy era particularly in the last seven years.⁶ In addition, the search strategy explored the service delivery and organisation of HIV healthcare in the UK and included service delivery models from other countries as a comparison.

The search included a combination of electronic sources, policy and guidance documents, conference material and topic specific journals and websites. The electronic sources searched were the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, PubMed, and ProQuest. Specific searches were also undertaken in the following journals; HIV Medicine, HIV Nursing Journal, AIDS Care, Culture Health and Sexuality, HIV Treatment Update. Abstracts and presentations from HIV conferences such as the National HIV Nurses Association, British HIV Association and International AIDS Society were explored within the search criteria. General healthcare policy documents were searched in relation to future service planning and specific HIV policy developments and guidelines were accessed through a combination of professional contacts and website searches.

The search terms included a combination of the following words: HIV, long-term condition, chronic disease, need, physical, psychosocial, patient experiences, patient involvement, self-care, models of HIV care, settings of care, roles in HIV care, HIV nurse-led care, HIV nursing roles, task shifting. Only full text articles in

⁶ The post antiretroviral therapy era (or post HAART as it is often referred to) is usually considered to be after 1996 when combination antiretroviral therapy was first manufactured. However, as HIV treatments have continued to be refined in terms of formulation, frequency and side effect profile, literature from 2005 were considered to be more reflective of the contemporary needs of people with HIV.

the English language were considered. Although the preliminary search was carried out at the initial stage of the research planning, more recent references from the last two years have been included where they supersede older references to reflect the shifting healthcare climate in the UK.

1.3.1 HIV as a long-term condition

There was a general consensus across much of the HIV policy literature that HIV has become a treatable chronic condition (Department of Health 2001; British HIV Association 2007; Independent Advisory Group on Sexual Health and HIV 2009; House of Lords 2011b; British HIV Association 2012). However, HIV has traditionally not been listed as a chronic long-term condition in many of the UK health policy reports or documents on long-term conditions (Department of Health 2005a; British Medical Association 2006; The King's Fund 2010; National Institute of Clinical Excellence (NICE) 2012). There is, nonetheless, some indication that this is starting to change in some respects. In a recent report on long-term conditions and mental health, the King's Fund define a long-term condition as "people with a range of conditions that can be managed but often not cured, such as diabetes, arthritis and asthma, or a number of cardiovascular diseases. To this we can add conditions such as HIV/AIDS and certain cancers, which have not traditionally been considered long-term conditions but which are increasingly experienced and regarded as such" (King's Fund 2012, 3). Likewise a Department of Health and Ipsos MORI survey of 701 patients with long-term conditions included HIV in their list of conditions, but did not recruit anyone with HIV to their study (Ipsos Mori 2011). Aside from these two examples, HIV as a

long-term condition appears to exist within a specialist domain of healthcare where policy and guidance is largely formulated within specialist bodies.

This raises questions about where HIV sits in relation to other chronic diseases from a health planning perspective particularly in the light of the financial re-organisation of the National Health Service (Department of Health 2010). At the time this research commenced there was much debate on the potential impact of this re-organisation on HIV healthcare delivery and where HIV services may be placed in the new commissioning structures (Cairns 2010; HIV I-BASE 2011; Miller and Gubb 2011; House of Lords 2011b; National AIDS Trust 2012). Since then, HIV has been designated a prescribed specialist service which means that inpatient and outpatient care will be commissioned by a national commissioning body and not locally by General Practitioner (GP) led Clinical Commissioning Groups (Clinical Advisory Group for Prescribed Services 2012). The criteria for a prescribed specialist service are based on rare conditions that are expensive and provided within a limited number of specialist centres (Ibid.). In essence, this means that those HIV services commissioned nationally will be standardised across the country and not subject to local commissioning priorities. However, it is not known how long these commissioning arrangements will remain in place and if the increasing numbers of people infected with HIV may change its status as a rare condition in the future. Whatever arrangements are in place for future commissioning, evidence will be required on optimal ways to deliver services and to sustain or improve disease outcomes (Department of Health 2010).

Thus, at present HIV is not considered in the same way as other chronic disease areas in the new NHS commissioning structures where the care of conditions such as asthma, multiple sclerosis and diabetes will be funded through local Clinical Commissioning Groups (NHS Diabetes 2012; Clinical Advisory Group for Prescribed Services 2012). It is not known if this different approach to HIV as a long-term condition will determine the way that services are organised or how HIV services might interface with other disease areas at a clinical level for patients with co-morbidities or co-infections.

The recent development of HIV disease categories for outpatient care may also influence the way HIV is viewed as a long-term condition in the future. As part of the process in formulating an HIV Payment by Results (PbR) tariff,⁷ an HIV Care Pathway has been developed that incorporates three categories of HIV patients: new patients; stable patients; and complex patients (Department of Health 2011a; Department of Health 2011b; Department of Health 2012b). Figure 1.4 shows a summary of the care pathway and outlines the definitions of the three designated groups.

⁷ A Payment by Results (PbR) tariff is based on units of healthcare and is the current method of calculating funding across the NHS.

HIV clinical care pathway categories		
Category 1: New patients	Category 2: Stable patients	Category 3: Complex patients
Newly diagnosed within one year or new to antiretroviral therapy within one year	Stable* on or off antiretroviral therapy for >1year *Defined by CD4 count >350 cells/mm and no active AIDS diagnoses	Current active AIDS diagnosis, co-morbidity such as TB, Hepatitis C, end organ disease, HIV related malignancy, persistent viraemia on treatment, pregnancy, active mental illness

Source: Department of Health 2012b

Figure 1.4: Summary of the HIV adult outpatient pathway

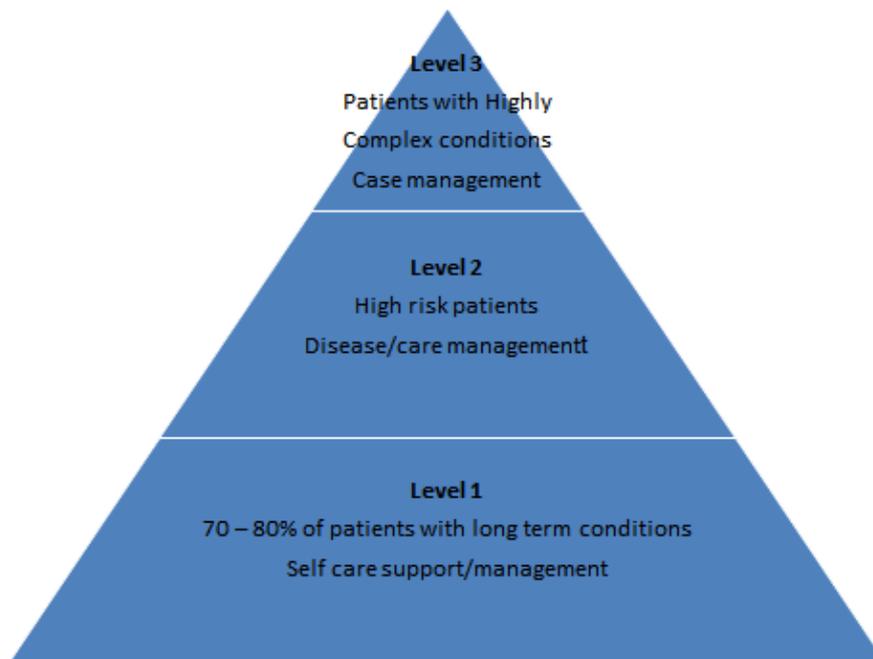
These categories were developed following an initial pilot data collection exercise carried out on 14,000 attendances in 8 HIV healthcare sites in 2009/2010 (Department of Health 2011a; Barton 2011), where clinicians were asked to categorise each patient attendance into provisional 'new', 'stable' or 'complex' categories. Once the categories were agreed they were further tested on 149,000 patient attendances across all Strategic Health Authorities (Barton 2011). The results of the data collection exercise are shown in Figure 1.5 and indicate that a significant majority of HIV patients attending outpatient services fall within the 'stable' category.

Result of data collection to inform HIV care pathway and PbR tariff		
Category 1 - New	Category 2 - Stable	Category 3 - Complex
10%	80%	10%

Source: Department of Health 2012b

Figure 1.5: Breakdown of HIV care categories by attendance

This HIV Care Pathway will now be utilised to underpin the commissioning of HIV Outpatient services from April 2013. There are striking similarities to other chronic disease models, such as the long-term conditions model adopted by the Department of Health in 2005 that has continued to inform long-term condition management in the UK. This model that utilises the Kaiser Permanente Triangle shows a similar patient distribution to the HIV Care Pathway, with 70-80% of patients being stable, 10% with high risk needs and 10% with highly complex needs as shown in Figure 1.6.



Source: Department of Health 2005a

Figure 1.6: Department of Health Long Term Conditions Model

The potential problem with the PbR categories in the HIV Care Pathway and its similarity to the current long-term conditions model is that it may inadvertently determine future service models within a chronic disease paradigm. More importantly, although this was a robust and extensive data collection process, the HIV Care Pathway has been based on quantifying service utilisation and identifying measurable disease outcomes to inform the financial tariff. This is not necessarily reflective of the needs or illness experience of people with HIV nor designed to determine the optimum way to deliver HIV healthcare.

1.3.2 Needs of people with HIV

Bravo, Edwards and Rollnick et al. (2012) suggest that HIV is not “just another chronic illness” in their phenomenological study on the psychosocial needs of people with HIV. Using thematic analysis, the authors concluded that HIV poses a psychosocial risk for patients due to stigma and discrimination that resulted in living in secrecy and non-disclosure of HIV status. This research focussed on the perspectives of support workers,⁸ some of whom were HIV positive, so did not specifically reflect the lived experience of people with HIV in keeping with a phenomenological approach. In addition, the methodology did not enable a comparison with other chronic disease areas.

The psychosocial needs of people with HIV are well documented in the literature (Anderson and Weatherburn 2004; Anderson and Doyal 2004; Ibrahim,

⁸ Support workers can function in a number of roles such as counselling and financial advice and support and are usually in charitable organisations.

Anderson and Bukutu et al. 2008; Weatherburn, Keogh and Reid et al. 2009; Clucas, Sibley, Harding et al. 2012; Catalan, Harding and Sibley et al. 2012; Sherr, Clucas and Harding et al. 2012). These psychosocial needs include anxiety, depression, mental health, social and financial issues. In 2004 Anderson and Weatherburn described the dominant needs of people with HIV as personal, social and economic in their questionnaire study of 1,821 people with HIV in the UK (Anderson and Weatherburn 2004). However, the measures used in this survey research had not been thoroughly validated and the incidence of reported needs was did not directly reflect the measures of subjective experience. In addition, low levels of employment and economic hardship have been described across a number of groups infected with HIV living in London (Ibrahim, Anderson and Bukutu et al. 2008).

A questionnaire study on the needs of people with HIV in 2009 found that anxiety and depression were experienced by 72% of participants in the last year, followed closely by issues with self-confidence, sleeping and sexual problems (Weatherburn, Keogh and Reid et al. 2009). This was an extensive research project on 1,777 people with HIV where need was defined in terms of perceived capacity to benefit. In this study 84% of patients reported experiencing four or more areas of need in the previous year with 48% experiencing eight or more areas of need (Ibid.). The authors included an analysis of how patients used a range of statutory and non-statutory services in relation to their perceived needs and concluded that only a small percentage of HIV patients have minimal needs (Ibid.). While this study gives a detailed perspective of perceived needs, the measure of need over one year may have led to either an overestimation of

transient need or to recall bias. A more recent investigation of the expectations of people with HIV in relation to outpatient care in London has been conducted by the same study group and the report for this was pending at the time of writing this thesis (Sigma Research 2013). However, there remains little evidence on how patients perceive their HIV as a condition and how this relates to the way they utilise services.

In addition to psychological issues, Harding, Lampe and Norwood et al. (2010) found a high prevalence of physical symptoms among people with HIV irrespective of whether they were on HIV treatment or not.. The authors reported a strong association between the number of symptoms and the ability of patients to adhere to their HIV medication and increased risks for sexual transmission of HIV. While this research used both univariate and multivariate regression analyses to measure the associations, it did not identify causal relationships between the variables due to the cross-sectional design. The tool used to measure symptoms had been validated in cancer patients and utilised in other disease areas and although this was useful for comparison, it may not have completely reflected the specific symptom experience of people with HIV. The same study also identified an association between psychological issues and the presence of physical symptoms, but further understanding is required with regard to how physical and psychological symptoms influence the way patients view the role of HIV services in their care.

High levels of adherence⁹ to antiretroviral medication are essential to maintain virological control and can present challenges for some HIV patients in the long-term. There are a range of factors that can influence adherence including beliefs about treatment (Horne, Cooper and Gellaitry et al. 2007), health status and side effects (Grierson, Koelmeyer and Smith et al. 2011), stigma and mental health (Li, Huang and Wang et al. 2011; Rao, Feldman and Fredericksen et al. 2012). As the use of antiretroviral therapy has recently been shown to significantly reduce the sexual transmission of HIV (Cohen, Chen and McCauley et al. 2011), future service models will need to incorporate long-term adherence support and monitoring.

Stigma and discrimination continue to present major problems for people with HIV and this is evident in healthcare settings as well as in mainstream society. In a survey of 400 people with HIV in the UK in 2008, 17% reported being refused healthcare based on their HIV status (The People Living with HIV Stigma Index 2008) and this has been recognised as a significant concern with regard to the planning of future healthcare services for people with HIV in the UK (House of Lords 2011b). The essence of this research by The People Living with HIV Stigma Index (2008) was to train people with HIV to support peers to fill out a stigma questionnaire to increase recruitment and empower people with HIV. However, there may have been some recruitment bias in this survey and the findings may not be reflective of those people with HIV who did not wish to disclose their status to others in their community. In their literature review of the

⁹ Adherence is the term used to describe the ability of patients to stick to their antiretroviral therapy regime and consistently take the right dose at the right time in the correct way. In order for antiretrovirals to achieve their maximum effect it is estimated that they need to be taken correctly 95% of the time.

decision needs of people with HIV, Bravo, Edwards and Rollnick et al. (2010) reported stigma, discrimination and isolation as key factors that underpinned the decision –making. This paper used thematic analysis of the literature but in view of the limited evidence on decision-making in people with HIV, the authors' conclusion was an interpretation of the relationship between psychosocial factors examined and decision needs. How stigma will influence the way patients engage with future models of HIV care has not been fully explored within the UK context.

1.3.3 Models of HIV care

This section of the literature review will explore the evidence for case management, clinical network services in HIV and models of care for patients who have been designated medically stable.

1.3.3.1 Case management

There was little evidence of recent primary research in the UK on models of HIV healthcare particularly within a chronic disease paradigm. An intervention review carried out from 1980-2002 identified that case management¹⁰ and multidisciplinary models of disease management may be associated with improving outcomes for HIV patients over this time period (Handford, Tynan and Rackal et al. 2006). However, the diverse nature of methodologies examined and the range of interventions and clinical outcomes included made comparison

¹⁰ Case management links people with different healthcare needs to the appropriate service to meet their individual needs.

difficult and the conclusions were tentative. Likewise, combination antiretroviral therapy was still at a relatively early stage in 2002 and the case management approach used then may not be relevant to the current situation. Further studies on the role of case management in HIV in the United States have focussed on the specific needs of prisoners and on linkage to care following diagnosis (Gardner, Metsch and Anderson-Mahoney et al. 2005; Wohl, Scheyett and Golin et al. 2011) but not across the general HIV population. The evidence for using a case management approach is mostly related to health systems in the United States and at present there is limited evidence for using case management for other long-term conditions in the UK (Young and Clegg 2010; Gage, Ting and Williams 2013). Further understanding of the spectrum of need across medically stable and complex patients is required before an evidence based case management model can be developed for HIV.

1.3.3.2 Clinical networks

The *Standards for HIV Clinical Care* recommend that HIV care in the UK is delivered through a combination of large HIV Centres with access to specialist inpatient facilities and smaller HIV Units that focus on uncomplicated outpatient management of HIV (British HIV Association 2007). These centres and units are intended to function within a clinical network structure using integrated care pathways across primary, secondary and tertiary healthcare settings and statutory and non-statutory services¹¹ (Medical Foundation for AIDS and Sexual

¹¹ Primary care is based in community healthcare services with, for example, General Practices and Community Nurses. Secondary care consists of hospital based services, such as outpatients in District General Hospitals, and tertiary care is more specialised hospital care. Statutory services are publicly funded services.

Health 2003; British HIV Association 2007). The *Standards for HIV Clinical Care* have been superseded by the recent launch of the *Standards of Care for People Living with HIV 2013* (British HIV Association 2012) and although HIV clinical networks are still recommended, the structure of services is no longer being specified. The principle of delivering clinical care through networks is based on equity of service provision to enable patient access to more specialised services, when required, and collaborative working using care pathways across service boundaries (Guthrie, Davies and Greig et al. 2010). The delivery of care through clinical networks has also been recommended in the current re-organisation of national health services, although this has been prioritised for cancer, cardiovascular disease and mental health (NHS Commissioning Board 2012a).

However, the evidence underpinning the role of clinical networks in improving patient outcomes is disputed. While some success in improving the quality and processes of care has been reported, it is difficult to attribute findings directly to the clinical network structures (Greene, Pagliari and Cunningham et al. 2008; Gale, Santhakumaran and Nagarajan et al. 2012). From an HIV perspective, the main evidence for clinical networks is based on the association between rates of mortality and level of disease specialisation (British HIV Association 2007). A recent meta-analysis on the relationship between the number of patients attending an HIV service and mortality rates shows that services with higher volumes of patients have better health outcomes (Handford, Rackal and Tynan et al. 2011). While the quality of evidence was very mixed in this meta-analysis, this supports the principle of networked services for HIV healthcare.

Nevertheless, there are reported concerns about the implementation of HIV network pathways and how HIV services work together to respond to local patient needs (Miller and Gubb 2011). Further understanding is required concerning the processes and identity of HIV services within these network structures to inform how they evolve to meet the needs of their caseload.

1.3.3.3 Models for medically stable patients

Over the past few years, several models of care have evolved for patients who have been designated medically stable. These are largely nurse-led models of care or virtual clinics that provide results either by telephone or e-mail twice a year with an annual doctor's appointment. A formative evaluation of the potential roles for nurses in providing follow-up clinics for stable patients identified high levels of approval from both patients and medical staff (Griffiths, Miles and Penny et al. 2006). A further audit by the same clinical team indicated that 94% of specialist nurse consultations with stable HIV patients were autonomous (Castro Sanchez, Kirkpatrick and Miles 2006) and that there was no difference in virological outcome between doctor and nurse clinics (Benn, Shuk Li and Castro Sanchez et al. 2007). However, these were audits of clinical practice as opposed to empirical research exploring the outcomes associated with nurse-led practice. Likewise, this area does not appear to have been further researched or evaluated and it is not empirically known which groups of patients may benefit from nurse-led face-to-face clinics as opposed to virtual services. Coyne, Kerley and Mandalia et al. (2008) undertook a review of HIV patients attending their

multidisciplinary virtual e-mail clinic and reported a high level of patient satisfaction and clinical outcomes that were similar to the standard of care.¹² This included a retrospective case notes review that compared clinical outcomes before and after the introduction of the virtual clinic but these were preliminary findings and longer-term outcomes were not reported. Iwuji, Whetham and Churchill et al. (2010) also compared their virtual results service with the usual standard of care and showed a considerable increase in number clinic appointment that were freed up through the provision of a virtual clinic. They did not however fully examine the reasons that patients declined to opt for a virtual clinic service. Again, there is a lack of evidence or academic theory on why patients choose virtual clinics and this would be helpful in determining the planning of future services.

1.3.3.4 Primary care and HIV

The role of primary care in HIV was developed in the early HIV epidemic where general practitioners (GPs) were involved with the palliative and terminal care needs of people with HIV at home. As the use of antiretroviral therapy has become an inherent part of clinical care in secondary care settings, the role of GPs is less defined. The current position on the role of primary care in HIV advises shared care¹³ models between GPs and HIV specialist centres (British HIV Association Position Statement), particularly with regard to managing co-morbidities such as diabetes and cardiovascular disease. However some studies

¹² The standard of care for routine monitoring of HIV patients, as defined by the British HIV Association (2011), is every 3-6 months and has traditionally been provided in face-to-face appointments by medical doctors.

¹³ Shared Care refers to joint care pathways with role definition between healthcare workers.

have raised concerns about serious prescribing errors in general practice (Benn, Miller and Evans et al. 2009). This retrospective notes review of 26 patients showed that of the 50% of patients in an HIV clinic who were prescribed statins by their GP, most experienced difficulty and 2 had potential life-threatening drug interactions. While this study raised important issues about the need to collaborate with GPs about prescribing for people on antiretroviral therapy, it did not capture the extent of the problem across the caseload. However, colleagues from the same clinic undertook a survey of 415 patients to determine their preferences for models of GP care (Munir, Edwards and Richards et al. 2009). The authors found that almost 60% of the patients preferred a model where a GP was based in the HIV clinic. Namiba and Anderson (2010) from Positively Women carried out stakeholder consultations with GPs, HIV clinicians and 200 people living with HIV on 5 existing models of GP care. They concluded that there was a high level of concern from all three groups and recommended targeted GP training, transitional GP clinics in HIV service sites and training for patients to access their GP with confidence. This was a user-led stakeholder consultation that highlighted the issues for patients and healthcare workers based in London. In the south of England, Defty, Smith and Kennedy et al (2010) showed that 60% of 124 GPs thought that GPs should manage common chronic conditions in HIV positive people. While this research shows what is possible, this study was based in an area of high HIV prevalence and GP training uptake and may not reflect the situation in the rest of the UK. All studies to date show that on-going training is required to fully engage GPs with HIV care and to increase patient confidence in accessing their GPs. As HIV becomes a more

chronic condition further understanding is required of what underpins patient concerns about using their GPs for part of their healthcare.

In other countries, the role of primary care in HIV is more established in the post antiretroviral therapy era. For example, in Australia GP clinics have evolved as specialist primary care centres for people with HIV (Newman, Kidd and De Wit 2011). In this setting, many GPs were involved with HIV care from the outset and are now reaching retirement age and questions are being raised about succession planning. In their study on the motivating factors to specialise in HIV in general practice, Newman, Kidd and De Wit (2011) concluded that choosing to work in HIV was often politically driven and was largely viewed as different from other areas of general practice. This highlights the possibility that there may be specific motivating factors for GPs to become involved in HIV care and this may be relevant for other developed countries. In Sub Saharan Africa, there is rapid decentralisation of HIV care from antiretroviral centres to primary care clinics as part of an epidemic management strategy (Bedelu 2007; Morris 2009; Shumbusho 2009) but there are considerable challenges with maintaining patient engagement and retention in care in this approach (Geng, Nash and Kambugu. 2010). So, there are difficulties with the general practice role in HIV healthcare across HIV epidemics and further work is needed to identify replicable models of shared care in the UK setting to improve the general healthcare needs of people with HIV.

1.3.3.5 Patient involvement in care

People with HIV have traditionally been highly active in participating in their own care and health service planning (Gazzard 2011; Sseruma 2011) and this has led to the development of a number of HIV advocacy and information sharing organisations such as the Terence Higgins Trust, National AIDS Manual and HIV I-BASE. This has considerably contributed to the development of “expert” patients with HIV and to the concept of partnership working between patients and healthcare workers in the HIV field (Campbell, Murat and McMaster 2007; Maxwell, Aggleton and Warwick 2008). Self-management strategies have previously been shown to be successful in HIV patients (Gifford, Laurent and Gonzalez 1998) and expert patient programmes that have been extensively evaluated for people with long term conditions have included some patients with HIV. How this translates as part of a strategy for future HIV healthcare provision is not yet known (Kober and Van Damme 2006) and we need to further understand how patients’ involvement in their care relates to the use of non-HIV healthcare services.

1.3.3.6 Non-NHS sector

Services for people with HIV have traditionally included a range of support services from non-NHS bodies that have been funded through a combination of NHS money and charitable grants. This is often referred to as 3rd sector care¹⁴ and includes continuing care, immigration advice, financial support, counselling,

¹⁴ 3rd sector provision is defined as that from self-governing non-profit organizations that “benefit to a significant degree from voluntarism” (London School of Economics 2006).

and peer support for people with HIV. As in other chronic disease areas, these services are viewed as central to supporting the non-medical needs of people with HIV (House of Lords 2011b; National AIDS Trust 2012). The introduction of a self-management programme comprising health trainers and an interactive website has indicated improvement in patient self-management strategies from a combination of internal and external evaluation (Power 2011). There were some difficulties with this project in engaging healthcare worker support in some areas and further understanding is required about the future of 3rd sector funding and how it might work alongside statutory healthcare services. For the purposes of this thesis, paid workers in 3rd sector care have been included as healthcare workers unless otherwise specified.

1.3.3.7 Roles of healthcare workers in HIV

As the clinical picture of HIV infection has changed at both ends of the illness spectrum since the advent of antiretroviral therapy, the role of healthcare workers in HIV is the topic of much debate. While the *Standards for HIV Clinical Care* have defined the macro structures of care delivery across organisations (British HIV Association 2007), the roles of healthcare workers are not explicitly demarcated. The draft national HIV service specification that is currently being drawn up for the NHS Commissioning Board lists a range of healthcare worker disciplines such as doctors, nurses and pharmacists and includes allied services such as mental health and clinical psychology (NHS Commissioning Board 2012b). The configuration of services is not yet known and further understanding

of how these roles contribute to HIV care is required for future planning at local and national levels.

1.3.3.7.1 The role of HIV physicians

There are currently 30 medicine specialities listed by the Joint Royal Colleges of Physicians' Training Board where HIV is listed under both Genito-Urinary Medicine and Infectious Diseases training pathways. Therefore HIV medicine is not at present defined as a separate medical speciality and this may have some influence on how HIV healthcare provision is viewed within the wider medical fraternity.

The more usual HIV training pathway is through Genito-Urinary Medicine that includes HIV inpatient and outpatient care. Trainees are required to undertake a recognised Diploma in HIV Medicine (The Society of the Apothecaries of London 2010) and doctors who are working in the acute hospital care of HIV patients are also expected to maintain their competence in acute internal medicine (British HIV Association 2007). This constitutes a fairly wide range of clinical skills to train and practice in HIV medicine that includes sexual health, HIV and acute medicine.

As the clinical picture of HIV changes the skills spectrum may need to widen even more and it is not clear how this may impact on future training. Over the past few years the British HIV Association have formulated a range of new

guidelines for conditions associated with HIV that include TB co-infection, Hepatitis co-infection, HIV associated malignancies, liver and kidney transplantation, pregnancy, immunisation and sexual and reproductive health (See British HIV Association website). This implies expanding responsibilities for HIV doctors and perhaps a level of sub-specialisation within HIV medicine. Where this will lead in the future and who has primary responsibility for an HIV patient who has multiple co-morbidities or co-infections is not yet clear.

In the HIV clinic setting, data from the HIV Care Pathway development project (discussed under section 1.3.1 in this chapter) indicates that overall HIV doctors were seeing 84% of patients who attend clinic appointments (Department of Health 2011c). These included new, stable and complex patients (see Table 1.2 in section 1.3.1). In view of the increase in the number of HIV patients and the increasing complexity of some patients with co-morbidities, further understanding is required of the role of doctors in caring for clinically stable patients that may comprise up to 80% of the clinic caseload.

1.3.7.2 The role of nurses in HIV healthcare

There is little primary research evidence on the role of HIV nurses in the UK other than the initial work to establish the potential for nurse follow-up clinics for routine stable HIV patients as discussed previously under section 1.3.3.3 in this chapter (Griffiths, Miles and Penny et al. 2006). Further evaluation by the same clinical team showed similar clinical outcomes for patients who attended doctor or nurse clinics (Benn, Shuk Li and Castro Sanchez et al. 2007). While this was

important seminal work on the potential roles for nurses in HIV care in the UK, it is difficult to get a sense of how this has translated beyond one clinical setting due to a paucity of published research material on HIV nursing roles in other UK settings. Furthermore, the nurses in this evaluation and audit were HIV specialist nurses who were specifically trained to undertake this role and who then undertook supplementary prescribing (Castro Sanchez, Kirkpatrick and Miles 2006). This had the potential to define a model of HIV nursing at the time, but there is again little evidence of how this has influenced the development of nursing roles since then.

The literature gives some indication of how nursing roles have changed from a case management approach before antiretroviral therapy (Whitehead 1996) to develop adherence support roles (Loughlin and Jensen 2000), nurse-led clinics (Griffiths, Miles and Penny et al. 2006) and latterly antiretroviral treatment clinics (Ward 2008). Few papers have however taken a systematic research approach to exploring HIV nursing roles and it is conference presentations that give some indication of the breadth of nursing activities being undertaken, by those who are able to attend to share their work. These roles include ageing clinics, annual reviews and nurse-led routine maintenance clinics (Ward 2010; Buckingham 2010; McPeake 2011), but are mostly presented as role descriptions or audits of nursing services. Likewise, there is little primary research on the role of community nurses in the UK or on how these roles contribute to the care of people with HIV since antiretroviral therapy has been established. However the complexity of the HIV community nursing role is frequently outlined in case reports in HIV nursing conferences and in topic specific journals (Thompson

2011; Jelliman 2011). There are some new roles appearing that are based on generic community matron¹⁵ models but no underpinning research as to how these models are applied to HIV care. Training for HIV nurses commonly takes the form of post registration specialist courses but this depends on local availability. There are however national competencies for HIV nurses across the spectrum of HIV care that have been linked to the nursing knowledge and skills framework defined by the Department of Health (National HIV Nurses Association 2007).

Other models of HIV nursing in developed countries tend to focus on advanced practice nursing roles where nurses are specifically trained to undertake physical assessment and non-medical prescribing. In the United States (US) there are HIV nurse practitioner models that work in primary care settings caring for caseloads of HIV patients within an advanced practice model (Trimble 2009). Advanced practice roles are more commonplace within the US setting with clearly defined certification (National Organization of Nurse Practitioners Faculty 2001) and HIV nurses have been incorporated into this established infrastructure. Wilson, Landon and Hirschhorn et al. (2005) compared HIV nurse practitioners with specialist and generalist doctors and concluded that nurse care scored higher on 6 of 8 quality measures than non-HIV generalist physicians. In comparison to HIV physicians, nurses had similar quality of care scores for 6 of 8 measures and scored higher for smear and protein derivative testing. This was a cross sectional study that reviewed medical notes and utilised statistical analysis

¹⁵ Community matrons are utilised in some settings to reduce admissions to hospital in patients with chronic disease although there is mixed evidence on the effectiveness of these roles.

and multiple logit regression to explore associations. However, this was part of a larger study evaluating quality of care training and therefore may not be applicable to areas where this training has not been implemented. In the Netherlands nurse consultants have been ranked in between general physicians and HIV specialist doctors in some aspects of quality care for patients with chronic HIV infection (Hekkink, Wigersma and Yzermans et al. 2005). The authors identified some areas for improvement in their care delivery but did not examine the perspectives of patients who chose not to utilise the nurse consultant.

In other settings, task-shifting¹⁶ of HIV care for stable patients on antiretroviral therapy to nurses and physician assistants has been adopted as an epidemic management strategy to address the volume of patients and shortage of doctors (World Health Organisation 2007). There have been a number of published reports on the successes of task-shifting HIV antiretroviral care monitoring to nurses and/or physician assistants in Sub Saharan Africa (Bedelu, Ford and Hilderbrand et al. 2007; Morris 2009; Shumbusho, van Griensven and Lowrance et al. 2009). Sanne, Orrell and Fox et al. (2010) in their landmark non-inferiority study have demonstrated the effective role of nurses in initiating and managing patients on antiretroviral therapy as part of a decentralisation strategy.

¹⁶ Task shifting is when a particular health task or role is devolved to another healthcare professional, usually from doctors to nurses or physician assistants, and is commonly used in developing countries as a strategy to manage trained staff shortages.

This highlights the lack of evidence concerning HIV nursing roles in the UK and where advanced practice roles may be situated. Given the increasing numbers of patients and the changing spectrum of HIV, it is important to establish how HIV nurses may contribute to the challenges facing HIV healthcare in the UK as nurses have in other countries and for other chronic disease areas.

1.4 Summary of what knowledge is required

The preceding sections have presented what is known about HIV healthcare in the UK and where appropriate has referred to other HIV epidemics or disease areas. Below is a summary of what is currently known and what knowledge is required to further understand the phenomenon of HIV healthcare and to inform the future planning of services. The latter has been placed in italics.

- There are increasing numbers of people infected with HIV in treatment and care and another 22,600 who will need HIV healthcare at some point in the future. *There is limited primary research into different ways of working and the roles of healthcare workers in HIV to inform sustainable models of HIV care within a financially constrained health service. The role of nurses in modernisation of HIV healthcare is relatively unexplored in the UK context.*
- There are diverse groups of people infected with HIV across the UK with specific needs relating to their risk group. *There is little empirical evidence on the models of care that are required to meet the future healthcare needs of the diverse groups of people infected with HIV.*

- The profile of HIV infection is changing. Many patients are classified as medically stable and there are also increasing numbers of patients with co-infections or co-morbidities that may be exacerbated by ageing. *Further understanding of how healthcare workers adapt their practice to respond to the changing needs of people with HIV is required to inform options for future service delivery. In addition, further insight into how HIV patients and services integrate with other healthcare areas is needed to plan cohesive care models.*
- HIV patients are now categorised into stable and complex groups. *However, it is not known how patients perceive their health status and how this may contribute to optimum service delivery.*
- HIV is considered a long-term condition but at present HIV services are delivered and funded differently from other chronic disease areas in the UK. *Further understanding of the concept of HIV as a long-term condition will assist in informing the way that services and care are organised.*
- People with HIV have a high prevalence of physical and psychological symptoms and many experience stigma or discrimination. *It is not known how these factors relate to the way services are viewed or utilised by HIV patients and how this may affect future planning.*
- There are excellent clinical outcomes and high levels of retention in care within the current model of specialist secondary care provision. *However, further exploration of the interactions involved in HIV healthcare is required to understand the factors that may contribute to achieving these outcomes and the implication of this for future care models.*

- Many people with HIV have traditionally been involved in decisions about their care. *It is not clear how this patient-centred model will translate across non-HIV services as utilisation of these services increases.*

In order to contribute to these gaps in knowledge, there was a need to discover what underpins the phenomenon of HIV healthcare as a specialist area in the UK. The overall purpose of this research was to generate an academic theory that explained what was involved in receiving and delivering HIV healthcare in order to inform sustainable future models of HIV healthcare. This research therefore set out to explore the interaction between the perceived healthcare needs of adults with HIV and the processes involved in the delivery of their care.

In keeping with an exploratory grounded theory approach, there were no specific research questions. Instead, the following objectives were intended as a focus for this investigation and were derived from the identified gaps in knowledge.

- To increase further understanding of how people with HIV perceive their condition and how this relates to the way they perceive the role of HIV services
- To explore the roles of healthcare workers in HIV in different service settings and how these respond to the changing needs of patients
- To increase understanding of HIV as a long-term condition from a healthcare perspective

1.5 Chapter summary

UNAIDS (2011) recommends that each country must decide on the best way to deliver HIV services to meet the needs of its HIV population. This introductory chapter has given an overview of HIV in the UK, the changing needs of people with HIV and the current evidence for models of HIV care including the roles of healthcare workers. The chapter includes a summary of what knowledge is required to inform future HIV service planning and has outlined the purpose, intention and focus of the research.

The following section will present the methodology and theoretical framework to address the research goals.

Section 2: Methodology and Methods

This section is comprised of two chapters. Chapter 2 will discuss the theoretical framework and methodological approach to addressing the gaps in knowledge in relation to HIV healthcare provision. The details of the study design will then be presented in Chapter 3 including examples of coding strategies, theory development and memo extracts.

Chapter 2: Methodology and theoretical perspectives

2.0 Introduction to the chapter

The nature of this research into HIV healthcare and the need to explore a range of perspectives on the experience of using and providing HIV healthcare services required an inductive, exploratory methodology conducted in the field. In view of the absence of an academic theory on HIV as a long-term condition, a flexible approach that enabled the researcher to inductively build theory was indicated. In order to capture the interactions between patients and healthcare workers, an appropriate theoretical framework was required to view the research planning process.

To address these methodological concerns, a relativist, constructivist approach to grounded theory has been utilised within a theoretical framework of symbolic interactionism embedded within a pragmatist philosophy.

This chapter will describe the philosophical positioning of the researcher and the application of a theoretical framework to view and understand the interactions that occurred in the HIV field setting. The methodology will be explored in

relation to the aim of the research and the chosen strand of grounded theory will be presented. The key methodological debates and criticisms of grounded theory will be included throughout.

2.1 Philosophical position

The exploratory approach of the research provided a foundation for the philosophical positioning. Therefore, in this thesis, the nature of the research determined the philosophical standpoint. Hence, a pragmatist philosophical approach was adopted that helped to identify the most appropriate methodology and method to explore the pertinent issues in the research topic (Schatzman and Strauss 1973; Mackenzie and Knipe 2006).

Pragmatism is common philosophy used in nursing research to reflect the exploratory nature of enquiry within the discipline. Weaver and Olsen (2006) describe the essence of pragmatism as rooted in action and practice. They state that “The term pragmatism is derived from the Greek word for action, from which the words ‘practice’ and ‘praxis’ originate” (Weaver and Olsen 2006, 466). Pragmatism is therefore a research philosophy that is driven by emerging concepts from the research data and incorporates a dynamic approach to utilising a range of research methods (Schatzman and Strauss 1973; Fulop, Allen and Clarke et al. 2001; Mackenzie and Knipe 2006).

The breadth of enquiry identified by the gaps in knowledge concerning HIV healthcare provision was indicative of a flexible philosophical approach that enabled the adaptation of methods throughout the course of the research. This pragmatist philosophical positioning was also influenced by the researcher's role as a clinician and the motivation to generate an academic theory that had some relevance for patient care and service delivery (Weaver and Olsen 2006). This approach enabled the researcher to explore across the range of micro, meso and macro levels of HIV healthcare delivery (Murphy 2001) and to compare and contrast across the wider healthcare environment. This pragmatic standpoint also assisted in keeping the research focussed on the realities of providing sustainable HIV healthcare services within the current economic climate. Likewise, it afforded the consideration of moral ethics, such as consequentialism and libertarianism, in the planning of future health services. The philosophical assumptions of this research are therefore based on a pragmatist philosophy that incorporates where HIV healthcare will sit within the wider public health agenda and society as a whole.

Some academics maintain that it is the underpinning philosophical beliefs of the researcher that influence the type of research that is undertaken and not indeed the other way round (Crotty 2006; Wisker 2008). This viewpoint however, assumes that research is undertaken exclusively within either a qualitative or quantitative paradigm (Fulop, Allen and Clarke 2001) and does not consider the place for a mixed method approach to research enquiry. Nevertheless, the pursuit of knowledge cannot exist in isolation from the worldview of the researcher (Cohen, Manion and Morrison 2000; Mackenzie and Knipe 2006) and

the pragmatist paradigm bridges the gap between the extremes of qualitative and quantitative research (Schatzman and Strauss 1973; Weaver and Olson 2006).

In order to capture the experiences of both users and providers of HIV healthcare services, a relativist ontology¹⁷ has been adopted for this thesis. This constitutes an ontological belief in an external reality that new models of care are required to respond to the changing needs of people with HIV. However, reality in this context is not believed to be absolute and is perceived to be socially derived by those involved in the research process (Schatzman and Strauss 1973; Strauss and Corbin 1990; Murphy 2001; Charmaz 2006). In essence the ontological view of this research was that reality is complex and multifaceted and the research was therefore not seeking out a single reality in the data. Conversely, the intention was to ascertain an interpreted reality from the data.

In epistemological¹⁸ terms, this research has adopted an interpretivist or constructivist approach; an approach which assumes that knowledge is constructed and that meaning is interpreted in relation to individuals' responses to situations (Cohen, Manion and Morrison 2000; Mackenzie and Knipe 2006). This was of particular relevance in considering the perspectives of a wide range of research participants and in interpreting and conceptualising their individual 'truths'. The interpretivist paradigm was also instrumental in situating the

¹⁷ Ontology refers to the nature of being and world view of reality.

¹⁸ Epistemology refers to the nature of knowledge and truth.

researcher as integral to the research process, given her length of experience in the HIV field (Schatzman and Strauss 1973; Struass and Corbin 1990; Charmaz 2006).

To summarise this section, this research into HIV healthcare in the UK was underpinned by a pragmatist philosophy. Reality was viewed from a relativist position and knowledge or truth perceived to be interpreted differently by individuals. This positioning influenced the selection of an appropriate theoretical framework that reflected the nature of the research and the interactions involved in the field of HIV healthcare.

2.2 Theoretical framework

“The elementary unit of social life is the individual human action. To explain social institutions and social change is to show how they arise as the result of the action and interaction of individuals” (Elster 1989: 13)

This is a study of healthcare services which set out to explore the interactions between the perceived needs of people with HIV and the processes involved in their healthcare provision. Healthcare services function within complex social systems that are comprised of complex social interactions at a number of levels (Chenitz and Swanson 1986; Pawson, Greenhalgh and Harvey et al. 2005; Conry, Humphries and Morgan et al. 2012). In order to capture this complexity,

symbolic interactionism has been utilised as the theoretical framework for this thesis.

Symbolic interactionism originated from a pragmatist philosophical belief that humans function as 'meaning-makers' in relation to each other and within the social contexts in which they exist (Blumer 1969). It assumes that people behave on the basis of symbolic meaning, that meaning is the result of interactions with others and is constantly revised (Blumer 1969; Aggleton 1990; Burbank and Martins 2009). Thus behaviour is believed to be socially determined and society constructed through symbolic interactions between individuals and social groups (Blumer 1969; Chenitz and Swanson 1986; Benzies and Allen 2001; Klunklin and Greenwood 2006).

The aim of using this symbolic interactionist approach was to adopt a framework which would allow the researcher to view and understand the interactions that occurred within the research field. This interactionist framework enabled the exploration of relationships and perceptions of HIV from patient and healthcare worker perspectives (Schatzman and Strauss 1973; Charmaz 2006a). The principles of symbolic interactionism were also used to view and interpret the data. This was particularly relevant in understanding the processes involved in how people with HIV perceived themselves in relation to their interactions with other people (Chenitz and Swanson 1986; Aggleton 1990). In this way, symbolic interactionism was utilised in conceptualising how people with HIV defined themselves in relation to their communities or to society in general. This

theoretical framework also helped to situate the different healthcare worker disciplines in relation to each other and to the wider healthcare environment.

Symbolic interactionism is partially informed by the evolutionary theory that individuals are constantly adapting to their environment and that successful adaptation will be influenced by both the social environment and the characteristics of the individual (Benzies and Allen 2001). In this context symbolic interactionism has been applied to a wide range of healthcare situations including disease classification and work environments (Chenitz and Swanson 1986; Burbank and Martins 2009). In order to capture the changing HIV healthcare environment, this interactionist framework was utilised to view the responses of patients and healthcare workers to the way care delivery had changed. Behaviour is believed to illuminate the symbolic meaning that underpins individual and group actions (Chenitz and Swanson 1986) and this was relevant for understanding the symbolic significance of the way patients used HIV services and healthcare workers organised service delivery.

The adaptive strategies of healthcare workers were also explored to compare the symbolic meaning underlying changes in service delivery with the illness perceptions of patients. The use of symbolic interactionism as a theoretical framework has therefore enabled a dynamic research approach that responded to the constantly evolving nature of HIV treatment and service provision (Burbank and Martins 2009).

The inherent difficulty with an interactionist approach is that meaning may be interpreted differently by different actors in the same situation (Blumer 1969; Schatzman and Strauss 1973; Aggleton 1990). For the purposes of this research, the understanding of those differences was the very essence of developing a theory on HIV healthcare. This understanding was assisted by the use of constant comparative analysis of concepts in the data and by exploring the data from a range of perspectives (see the following section for methodological detail). In addition, the approach to conducting the research interviews was intended to elicit meaning and co-construct knowledge. Therefore, the interviews were viewed as interactional events (Holstein and Gubrium 1995; Rapley 2006) and utilised as an opportunity for the interviewer and interviewees to develop shared meaning (Holstein and Gubrium 1995, 1998; Roulston 2010). In this way each interview was actively navigated to explicate individual and symbolic meaning for the range of participants in the research.

The use of symbolic interactionism as a theoretical framework for this research has enabled the researcher to view the complexities of HIV healthcare within a cohesive structure that focuses on the meaning of interactions. This has been instrumental in situating the perceptions of patients and healthcare workers in using and delivering HIV services and in capturing the symbolic meaning associated with a changing disease profile.

2.2.1 Ethical framework

In addition to the theoretical framework and philosophical approach, there were various bioethical considerations involved in undertaking this research. In the process of applying for NHS research ethics approval, a principlist ethical framework was adopted utilising Beauchamp and Childress' (2001) four principles of justice, respect for autonomy, beneficence and non-maleficence.

While a principlist bioethical approach was steered by the NHS ethics approval application, it also provided a structure against which to assess and balance the potential value of the research and the potential risks and benefits to participants. In this sense, principlism provided a moral compass which informed some aspects of the research method. Although the ethical considerations in this research are discussed in more detail in Chapter 3, Figure 2.1 shows how the four bioethical principles impacted on the study design.

Bioethical principle	Relevance to this research topic	Impact on research method
Justice	Fairness and right to participate and right not to participate for patients and staff	<ul style="list-style-type: none"> • Recruitment and sampling techniques • Appropriate use of gatekeepers • Confidentiality of those declining to participate
Respect for autonomy	Freedom of patients and staff to choose to participate	<ul style="list-style-type: none"> • Passive recruitment with opt in participation • Informed choice to participate
Non-maleficence	Do no harm – protect confidentiality, potential for psychological distress or anxiety, concerns about future healthcare provision	<ul style="list-style-type: none"> • Assess capacity to consent • Identify support structures in event of psychological distress • Interview agenda and approach to questions • Exclusion criteria • Participant coding strategy • Data protection
Beneficence	No direct individual benefit from participation but results intended to inform future HIV care delivery	<ul style="list-style-type: none"> • Explicit participant information to enable informed consent • Written consent • Formation of Patient Advisory Panel

Figure 2.1: Application of bioethical principles to the research method

This moral compass guided the decision to include HIV positive patients in the research. For example, the principles of autonomy and justice guided the study design so that HIV patients were offered the opportunity to participate. Using the concept of non-maleficence, one could equally argue that excluding patients with HIV would significantly reduce the end value to users of the services.

Although the principlist approach is well-recognised in research ethics (Department of Health 2005b), there is considerable debate surrounding whether this approach is too structured and represents moral imperialism in healthcare (Harris 2003; Campbell 2003). Macklin (2003), for example, suggests that the principlist approach disregards the social context of the four principles and that they are open to interpretation and different analysis. Others suggest that the principlist approach serves merely as a checklist for potentially complex ethical circumstances as one principle will inevitably take precedence over the other three (Gillon 1994; Harris 2003; McCarthy 2003; Lawrence 2007). Gillon (2003), for example, suggests that respect for autonomy overrides justice, beneficence and non-maleficence and that free will underpins the evaluation of justice, beneficence and non-maleficence in healthcare ethics.

This implies that the principlist approach to bioethics may not be consistent with the relativist ontology of the researcher that incorporates multiple interpretations of reality. However, in this research on HIV healthcare this was mitigated by the use of 'reflective equilibrium' where each ethical principle was given equal consideration (Beauchamp and Childress 2001; McCarthy 2003; Lawrence 2007). The opinion of service users in the ethics application also contributed to the inclusion of the relativist approach in the bioethical framework.

In addition, narrative ethics were applied in research practice when, for example, capacity to consent to participate in the research was a potential issue. Narrative ethics focus on an individualistic approach to balancing the four principles of

bioethics and are more concerned with intuition and critical skills than with the prescribed norms of the principlist approach (Lawrence 2007). This approach advocates assessing individual situations and facilitating discussions about potential conflicts in ethical values (Frank 1995; McCarthy 2003).

Finally, moral ethics were considered in exploring how the care of people with HIV could be situated within the wider healthcare environment. The financial constraints on the health service require a fine balance between a libertarian philosophy that protects the rights of individuals and a consequentialist philosophy that is concerned with maximising the greater good for the most number of people. Therefore, these ethical philosophies were integrated into data collection, analysis and theory development. In this way a combination of ethical frameworks was adopted across the research process in keeping with a relativist ontology and pragmatist philosophy.

This section has presented the philosophical positioning and theoretical perspective of the research and explained the ethical approaches used throughout. The pragmatist philosophy and symbolic interactionist framework were integral to defining an appropriate methodology for conducting this research and this will be discussed in detail in the following section.

2.3 Methodology

This section will present the methodological approaches that informed the data collection and analysis. It will include the rationale for utilising a grounded theory approach and describe why dimensional analysis was indicated for this research. The section will outline the core components of grounded theory and examine the particular strands of grounded theory that were used to develop a substantive theory of HIV healthcare provision. The key debates in grounded theory will be explored throughout the section.

2.3.1 Introduction to the methodology

In order to attend to the gaps in knowledge and the aim of the research outlined in Section 1.4, an appropriate methodology was required to reflect the dynamic nature of HIV as an illness and the changing picture of HIV service provision. As little was known about the future configuration of HIV services, an inductive as opposed to deductive approach was indicated (Murphy 2001). A flexible methodological approach was also required to capture the variation in need and practice across HIV services and to incorporate the perspectives of different stakeholders. In the absence of an academic theory on HIV service provision or the transferability of other chronic disease models, an appropriate sampling strategy was necessary to explore emerging concepts from the research data (Charmaz 2006). Ultimately, in order to inform future models of HIV service

delivery, the research methodology was required to lead to the evolution of a substantive or middle-range¹⁹ sociological theory in the field of HIV healthcare.

2.3.2 Introduction to grounded theory

Grounded theory is methodology that studies humans in a real world setting, develops theory derived from field data and utilises an inductive approach that responds to emergent data. This methodology uses theoretical sampling to support the development of theory. Grounded theory is more commonly used for qualitative inquiry, but it does not exclusively sit within a qualitative paradigm and can access a range of data sources to contribute to theory building (Glaser and Strauss 1967; Glaser 1978; Glaser 2004; Glaser 2007; Stern 2007).

There are considerable debates on the essence of grounded theory as a methodology that are largely centred on how data is perceived and analysed and how theory is built from data concepts (Cutcliffe 2000; Boychuk Duchscher and Morgan 2004; Heath and Cowley 2004; Warburton 2005; Hood 2007; Buckley and Waring 2009; Walls, Parahoo and Fleming 2010). These factors will be explored in detail in Section 2.3.4. However, there are core components of grounded theory that set it aside from other qualitative methodologies and that are evident in the key texts of leading academics in the field (Glaser 1978, Strauss and Corbin 1998; Glaser 2004; Charmaz 2006a; Bryant and Charmaz 2007; Morse 2009; Stern 2009; Urquhart 2013. These can be summarised as follows:

¹⁹ Middle-range sociological theories are theories derived from empirical evidence

- Core components of grounded theory
 - Systematically generating concepts from the data
 - Constant comparative analysis of data concepts
 - Developing and relating concepts in the data
 - Defining the process that is occurring in the data
 - Developing a substantive or formal theory that is grounded in data

Grounded theory as a methodology is therefore of particular relevance in a research area where little is known or understood about the phenomenon under investigation. It is these core components that underpinned the justification for using a grounded theory approach in this research.

2.3.3 Rationale for using grounded theory

Grounded theory has a long history of developing substantive and formal theories that are derived from research data. Many of the early studies in grounded theory were in healthcare institutions exploring patient or healthcare worker behaviours (Glaser and Strauss 1968; Strauss and Corbin 1990; Charmaz 1994; Kools, McCarthy and Durham et al. 1996). Likewise, grounded theory has commonly been used as a methodology to understand and define complex social phenomena. Some of the theories that arose from those early studies included status passage (Glaser and Strauss 1971); negotiated order (Strauss, Schatzman and Ehrlich et al. 1994); identity in chronic illness (Charmaz 1990); and nurses' philosophies of aging (Kools, McCarthy and Durham et al. 1996).

In the HIV setting, grounded theory has been used to explore risk behaviours, patient experiences and healthcare workers' perceptions (De Wit, Teunis and Godfried et al. 1994; Barfod, Hecht and Rubow et al. 2006; Perrett and Biley 2012). Some theories that have emerged from the HIV studies are believability of patient statements on adherence (Barfod, Hecht and Rubow et al. 2006) and negotiating uncertainty in adapting to HIV (Perrett and Biley 2012). The substantive or formal theory that develops from this methodology is grounded in data, lasting and abstract of time or place (Glaser and Strauss 1967; Glaser 1978; Strauss and Corbin 1990; Charmaz 2006) and was therefore of particular relevance for informing the future delivery of HIV healthcare at regional and national levels.

To incorporate the multiple perspectives across patient and healthcare worker participants, a robust strategy for analysis was indicated. The constant comparative analysis strategy is fundamental to grounded theory methodology and involves a continual process of comparing concepts that arise from data (Glaser and Strauss 1967; Schatzman and Struass 1973; Strauss and Corbin 1990; McCann and Clark 2003b; Charmaz 2006; Charmaz 2009; Bowers and Schatzman 2009). This was particularly useful in capturing the breadth and variability in the HIV data and to inform further data collection or data interrogation.

One strand of grounded theory utilises an additional analysis strategy alongside the constant comparative method. This is known as dimensional analysis and makes use of the natural ability of people to analyse everyday situations (Schatzman and Strauss 1973; Schatzman 1991; Robrect 1995; Bowers and Schatzman 2009). This approach was consistent with the researcher's primary role as a clinical nurse and enabled that experience to be appropriately utilised in analysing data and developing theory.

As this HIV research intended to explore the interactions between patients with HIV and the processes of their healthcare, a systematic approach was required to develop concepts from across the participant data. The key methodological texts on grounded theory provide a range of structured processes for generating concepts from the data and for making links between conceptions (Strauss and Corbin 1990; Schatzman 1991; Kools, McCarthy and Durham 1996; Glaser 2002; Charmaz 2006). This enabled a tried and tested approach to organising data concepts and linking those concepts as building blocks to be used to develop a theory that could inform future HIV healthcare planning. Given the complexity between patient perceptions, service utilisation and service delivery, a methodology was required that had the potential to explain the intricacy of the data and the connections between them.

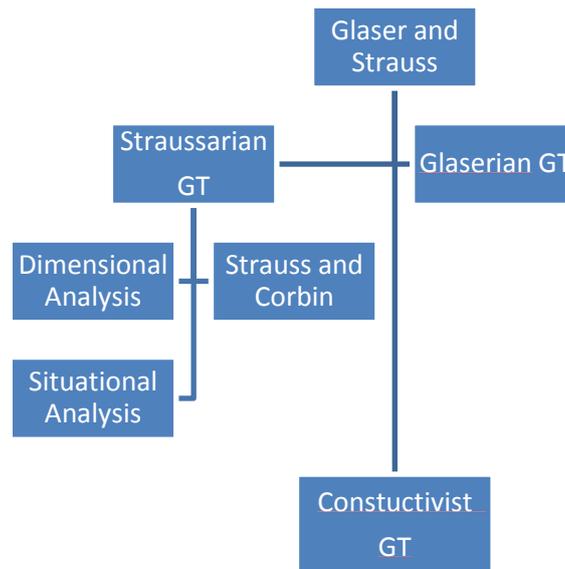
In addition, grounded theory was initially rooted in symbolic interactionism. Although not all current approaches to grounded theory recognise symbolic interactionism as an underpinning theoretical framework, many of the seminal

texts support and recognise its role (Schatzman and Strauss 1973; Strauss and Corbin 1990; Charmaz 2006). There are evident similarities between the principles of grounded theory and the fundamental tenets of symbolic interactionism and this was consistent with the exploration of interactions in the HIV healthcare setting.

As a methodology, grounded theory had many elements which would address the research aim and guide the development of theory in the field of HIV healthcare delivery. However, many different approaches to grounded theory have developed over the past forty years and the following section will examine these and present the approach undertaken in this thesis.

2.3.4 The strands of grounded theory

Since the publication of the first grounded theory text *Discovery of Grounded Theory: strategies for qualitative research* by Barney Glaser and Anselm Strauss in 1967, several strands have evolved. These include Glaserian grounded theory, Straussarian grounded theory, Dimensional Analysis, Constructivist grounded theory and Situational Analysis (Morse 2009) as shown in Figure 2.2.



Source: Adapted from Morse 2009

Figure 2.2: Strands of Grounded Theory (GT)

These strands represent different philosophical positioning on grounded theory as a methodology and influence all aspects of the research cycle from literature searching to the integration of theory. In this sense, grounded theory methodology has been viewed as a “way of thinking about data” (Morse 2009, 14) and this will be explored further in relation to the strand of grounded theory that was utilised for this research.

Philosophically, grounded theory has developed down two main ontological and epistemological pathways (see footnotes 17 and 18 in Section 2.1). Glaser (2004) has maintained a realist, objectivist approach to grounded theory and advocates that research is conducted from a value-free standpoint. Although Glaser refutes that the data itself represents ‘truth’ or ‘reality’ (Glaser 2007), elsewhere he maintains that the data reflects what is really happening (Glaser

2004). He also upholds the view that the pattern in the data and the inherent social process is 'discovered' through constant comparison and conceptualising (Glaser 2007). This equates to a world view or ontology that reality exists independently and an epistemology that embraces the concept of truth that is waiting to be discovered (Crotty 2006; Cohen, Manion and Morrison 2000; Mackenzie and Knipe 2006). This classic grounded theory philosophy assumes that research is undertaken from a value-free position and that the researcher has minimal impact on the research or the interpretation of results. It also assumes that conceptualisation exists independently of interpretation.

In contrast Anselm Strauss, the co-author of the original text on the *Discovery of Grounded Theory* (1967) had a relativist view of the world and believed that knowledge was constructed and interpreted differently by individuals (Strauss and Corbin 1990; Strauss and Corbin 1998; Corbin and Strauss 2008). Strauss' *way of thinking about data* was not to deny the existence of reality or truth but to view it as relative and experienced from multiple perspectives (Strauss and Corbin 1990; Strauss and Corbin 1998; McCann and Clark 2003b; Mills, Bonner and Francis 2006). This approach acknowledges the influence of the researcher in the research process although this is treated differently in the diverse strands that exist within this ontological and epistemological view of grounded theory (Schatzman and Strauss 1973; Schatzman 1991; Charmaz 2006). The seminal text *Discovery of Grounded Theory* (1967) therefore originated as a hybrid of two world views (Morse 2009; Charmaz 2009) but it was mostly Strauss's approach that went on to inform the development of other strands of grounded theory (Schatzman and Strauss 1973; Strauss and Corbin 1990; Schatzman 1991;

Charmaz 2006; Corbin and Strauss 2008; Charmaz 2009). These strands, that include Staussarian grounded theory, Dimensional Analysis and Constructivist grounded theory have become known as second generation grounded theory (Morse 2009). A summary of the philosophical pathways that have evolved in grounded theory is shown in Figure 2.3.

OBJECTIVIST GROUNDED THEORY	CONSTRUCTIVIST GROUNDED THEORY
Ontological Assumption: Realist	Ontological Assumption: Idealism or relativism
Epistemology: Objectivism	Epistemology: Constructivism
Theoretical Perspective: Postpositivism	Theoretical Perspective: Interpretivism/Constructivism
Research area is devoid of pre-existing theory	Inherent relationship between the researcher and the chosen area of research
Data is real and discovered by the researcher	Data and analysis are socially constructed
Theory is emergent	Theory is an interpretation of emerging concepts

Figure 2.3: Summary of philosophical pathways in grounded theory

The philosophical pathways discussed above illustrate the different approaches towards grounded theory as a research methodology. Certainly, one of the main criticisms of grounded theory methodology is that it does not have a consistent ontological and epistemological approach to thinking about data (Cutcliffe 2000; Boychuk Duchscher and Morgan 2004; Heath and Cowley 2004; Warburton

2005; Buckley and Waring 2009). Some consider that this “internal misalignment” may affect its standing as a research methodology (Jones and Alony 2011, 98).

Glaser (2004, 2007, 2010c) posits that classic grounded theory is a pure method-methodology package in itself that is not based solely on the core principles of constant comparison, emergent concepts and development of theory grounded in data. He therefore believes that any deviance from the classic grounded theory package cannot be called grounded theory (Glaser 1978; Glaser 2010c). As such, he views it as a method and as a product in the same way as a randomised control trial is applied in other research situations (Glaser 2010c). On the contrary, Bryant and Charmaz (2007) view grounded theory as a ‘family of methods’ that share similarities and principles in application but that may be approached from different philosophical standpoints. The strands of grounded theory that have evolved in the past forty years are testament to this concept of family variances and to the contemporary application of grounded theory to different areas of study (Bryant and Charmaz 2007; Morse 2009).

The very essence of a grounded theory enquiry is that methods will evolve as the study progresses (Schatzman and Strauss 1973; Schatzman 1991; Charmaz 2006; Charmaz 2009) and therefore it can be difficult to adhere to a specific set of procedures. In this sense a pragmatic approach was taken to using the strands of grounded theory methods that were appropriate for the research aim

and the evolving concepts from the HIV research data (Schatzman and Strauss 1973; Schatzman 1991; Charmaz 2006; Mackenzie and Knipe 2006). This “way of thinking about data” in this HIV research was to embed the core components of grounded theory (Section 2.3.2) and utilise relevant grounded theory methods to fit the emerging data while aiming to maintain a consistent relativist and interpretivist position.

The methodology used for this research has been referred to as a grounded theory approach in order to distinguish it from the classic grounded theory strand that is viewed as a method/methodology package (Glaser 1978; Glaser 2010c). While the specifics of this approach to using grounded theory will continue to be explored in the rest of this chapter and are summarised in Section 2.4, the use of the term *grounded theory approach* is made within the context of second generation constructivist grounded theory. This approach refers to the use of a family of recognised grounded theory methods and therefore is not considered as generic qualitative data analysis.

2.3.5 Methodological considerations when using grounded theory

The following methodological considerations will be explored in this section:

- The use of literature
- Comparison of concepts and cases
- Dimensional analysis
- The role of the researcher

- Development of theory

2.3.5.1 The use of literature in grounded theory

A preliminary literature search was undertaken to situate the research and identify gaps in knowledge in the field of HIV healthcare provision. While this is usual practice in most research methodologies, the use of a literature review prior to undertaking grounded theory research is highly contested between classic grounded theorists and second generation proponents of grounded theory. This debate is centred on a belief in the role of literature in forming *a priori* theories about the research subject (Chenitz and Swanson 1986; Cutcliffe 2000; Heath and Cowley 2004; Bryant and Charmaz 2007).

Glaser (1978, 2010d) believes that conducting a literature search prior to entering the field exposes the researcher to existing theories in the topic, will influence how they perceive emerging data and may lead to forced conceptions. He maintains that extant theories should only be explored to test theories that emerge from the data (Glaser 2010d; Walls, Parahoo and Fleming 2010). Other grounded theorists support the use of a preliminary literature review to sensitise the researcher to the topic and key debates in the subject area (Strauss and Corbin 1990; Charmaz 2006; Walls, Parahoo and Fleming 2010).

The rationale for undertaking a literature review for this study was threefold:

1. The nature of the reflexive²⁰ approach to constructivist grounded theory is intended to acknowledge preconceptions in the field and this could include assumptions from the literature.
2. The constant comparative analysis method is designed to seek out concepts within the data and further distance preconceptions from emerging theory (Schatzman 1991; Glaser 2004; Charmaz 2006; Corbin and Strauss 2008).
3. The researcher needs to be aware of the dialogue within their discipline to be sure they are adding to the existing body of knowledge (Cutcliffe 2000; Heath and Cowley 2004; Bryant and Charmaz 2007).

This third point has been summarised by Lempert: “In order to participate in the current theoretical conversation, I need to understand it. I must recognise that what may seem like a totally new idea to me (an innovative breakthrough in my research) may simply be a reflection of my ignorance of the present conversation” (Lempert 2007, 254). This statement had particular relevance for the researcher who was unfamiliar with the academic theories in the field. Therefore a pragmatic approach was adopted and a preliminary literature search undertaken to situate the HIV research and sensitise the researcher to the main issues and theories in HIV healthcare and chronic disease models.

²⁰ A reflexive approach or reflexivity is a self-reflective process that explores the researcher’s beliefs about the world and how these may impact on the research findings and the development of theory.

Literature sources were also utilised to explore concepts as they arose in the data and as theory was being developed. This was again reflective of the above comments made by Lempert (2007, 254) and intended to guide the development of theory and validation of concepts (Strauss and Corbin 1990; Charmaz 2006; Walls, Parahoo and Fleming 2010). At times literature was also used as a secondary data source to place the research findings within a wider healthcare context. One criticism of this is that it has the potential to create difficulties by forcing concepts or generating theory too early (Glaser 1978; Heath and Cowley 2004; Glaser 2010d). However, this was addressed again through the constant comparison method and by keeping the concepts and theory grounded in the data (Strauss and Corbin 1990; Cutcliffe 2000; Charmaz 2006; Walls, Parahoo and Fleming 2010). Glaser, himself, refers to constant comparative analysis as the panacea for managing potential bias in theory development. If undertaken correctly, in Glaser's own words, "constant comparison will show the underlying bias as it emerges – for bias is just another variable" (Glaser 2007, 7).

In dimensional analysis, interpreted theory is judged in terms of its relevance to other data concepts (Schatzman and Strauss 1973; Schatzman 1991). The act of moving between the data concepts, categories, literature sources, memos, and reflexive diaries can successfully protect against forcing received theories onto the data (Charmaz 2006; Hoare, Mills and Francis 2012). Literature sources were therefore used initially to sensitise the researcher to the issues and dialogue in HIV healthcare and later to explore concepts and theories that were consistent with the emergent themes from the research data.

2.3.5.2 Identifying the field

In order to explore the interactions and processes within HIV healthcare and to inform future models of HIV healthcare delivery, it was necessary for the researcher to immerse herself into the worlds of the participants to gain a deeper understanding of the research topic. Grounded theory is undertaken in real world settings to enable the study of naturally occurring phenomena in situ (Schatzman and Strauss 1973; Emerson 2004; Denzin and Lincoln 2005). As a methodological approach, working in the field can assist in leading the researcher to identify the real problem during the course of the study (Schatzman and Strauss 1973).

The 'field' or 'world setting' for this research that was identified as common to both patients and healthcare workers was the HIV clinic setting. This setting enabled the researcher to explore study participants and their interactions in their shared environment (Schatzman and Strauss 1973; Lincoln and Guba 1985; Gillham 2000; Emerson 2004) and to incorporate some participant observation in the research design. Although this was perceived as the shared world for potential participants, at times, the field extended beyond the HIV clinic setting to include other HIV services or healthcare professionals working with people with HIV. This was influenced by emerging data concepts or by working hypotheses as data analysis progressed (Schatzman and Strauss 1973).

2.3.5.3 Concepts and cases for comparison

As discussed earlier, constant comparative analysis is one of the core components of a grounded theory approach. Constant comparative analysis is a continual process of comparing concepts in the data to explore similarities and differences and as a stepping stone towards developing theory (Glaser and Strauss 1967; Strauss and Corbin 1990; McCann and Clark 2003b; Charmaz 2006). The use of constant comparative analysis highlights where the researcher has placed their own values on the data concepts and continual comparison dilutes this effect (Glaser 2007). This comparing of concepts across the data was of particular relevance in conceptualising what was occurring in the utilisation and delivery of HIV healthcare from the perspectives of both patient and healthcare worker participants. This method enabled the researcher to further abstract from her experience in the field and to explore the research topic through the concepts that were emerging (Glaser 2002; 2007).

Constant comparative analysis is intended to commence at the beginning of data collection (Glaser 2002; Strauss and Corbin 1990). This can, however, lead to the forcing of concepts early in data analysis before there are sufficient and grounded data concepts to compare (Schatzman 1991; Bowers and Schatzman 2009). Therefore, constant comparative analysis was utilised in this research following initial data collection and the development of initial concepts.

In order to increase the transferability of the research findings, several HIV service sites were included in the data collection (Strauss and Corbin 1990).

These research sites served as cases for comparison to assist the analysis strategy and to increase the trustworthiness and transferability of the research findings (Erlandson, Harris and Skipper et al. 1993; Stake 1995; Gillham 2000; Yin 2009). The methodology therefore utilised discrete contexts to generate and compare concepts in the data with regard to the interactions and processes involved in HIV healthcare in a UK setting (Schatzman and Strauss 1973; Strauss and Corbin 1990).

One of the main criticisms of selecting cases for comparison is the limited generalisability of the findings given the contextual nature of the data (Stake 1995; Yin 2009). For this reason the research sites were purposively selected to represent variance in service structure. HIV services were generally delivered through HIV Units²¹ or HIV Centres²² within clinical or managed network structures²³ (Medical Foundation for AIDS and Sexual Health 2003; British HIV Association 2007). The number of patients within these services varies from around two hundred patients to several thousand. The selection of different sites representing these structures enabled an understanding of context in relation to the symbolic interactions of HIV patients and healthcare workers in a range of settings (Stake 1995; Fulop, Allen and Clarke 2001; Flyvbjerg 2004).

²¹ HIV Units as defined by BHIVA Standards “providing outpatient care for the majority of patients with uncomplicated HIV infection” (British HIV Association 2007, 1).

²² HIV Centres as defined by BHIVA Standards “providing services for patients with more specialised needs, including complex outpatient care, inpatient care and referral/advice services” (British HIV Association 2007, 1).

²³ HIV Service Networks Comprised of HIV Units and HIV Centres with linked pathways of care across organisations in the network including community and mental health services and non-statutory support services (Medical Foundation for AIDS and Sexual Health 2003; British HIV Association 2007).

In qualitative research generalisation of findings is more applicable to the nature of the process than it is to populations (Gobo 2004). However, the use of different service contexts was intended to increase the transferability of the findings beyond the chosen research sites (Erlandson, Harris and Skipper et al. 1993; Flyvbjerg 2004). This approach enabled the researcher to seek out the 'black swan' in the data to support and strengthen the data concepts and theoretical development (Flyvbjerg 2004). The definition of a 'case' for comparison was based on a theoretical boundary as opposed to a geographical boundary in order to reflect the exploratory nature of the research and to increase the opportunities for sampling based on theoretical concepts (Schatzman and Strauss 1973). In this way there was the potential to generate theory that may be applicable to other areas.

These cases for comparison were explicitly used to compare concepts in the data utilising a grounded theory approach where and when this was relevant to emergent data conceptions (Schatzman 1973; Strauss and Corbin 1990).

2.3.5.4 Dimensional analysis

In addition to the constant comparative method, the analytical approach in this HIV healthcare research was based on utilising the researcher's "dimensions of experience" (Schatzman 1991, 307) to name and develop concepts in the data and also to build a theory from the data. This is known as dimensional analysis and draws on the natural ability of individuals to analyse complex situations and

derive meaning (Schatzman 1991; Robrecht 1995; Kools, McCarthy and Durham 1996; Bowers and Schatzman 2009).

Dimensional analysis is a strand of grounded theory that evolved early in the genealogy of the methodology (Schatzman and Strauss; Schatzman 1991; Robrecht 1995; Kools, McCarthy and Durham et al. 1996; Morse 2009). This strand was developed by Leonard Schatzman who worked with both Glaser and Strauss in the University of California and was involved in field research with Strauss in psychiatric institutions (Schatzman and Strauss 1973; Bowers and Schatzman 2009; Gilgun 2010). Dimensional analysis is informed by the symbolic interactionist belief that humans respond to situations based on the meaning they interpret in those situations (Robrecht 1995; Kools, McCarthy and Durham 1996) and therefore inherently includes the researcher perspective as part of the research process.

The experience of the researcher in the field of HIV healthcare had the potential to influence the research process and the development of a robust substantive theory. However, the perspective of the researcher, her professional experience and professional networks were viewed as “contextual controls” in the research process (Schatzman and Strauss 1973, 9). Schatzman treats these perspectives as “angles of observation” that increase analytical ability and agility (Schatzman and Strauss 1973, 55). The publication *Field Research; Strategies for a Natural Sociology*, although nominally co-authored by Strauss, was one of Schatzman’s main publications on the concept of dimensional analysis. In this text, analysis is

described as “thinking, objectified and operationalized” (Schatzman and Strauss 1973, 109) and is approached in a systematic fashion that both engages the researcher’s experience in the identification of data concepts and distances the researcher by the application of multiple perspectives when conceptualising theory. In this way, data analysis involved using the researcher’s experience of working in the HIV field to analyse the data and break it down into components to derive meaning (Schatzman 1991; Kools, McCarthy and Durham et al. 1996).

This methodology of data analysis assumes that the researcher can hold multiple perspectives at the same time in the same way that people do in everyday situations (Schatzman 1991; Morse 2009). The use of both patients and healthcare workers contributed a range of different perspectives on the research topic and data analysis was therefore based on a combination of the researcher’s perspective or ‘dimension’ and the perspectives of the research participants (Bowers and Schatzman 2009).

The concept of perspective was also fundamental to the development of theory where an explanatory matrix was used to identify the key dimension or perspective that was central to explaining the relationships between the concepts (Schatzman 1991; Kools, McCarthy and Durham 1996; Gilgun 2010). This central organising perspective highlighted which dimensions served as context, conditions, processes and outcomes and subsequently provided the foundation for the theory of the healthy-illness representation of HIV. Therefore, perspective

was embedded throughout the methodology and was instrumental in informing the methods used for the research.

The coding of data was integral to the process of analysis and in view of the breadth of the research aim a coding strategy that captured the phenomenon of HIV healthcare was required. The aim of dimensional analysis is to explain “what ‘all’ is involved here” (Schatzman 1991, 310) and constitutes the labelling of component parts of what is occurring in the data. This involves the naming or designation of data chunks and the development of dimensions and their properties. As described by Kools, McCarthy and Durham “The key process in dimensional analysis is the construction or novel reconstruction of the multiple components of a complex social phenomenon” (1996, 316).

Therefore, instead of the line by line coding advocated by some grounded theorists (Strauss and Corbin 1990; Charmaz 2006), chunks of data were coded or named as data collection commenced. This naming or designation of data represented the beginning of developing concepts from the data and the formation of dimensions and properties. These dimensions were viewed as abstract concepts that were broken down into component parts or properties (Kools, McCarthy and Durham 1996). It was these dimensions and properties that comprised the main concerns of participants in the study.

Although Strauss and Charmaz utilise different coding strategies, both authors support the premise that the ‘naming’ of a concept gives that concept some

meaning or classification (Strauss 1977; Charmaz 2006b). This approach to viewing dimensions as abstract concepts also served to move the researcher away from concrete processes and to develop conceptual perspectives of the data (Schatzman and Strauss 1973; Schatzman 1991). As more data was gathered and dimensions revised, this enabled further abstraction and conceptual development.

The dimensional analysis strand of grounded theory therefore provided a framework that used perspective to capitalise on the experience of the researcher while utilising recognised approaches to scrutinise the researcher effect and create conceptual distance during analysis.

2.3.5.5 Developing theory

Grounded theory is the study of a concept that goes beyond description and is intended to make a theoretical contribution to the area under study (Glaser 2010a). The use of coding strategies and comparative analysis is the first stage in developing theoretical concepts in grounded theory. The methodological approaches to these and the use of dimensional analysis and an explanatory matrix have been covered earlier in this chapter. However, there were a number of other methodological considerations for developing a substantive theory that related to the interactions involved in HIV healthcare. These will now be addressed in this section.

1. Theoretical sampling

Theoretical sampling is a sampling strategy that is based on exploring the emerging theory in the data (Glaser 1978). This involved the selection of participants with particular characteristics that enabled further exploration of theoretical constructs. This sampling approach was utilised once consistent data concepts were developed (Schatzman and Strauss 1973; Corbin and Strauss 2008) and drove the subsequent recruitment strategy. Theoretical sampling occurred alongside coding, constant comparison and formation and revision of dimensions. Thus, an inductive-deductive cycle of exploring and collecting data ensued (Glaser 1978; Hoare, Mills and Francis 2012).

2. The researcher as the main research tool

In field research, such as grounded theory, one or more researchers are usually the main research tool and this can have an impact upon data quality and the trustworthiness of the research undertaken (Gobo 2004; Denzin and Lincoln 2005). Proponents of second generation grounded theory view the researcher as central to the interpretation of the research findings (Schatzman and Strauss 1973; Strauss and Corbin 1990; Schatzman 1991; Charmaz 2006; Charmaz 2009). Schatzman and Strauss (1973) maintain that the research findings are actually the researcher's findings although this is more reflective of the views of Schatzman than those of Strauss. Charmaz states "the 'it' we take apart is seldom something so concrete and tangible that everyone views it from the same starting point and standpoint" (Charmaz 2009, 146).

This was of particular relevance given the researcher's experience in the field of HIV and the need to balance this experience with maintaining data quality and trustworthiness (Gobo 2004; Denzin and Lincoln 2005). While the use of constant comparison and dimensionalising assisted in creating conceptual distance from the data, the implicit assumptions of the researcher needed to be actively managed. This involved the use of extensive field notes and a systematic approach to reflexively managing the data to maintain sociological distance throughout data collection, data analysis and theoretical integration (Schatzman 1973; Nightingale and Crombie 1999; Willig 2001; Charmaz 2006).

Reflexivity is described as the researcher's awareness of their inherent involvement in the research process and assumes that objectivity cannot exist in research practice (Willig 2001; Roulston 2010). The application of reflexivity in this research involved exploration by the researcher in relation to how she individually shaped and interpreted the research (Nightingale and Cromby 1999). This approach was distinct from 'reflection', which is a process of learning from one's own experience through critical examination and is more commonly applied to clinical practice settings, such as nursing (Johns 1998). While both reflection and reflexivity were used throughout the research cycle, reflection is more concerned with personal and professional development whereas reflexivity is concerned with the core of who we are as individuals and how our beliefs and values can permeate each stage in the development, delivery and interpretation of a research project (Strauss and Corbin 1990; Nightingale and Cromby 1999; Charmaz 2006).

In this research, reflexivity focussed on balancing the 'emic' and 'etic' influences on the research. The 'emic' or insider role of the researcher was explored in a reflexive diary with regard to participant sampling and data collection in the field (McCann and Clarke 2003a). This was conceptually separated from the 'etic' or outside approach in relation to analysing data and developing theoretical concepts (Willig 2001; McCann and Clarke 2003a; Roulston 2010). Thus the 'emic' approach involved the researcher's natural ability to empathise and utilise insider knowledge while conducting interviews and the 'etic' involved the ability to detach when conceptualising data.

The reflexive diary was therefore a tool for managing researcher effect and maximising the validity and trustworthiness of the data (Schatzman and Strauss 1973; Willig 2001; Glaser 2002; Charmaz 2006).

3. Theoretical sensitivity

Theoretical sensitivity has been described as "the ability to 'see' with analytical depth what is there" (Strauss and Corbin 1990). As a novice to grounded theory, the researcher used a number of methodological approaches to explore the data and develop theoretical constructs.

In order to gain "conceptual entry" into the data (Schatzman and Strauss 1973, 11) and establish some sociological distance, a theoretical lens was adopted to view the research planning and interpretation of the findings. The theoretical lens used initially to view the data was the concept of healthcare sustainability that

focuses on improving quality of care within a financially challenged health service (NHS Institute for Innovation and Improvement 2006-2013). A chronic disease lens was also utilised to view the data from a different perspective and as the theory took shape, the lens changed to reflect the emerging theory.

Conceptual levers were also utilised to interrogate the data (Strauss and Corbin 1990, 1998) and to uncover the grounded key in the data. Working hypotheses were developed throughout data analysis and further explored through subsequent interviews (Schatzman and Strauss 1973; Charmaz 2006). Theoretical sensitivity was also developed through a persistent cycle of moving between data, participants, literature and concepts (Hoare, Mills and Francis 2012; Urquhart 2013).

The use of memos throughout data collection and theory development is a strategy that is recognised by all grounded theorists. Memos serve to articulate the thought processes of the researcher during the cycle of data collection, data analysis and theory development (Kools, McCarthy and Durham et al. 1996; Charmaz 2006; Bryant and Charmaz 2007). These memos were either analytical or theoretical depending on the stage of the research. Analytical memos were used during early analysis in order to advance the construction of theory and consciously abstract from the raw data. In the words of Schatzman and Strauss, analytical memos “are likely to become the heart of [the researcher’s] final set of ideas” (1973, 104).

Theoretical memos were utilised to explore and examine the emerging theory and to provide an audit trail for the theoretical development (Glaser 1978; Charmaz 2006; Glaser 2007; Corbin and Strauss 2008). The use of extant literature was also instrumental in developing theoretical sensitivity with regard to the emerging theory.

4. Integrating theory

The theory developed for this thesis was based on concepts that emerged from the data (Glaser and Strauss 1967) and on an interpreted reality of the cultural and structural contexts of the data (Schatzman and Strauss 1973; Strauss and Corbin 1990; McCann and Clark 2003b; Charmaz 2006). The approach to constructing this theory was based on developing and relating concepts in the data and explaining the process inherent in HIV healthcare.

During the process of developing theory the methodological approach was to use the central organising perspective to underpin the resultant substantive theory (Schatzman 1991). This approach was taken to minimise the forcing of theory into existing coding families or conditional matrices that are used by other proponents of grounded theory (Glaser 1978; Strauss and Corbin 1990). It is acknowledged that this latter approach takes longer to develop a substantive or formal theory.

The use of social process to explain the theoretical constructs in grounded theory is common amongst some proponents of the methodology (Glaser 1978;

Strauss and Corbin 1990). The resultant theory is commonly presented as a social process or as a gerund (the “ing”) that is occurring in the data (Glaser 1978; Strauss and Corbin 1990; Charmaz 2006; Jones and Alony 2011). However, the methodological approach used in this research did not view a single social process but focussed on explaining “what ‘all’ is involved here” (Schatzman 1991, 310). While Schatzman does not specify the use of a social process per se, he acknowledges that a complex set of concepts cannot be explained without some reference to social relations or process: “How can anyone describe a complex, ongoing scene without coming to terms with process, or describe social relations – other than in list form – without developing a sense or model of structure” (Schatzman 1973, 119). Although Schatzman refers to description here, this is within the context of explanatory theory. This thesis utilised the concept of *what all is involved here* in constructing a theory that accounted for the main concerns of the research participants (Schatzman 1991; Robrecht 1995; Kools, McCarthy and Durham et al. 1996; Bowers and Schatzman 2009).

The writing of the research findings contributed to the development of the theory by illuminating the connections between the data concepts (Glaser 1978; Charmaz 2006). Metaphors were also used to assist in organising the dimensions and properties and in testing the central organising perspective. The theory that developed from this research was adapted from an existing theory of illness representation following saturation of the data categories and identification of the explanatory perspective.

5. Verification

In order to test the emerging theory from this research data, a number of strategies were used that will be discussed in detail in Chapter 3. The approach to verification was based on the concept of the theory having 'fit' or 'grab' within the subject discipline (Glaser 1978; Kools, McCarthy and Durham 1996; Strauss and Corbin 1998; Charmaz 2006).

This involved considerable consultation with participants, colleagues, critical friends and a patient advisory panel. Glaser (1978) maintains that theoretical concepts may not be accessible to participants and that they need to remain within the domain of academics and related only to other relevant academic theories. However, as participants were central to the research aim and their data an inherent part of the theory development in this research, verification of the theory included their input on the relevance of the component parts of the proposed theory to their perspective on HIV and healthcare provision.

2.4 Summary of the strands of grounded theory used

In summary, the approach to grounded theory that has been used for this research into the interactions and processes in HIV healthcare has drawn on many of the strands of grounded theory that have evolved since the *Discovery of Grounded Theory* in 1967. This has enabled a flexible approach to data collection, analysis and theory development. The core components of grounded theory have been viewed as constant comparative analysis, developing and

relating concepts in the data, defining the process inherent in the data and building theory that is grounded in the research data. In addition to these intrinsic components, a dimensional analysis strategy was utilised as a *way of thinking about data* (Schatzman and Strauss 1973; Schatzman 1991; Robrecht 1995; Kools, McCarthy and Durham 1996; Bowers and Schatzman 2009). The approaches to relating concepts and developing theory have been drawn from key grounded theory texts (Glaser and Strauss 1967; Schatzman and Strauss 1973; Glaser 1978; Schatzman 1991; Strauss and Corbin 1990, 1998; Charmaz 2006; Glaser 2007) as well as from other proponents of grounded theory. The central organising perspective and substantive theory was developed through the use of the explanatory matrix used in dimensional analysis.

2.5 Chapter summary

The philosophical positioning of this research was based on a relativist ontology and constructivist epistemology within a pragmatic philosophical paradigm. Symbolic interactionism has been utilised as a theoretical framework to assist in understanding the interactions of people with HIV with their healthcare services. This chapter has identified the rationale for using a grounded theory approach to inductively build concepts in the data and develop an academic theory on the delivery and utilisation of HIV healthcare services. Dimensional analysis has enabled the exploration of multiple perspectives in the data and has used the experience of the researcher as a contextual control to make sense of the complexity of concepts and interpret what was occurring in the field.

The core components of grounded theory have been presented and the brand of grounded theory utilised for this research has been examined. The development of the substantive theory has been inspired by existing theories that have been adapted to reflect the main concerns of participants in this study.

Chapter 3 will now give a detailed description of the method and data collection tools.

Chapter 3: Method and data analysis

3.0 Introduction to the chapter

This chapter will present the methods used to conduct the research and the data analysis based on the theoretical approach outlined in the previous chapter. In keeping with a pragmatist philosophy and the grounded theory methodology discussed, a range of methods were utilised including observation and semi-structured interviews. This chapter will cover the methods used for sampling, recruitment and data collection. The procedures for data analysis and the strategies used to develop a substantive theory will then be presented.

The chapter will commence with an overview of how people with HIV were involved in the planning and analysis of the research and the actions undertaken to address the potential ethical issues in conducting this study.

3.1 No decision about me without me

To enable a more grounded approach to the research on HIV healthcare and to ensure that people with HIV were well represented in the planning and execution, a patient advisory panel was established. The aim of the patient

advisory panel was to keep the research rooted in the issues that were important for patients in line with current research and health policy (Staley 2009; Department of Health 2010a). This incorporated the concept of “no decision about me without me” that was integral to the White Paper *Equity and Excellence: Liberating the NHS* (Department of Health 2010a). This was believed to be of particular relevance as the research was carried out during a full time academic scholarship and the researcher was not in clinical practice over this period of time. In view of the constantly changing nature of HIV disease management, the researcher wanted to ensure that the findings were relevant to the experience of patient advocates as well as to the everyday experiences of people with HIV. Involving end users in a study has been shown to increase the integrity and profile of that research and to facilitate investigations that are pertinent to the issues of health service users (Staley 2009).

The advisory panel consisted of four service users that were in advocacy roles in England, two of whom were in salaried positions for government and non-governmental organisations. The panel comprised of one female of African ethnicity, and two men who have sex with men, of whom one was over 50 years of age and the other was a heterosexual haemophiliac male. The panel members therefore spanned 3 HIV risk groups although they were primarily approached for their profile as patient advocates and their involvement in national projects.

The patient advisory panel were involved with both the planning and design of the research activities (Staley 2009). The panel was intrinsic to the study design and ethical considerations of the research and contributed to the content of the participant information leaflet and planning of the interview agenda. The panel were consulted on the purposive recruitment strategy of patients and were pivotal in informing the favourable ethics opinion for this approach to recruitment. In addition the panel were consulted during data analysis and emergent themes were discussed for trustworthiness (Denzin and Lincoln 2005; McCann and Clark 2003a). At the final stages of the project the patient panel were accessed for verification purposes to test the emerging theory for grab, fit and relevance (Glaser 1978; Kools, McCarthy and Durham 1996; Strauss and Corbin 1998; Glaser 2002; Charmaz 2006a). In this context, the patient advisory panel were viewed as an integral part of the construction of knowledge for this research project because they provided another essential layer of perspective.

3.2 Ethical considerations

The philosophical approach to the ethical considerations for this research has been discussed in Chapter 2. In practice, there were several ethical issues to manage throughout the research project. These were: researching a vulnerable patient group; the use of gatekeepers in recruitment; insider research dynamics and confidentiality of staff and patients who were approached or who participated in the research.

3.2.1 Researching vulnerable groups

HIV patients have been defined as a vulnerable group in research as they can be subjected to stigma and discrimination as a result of their HIV positive status (Alexander 2010). Therefore the risks and benefits of including HIV positive patients as participants were considered in order to offer them their right to be researched but also protect them from the potential harm (McCabe and Holmes 2007; Smith 2008).

In practice, a risk assessment of the potential harm in involving patient participants was undertaken. This identified that patient participants may find it difficult to discuss their future healthcare needs or that the interview may remind them of care issues that were distressing in the past. These risks were minimised by explicit participant information leaflets and signed informed consent procedures (National Patient Safety Agency and National Research Ethics Service 2011; See also Appendix 2 and Appendix 3). In addition, local site referral pathways were identified for participant support in the event of any psychological distress arising from the interview discussion (Charmaz 2002; Kvale 1996). The patient advisory panel was involved in identifying potential risks in this context (Staley 2009).

During the recruitment process, potential participants were informed of the aims of the study and what was involved in taking part in the research. The risks and benefits were outlined and information included on confidentiality and anonymity of results (National Patient Safety Agency and National Research Ethics Service

2011). This was supported by a participant information leaflet for both patient participants and healthcare worker participants (see Appendix 2 and Appendix 4) and all participants were given a minimum of 24 hours to decide if they wished to participate.

Capacity to consent for some patient participants was assessed in conjunction with their clinicians where this was relevant, for example, in the case of a patient participant who had recently had brain surgery for swelling of his brain. This was in keeping with statutory guidance on assessing mental capacity in research participants (The Stationery Office Limited 2007). Written consent was obtained by the researcher once participants had opted into the study.

3.2.2 Gatekeepers in recruitment

The use of gatekeepers to recruit patient and staff participants for research projects can result in undue influence on potential participants to consent to the research. Conversely, gatekeepers may assume that some potential participants may not wish to participate (Alexander 2010; Reeves 2010). These two factors may threaten an individual's right to be researched or the equal right not to be over-researched (Williamson 2007). To minimise these potential effects, a passive recruitment strategy was introduced in addition to using gatekeepers for recruitment in line with the principles of justice and autonomy.

3.2.3 Insider research

It was possible that staff or patients may have been known to the researcher due to her clinical role, length of time in the HIV field and national involvement in HIV nursing issues. There was therefore potential for the insider researcher effect and coercion of patient and healthcare workers to participate in the research (Hockey 1993; Hewitt-Taylor 2002; Asselin 2003; Van Heugten 2004) that may have compromised the autonomy of possible participants at some sites. Therefore any patients who had been part of the researcher's caseload were excluded from the study. Staff who had been managed/supervised by the researcher or who had been in a day-to-day working relationship were also excluded. In addition, a reflexive journal and supervision sessions were utilised to identify and manage any role duality or possible conflict with the previous and future clinical role of the researcher (Gough 2003). The potential of insider research was a factor in how each of the sites were utilised and this will be discussed further throughout this chapter.

3.2.4 Confidentiality

Stigma and discrimination continue to affect people with HIV in the UK (The People Living with HIV Stigma Index 2008; Bravo, Edwards and Rollnick et al. 2010; House of Lords 2011b) and therefore confidentiality is even more imperative when working with people with HIV infection. A breach in confidentiality through poor study design or inadequate data protection measures could compromise the ethical principles of non-maleficence and autonomy. Patient participant details were therefore anonymised and data stored in line with

the *Data Protection Act (1998)*, *NHS Research Ethics* and the *Information Commissioner's Office*. Figure 3.1 shows the data protection actions undertaken in this respect.

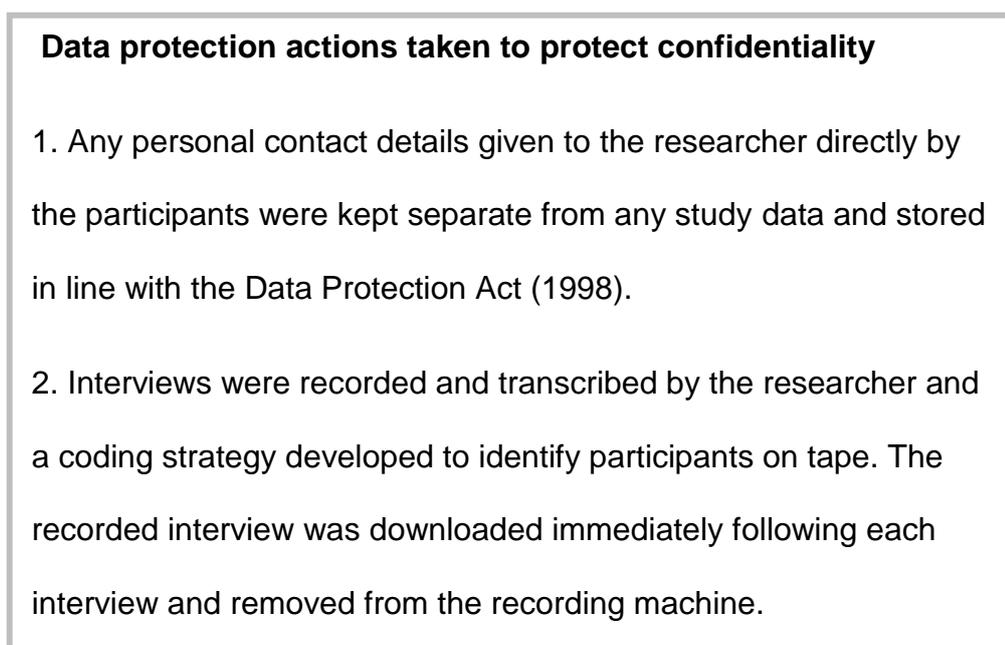


Figure 3.1: Data protection actions undertaken

In addition, patient participants were given a pseudonym and all identifying factors were removed other than age and gender. This was intended to prevent deductive disclosure of patient participants particularly within the individual research sites (Kaiser 2009; Houghton, Casey and Shaw et al. 2010). Likewise, where potential healthcare worker participants represented a minority staff group or were at risk of deductive disclosure, a coding strategy was put in place to protect the confidentiality of individual post holders (Kaiser 2009; Houghton, Casey and Shaw et al. 2010). For example, nurses were referred to as either senior nurses, staff nurses or by generic job role. Similar descriptions were

allocated to medical staff and other staff were referred to broadly in relation to job role.

In preparation for presenting the findings, all participants were given a consecutive interview number. Pseudonyms were then allocated to the interview numbers and coded for each site to assist with comparative analysis.

Ethical approval was given by a Local Research Ethics Committee on 4th February 2011, REC Reference Number: 10/H1107/76. Research and Development Approval was given by four NHS Trusts to include the option of recruiting staff from Community Trusts as well as Acute NHS Trusts.

3.3 Sampling

This section will discuss the selection of the research sites and the participant sampling.

3.3.1 Selecting the research sites

In preparation for choosing the research sites, an initial scoping exercise was undertaken by a combination of telephone interviews, professional networking and literature searching of local or regional service reports. The aim of the scoping exercise was to identify a range of HIV services of different size,

casemix and geographical location which were interested in participating in the research. This involved finding HIV clinics that reflected a variety of service delivery options to meet the breadth of the research aims. The sites were therefore purposively selected prior to data collection as opposed to theoretically sampled once data collection commenced. This constituted a strategic selection of the sites to maximise variability of service structure and service provision and provide cases for comparison (Stake 1995; Flyvbjerg 2004). This approach was also influenced by the timescales for ethical and research and development approval processes that needed to be factored into the research planning.

As a result of this scoping exercise, three research sites were chosen for the following reasons:

1. To loosely reflect the structure of HIV services at the time of the research as recommended in the British HIV Association Standards for HIV Care (British HIV Association 2007). For example one HIV Unit²⁴ was chosen and two HIV Centres²⁵ which functioned as part of an HIV service network.
2. To incorporate a range of role and service descriptions, such as nurse-led clinics, joint clinics and different models of care for stable HIV patients.
3. To reflect the broad demographic of risk groups with HIV infection in the UK.

²⁴ HIV Unit(s), as defined by BHIVA Standards, provide “outpatient care for the majority of patients with uncomplicated HIV infection” (British HIV Association 2007, 1).

²⁵ HIV Centres, as defined by BHIVA Standards, provide “services for patients with more specialised needs, including complex outpatient care, inpatient care and referral/advice services” (British HIV Association 2007, 1).

4. To reflect the geographical distribution of HIV across England.

The reference to a structural component in this site selection was not intended to direct the research towards an evaluative design but instead to capture service arrangement and variance to increase transferability of the findings (Strauss and Corbin 1990; Stake 1995). Once these sites had been identified, a letter was written to the medical and nursing leads in the centres to confirm their interest in participating in the study prior to NHS Research Ethics Application and Research and Development approval (see Appendix 1).

The context for these cases for comparison was defined as:

An HIV Unit or HIV Centre and associated statutory and non-statutory services that are connected with meeting the needs of people with HIV who attend the HIV Unit or HIV Centre

This broad definition enabled theoretical sampling within and around HIV services as data concepts emerged. For example, it allowed the inclusion of healthcare workers from the voluntary sector and those working with HIV services in associated specialities such as cardiovascular medicine. In addition, this description of the cases for comparison facilitated the flexibility to review the appropriate use of the research sites as working hypotheses were developed (Charmaz 2006a). However, there were occasions when sampling led outside the sites in order to test theoretical concepts at a later stage in data collection (Schatzman and Strauss 1973).

It was agreed at the outset of the study that the research sites would remain anonymous to encourage recruitment but more importantly to prevent the deductive disclosure of sites and potentially of individual staff members or patients (Kaiser 2009; Houghton, Casey and Shaw et al. 2010). The HIV service community was known to a number of practitioner and voluntary sector organisations and in particular to agencies involved in disease reporting such as the *Health Protection Agency*. In addition, national audits have been carried out by the *British HIV Association* across all HIV service sites and therefore some services may be recognisable by their specific caseload demographics or service configuration. It was also anticipated that the HIV community may assume that the researcher utilised her own place of work as one of the research sites. For these reasons, the sites were selectively used for sampling to minimise identifying features. In addition, the site characteristics have been blended where there was a perceived risk of recognising a specific centre. The three sites were also given the fictitious town pseudonyms Springfield, Metropolis and South Park.

3.3.2 Participant sampling

The sampling approach was based on the most appropriate method for developing a substantive theory in the research topic and the practical aspects of working across three sites in different parts of England. Therefore a combination of convenience, purposive and theoretical sampling was undertaken.

In the initial stages of recruitment, a convenience sampling approach was used for patient participants (Strauss and Corbin 1990, 1998). This sampling approach was designed to coincide with the study site visits and therefore was restricted to those days when the researcher was present on site (Gobo 2004). For healthcare worker participants a purposive sampling strategy was employed at this stage based on role definition and discipline in order to explore different perspectives within this group. Sampling was undertaken within defined eligibility criteria as shown in Figures 3.2 and 3.3.

HIV PATIENT SAMPLING CRITERIA	
<p>Inclusion</p> <ul style="list-style-type: none"> ❑ HIV positive for > 6 months ❑ Over 18 years of age 	<p>Exclusion</p> <ul style="list-style-type: none"> ❑ Patients with a life expectancy of < 3 months ❑ Patients who have been admitted to hospital with a physical or mental health problem within the last month ❑ Patients who have previously been in the researcher's caseload

Figure 3.2: Inclusion and exclusion criteria for patient participants

HEALTHCARE WORKER SAMPLING CRITERIA	
Inclusion	Exclusion
Healthcare workers have been in post in their current workplace for a minimum of 6 months	Staff who have previously been in a close day-to-day working relationship with the researcher

Figure 3.3: Inclusion and exclusion criteria for healthcare worker participants

While a representative sample is not indicated within a grounded theory design (Strauss and Corbin 1990, 1998), the initial sampling approach set out to include a range of patient participants from different HIV risk groups where this was possible. It was not believed to be in the best interests of patients who were dying or who were acutely unwell to participate in the study and this group were unlikely to reflect the experiences of the majority of patients accessing HIV services. The broad inclusion criteria were intended to enable HIV outpatients with a range of co-morbidities and/or co-infections to participate. The convenience sampling of patient participants and purposive sampling of healthcare workers was intended to generate some preliminary data concepts to inform theoretical sampling.

Theoretical sampling has been described by Strauss and Corbin as “sampling on the basis of concepts that have proven theoretical relevance to the evolving theory” (Strauss and Corbin 1990, 176). Following initial data analysis and the development of concepts and categories, theoretical sampling was then undertaken to explore working hypotheses that emerged from using constant comparative analysis (McCann and Clarke 2003a; Charmaz 2006a). In this way sampling became more focussed and targeted to explore specific properties in the data in order to test the evolving categories and construct the substantive theory (Glaser 1978; Chenitz and Swanson 1986; Corbin and Strauss 2008; Urquhart 2013). For example, data analysis indicated that patients who initially come forward for the study all described themselves as medically stable and theoretical sampling was then undertaken in patients who were perceived as having more complex health needs to explore whether there were similar concepts from their perspective. The use of several research sites assisted in theoretically sampling different groups of patients and some theoretical sampling was intended to explore whether similar data concepts existed within different conceptual boundaries (Strauss and Corbin 1990, 1998; McCann and Clarke 2003a). There were a number of data concepts that arose from the early analysis that went on to inform the theoretical sampling strategy. These concepts included:

- Patient - provider relationships in HIV healthcare
- The ‘exceptionalist’ approach to HIV healthcare
- Engagement in HIV care
- Evolution of service delivery models
- ‘Fragility’ in patient participants

These concepts directed the selection of study participants by seeking out characteristics to enable further exploration. Figure 3.4 shows how the above concepts directed theoretical sampling.

Data concept from initial analysis	Impact on sampling strategy
Patient - provider relationships in HIV healthcare	<ul style="list-style-type: none"> • Sampling of patients who had expressed concerns about future HIV healthcare provision
The 'exceptionalist' approach to HIV healthcare	<ul style="list-style-type: none"> • Sampling of healthcare workers in non-HIV settings • Sampling of healthcare professionals who had worked in HIV for different time periods • Sampling of patients who access other healthcare services
Engagement in HIV care	<ul style="list-style-type: none"> • Sampling of patients who had expressed concerns about future HIV healthcare provision • Sampling of patients who access other healthcare services
Evolution of service delivery models	<ul style="list-style-type: none"> • Sampling of healthcare workers involved in a range of service delivery models • Sampling of patients receiving a range of service delivery models
'Fragility' in patient participants	<ul style="list-style-type: none"> • Sampling of patients receiving a range of service delivery models

Figure 3.4: Data concepts and theoretical sampling strategy

The sites (or cases) for comparison were also utilised in different ways for sampling. While this was guided by practical considerations, the research sites

enabled a range of sampling strategies that reflected the different stages of data analysis and exploration of evolving data concepts. Convenience sampling of patient participants commenced in Springfield alongside the purposive sampling of healthcare workers in both Springfield and South Park. This enabled constant comparative analysis across patient and healthcare workers at an early stage of data collection (Strauss and Corbin 1990; Glaser 2002; Charmaz 2006a). Theoretical sampling commenced after the eleventh interview across all three research sites although Metropolis was used exclusively for theoretical sampling. Patient participant sampling was undertaken in Springfield and Metropolis only. The initial reason for this was based on the researcher's insider knowledge of the South Park site and the intention to utilise this site for theoretical sampling of patient participants at a later stage in the research. This approach was proposed to maintain conceptual distance from familiar patient care delivery models. However, as no new concepts arose from the patient participant data through theoretical sampling in Metropolis, South Park was not utilised for this purpose and may be considered as a future site to test out the substantive theory. Therefore, sampling in South Park focussed on a range of healthcare worker and third sector roles to generate initial data concepts and test working hypotheses from a healthcare worker perspective. Figure 3.5 shows a summary of the sampling strategy across sites and participant groups.

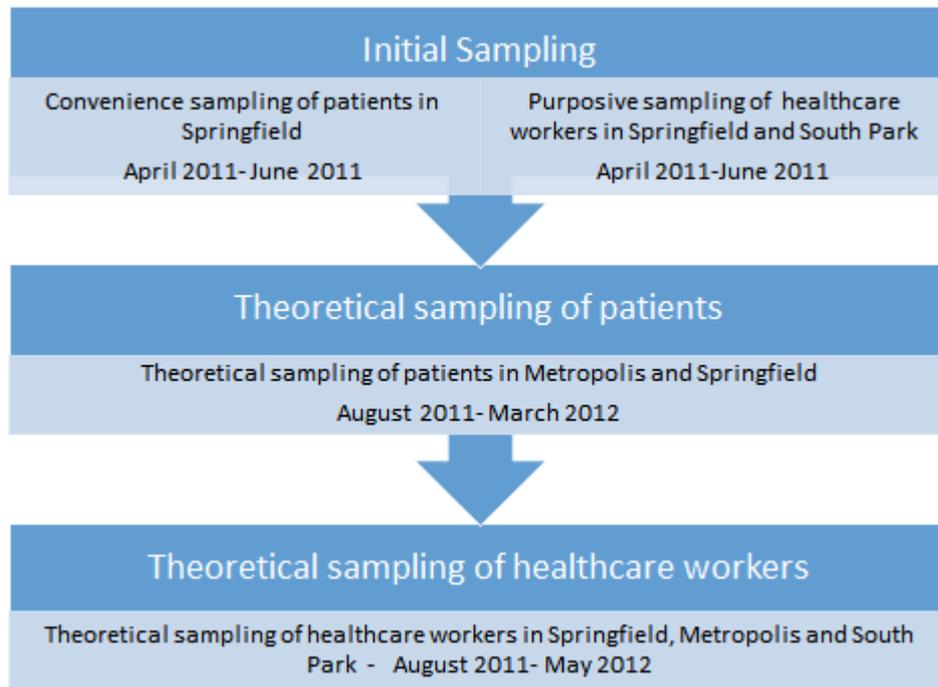


Figure 3.5: Sampling across sites and participant groups

On one occasion theoretical sampling led outside the sites to a healthcare worker who had worked across a number of services nationally and who was approached to test out the theoretical constructs from this perspective.

3.3.3 Recruitment

A pragmatic approach was also taken to recruitment in order to navigate the three research sites and to work within organisational and patient schedules (Schatzman and Strauss 1973). The researcher worked alongside local site hosts to establish a suitable recruitment strategy for both patients and staff in each site.

As the sites were predominantly outpatient settings, recruitment of patient participants was gauged around the frequency of patient attendances particularly when the site location involved travelling for the researcher and the participants. For example, patients usually attended for routine monitoring tests two weeks prior to receiving their results face to face or by telephone or e-mail. Therefore one recruitment strategy targeted blood clinics and scheduled interviews for two weeks later after patients had consented to participate. Another strategy was to work with clinical staff to identify eligible patients in their clinics and inform them of the study. These two approaches to recruitment were used in conjunction with the distribution of study fliers at reception or in the clinic waiting areas to give all patients who were attending an opportunity to participate in the study. All these strategies were adopted while the researcher was on site in order to deal with any questions about the study and minimise workload for the clinic staff. Figure 3.6 shows how these approaches were applied to patient participant recruitment across two of the research sites.

SPRINGFIELD	METROPOLIS
Patients due to attend clinic on specific dates were sent a letter by the host site with a participant information leaflet	Researcher arranged a number of site visits for recruitment purposes
Researcher arranged to be on site when the same patients attended the clinic	Fliers were handed out at reception on the days the interviewer was on site
In addition, fliers were handed out at reception when the interviewer was on site	In addition, clinic staff were asked to approach some patients with specific characteristics, such as people with more complex needs
Patients invited to speak to researcher by reception team or clinic staff	Patients invited to speak to researcher by reception team or clinic staff
Patients who expressed interest were informed of the study by the researcher	Patients who expressed interest were informed of the study by the researcher
The first 5 patients to express an interest were recruited	Theoretical sampling
Informed consent obtained for those who chose to participate	Informed consent obtained for those who chose to participate
Interview arranged to coincide with next clinic appointment	Interview arranged in the clinic at a convenient time for the patient participant

Figure 3.6: Patient recruitment pathways at Springfield and Metropolis

The mixed approach to recruiting was intended to maximise recruitment opportunities and to ensure an opt-in strategy was in place for patient participants from an ethical perspective (McCabe and Holmes 2007; Smith 2008). To manage the theoretical sampling strategy in Metropolis, the

recruitment fliers specifically stated that the selection of patients would be based on particular characteristics to reflect the needs of different groups of patients. This was in addition to working alongside the clinical teams to identify patients who fulfilled the theoretical sampling criteria.²⁶

Seven patients expressed an interest in the study during the first wave of recruitment at Springfield and the first five were enrolled in the study to generate initial data concepts (Charmaz 2006a; Bowers and Scahtzman 2009). The majority of those patients who were recruited had received a study flier prior to attending the clinic. In Metropolis, eight patients were recruited to the study, seven of whom were informed of the study by clinic staff. Only one patient participant contacted the researcher independently having read the study flier in the clinic. All participants who were recruited attended for interview.

Healthcare worker roles were identified through the use of a site questionnaire that was completed during the study set up visit in each site (see Appendix 5). Potential staff participants were contacted by e-mail either directly by the researcher or via the local site lead, depending on site preference. Staff were given information on the study and invited to contact the researcher by phone or e-mail for further information or to express an interest in participating (see Appendix 4 and Appendix 6).

²⁶ See Figure 3.4 for an example of the theoretical sampling criteria.

Twenty one healthcare workers were recruited across the three sites, including one role that was specifically targeted for a national perspective on nursing roles. A further five healthcare workers were approached but did not respond to the recruitment e-mails. Several other healthcare workers in the study sites offered to be interviewed, but did not at the time fit the sampling profile and were instead offered an informal interview. Although the original intention was to interview at least as many patient participants as staff participants, this was reviewed in order to incorporate the range of healthcare worker roles across the sites and was influenced by emerging data concepts, working hypotheses and theoretical sampling techniques.

All participants were offered travel reimbursement, although this was only claimed by patient participants.

3.4 Data collection

Although the majority of the data collection was through semi-structured interviews, a number of other methods were utilised to conduct this research (Schatzman and Strauss 1973; Charmaz 2006a). They included passive observation and the use of other data sources. This section will present the range of data collection methods used and give examples of how these were applied.

3.4.1 Passive observation

The aim of undertaking some observation was to explore “what ‘all’ is involved here” (Schatzman 1991, 310) in keeping with the naturalistic field approach to the research (Schatzman and Strauss 1973; Emerson 2004; Denzin and Lincoln 2005). In this context observation was viewed as passive as the researcher was not participating in any tasks while undertaking observation (Schatzman and Strauss 1973; Davis 1986; Delamont 2004).

The observation included sitting in the reception and waiting room areas and consciously noticing the layout, atmosphere and interactions between staff and patients (Davis 1986). There were limitations to this in view of the confidentiality of patient information and therefore it was mostly body language and initial greetings that were observed in the general waiting areas. Where permission was given to sit in staff areas, there was the opportunity to observe the roles, tasks and interactions of and between staff groups (Delamont 2004). The observation that occurred in staff and patients areas enabled further insight into the field environment and how this may have contributed to the experience of attending the research sites as a patient or of working as a staff member. This was particularly evident in noticing the structural layout to maintain privacy at reception and in the use of first name terms with patients attending the clinic. Although passive observation was a small component of the data collection method, it led to a number of informal discussions with staff about their role and the processes involved in HIV care. These ‘situational conversations’ formed part

of the data analysis but also helped to inform the subsequent questions asked during the interviews (Schatzman and Strauss 1973).

3.4.2 Semi-structured interviews

Interviews were chosen as the main data collection tool as they are a well-recognised method for exploring the actions and interaction of people in complex situations and to elicit meaning in a particular research area (Schatzman and Strauss 1973; Holstein and Gubrium 1995; Charmaz 2002; Wengraf 2006). In keeping with a grounded theory approach, 'partially scripted' semi-structured interviews were conducted in order to gain insight into the world of research participants (Holstein and Gubrium 1995; Wengraf 2006).

This data collection method required some skill development for the researcher particularly in moving from a clinical consultation style to a research interview. This development included working through possible assumptions based on the previous clinical experience and role remit of the researcher. In interview research, "pre-conceived notions are as much a danger in the research interview as in a medical interview" (Gillham 2004, 3). For this reason, seven trial interviews were undertaken with professional colleagues and the patient advisory panel to explore the interview agenda and to familiarise the researcher with balancing the structure and flexibility of the interview process (Gillham 2004; Wengraf 2006; Roulston 2010).

This enabled the researcher to develop skills in asking the right questions to explore the research topic and stay within the goals of the research while keeping the interviews open to develop their own plot (Holstein and Gubrium 1998; Kvale and Brinkmann 2009). In addition, these trial interviews offered the opportunity to explore the appropriate use of probing and prompting questions (Gillham 2004; Kvale and Brinkmann 2009) and to reflect on the researcher's responses and ability to steer the interviews (Charmaz 2002; Roulston 2010). They were therefore not pilot interviews but an opportunity for the researcher to test out questions and develop an interview style consistent with a grounded theory approach. For example, this helped in identifying the opening question for the initial interviews and was particularly useful in view of the procedural delays in receiving site Research and Development approval and the need to obtain data in a timely fashion.

Interview agenda

An initial interview outline was drawn up based on the identified gaps in knowledge around HIV healthcare provision and a reflexive review of the trial interviews. These questions were aimed at exploring the interactions between how patients perceived their HIV care needs and the processes involved in that care. Figures 3.7 and 3.8 show how the initial interview agenda related to the identified gaps in knowledge presented in Section 1.4.

Initial interview agenda for <u>patients</u>	Rationale for question
1. Current healthcare appointments	To explore patient perceptions of HIV healthcare
2. Recent changes to the way healthcare services are provided	To explore responses to changes in the processes of care
3. Future care scenarios	To explore values in HIV healthcare and the perceived role of HIV healthcare services
4. Patients' role in healthcare	To explore how patients view their own role in their healthcare

Figure 3.7: Rationale for interview agenda for patients

Initial interview agenda for <u>healthcare workers</u>	Rationale for question
1. Current services and individual role in HIV healthcare	To explore the roles and processes of HIV care
2. Recent changes to the way HIV healthcare is provided	To explore the approaches to changes in HIV healthcare provision
3. Future care options	To explore values in HIV healthcare and the perceived role of HIV healthcare services
4. Patients' role in healthcare	To explore healthcare worker perceptions of the role of patients in their

Figure 3.8: Rationale for interview agenda for healthcare workers

Therefore a conceptual approach was taken to develop the interview questions in order to gain an in-depth understanding of the interactions and processes in HIV care from both patient and healthcare worker perspectives (Kvale and Brinkmann 2009). The introductory questions were generally posed in an open-ended way to facilitate individual perceptions of the HIV care experience (Charmaz 2002; Wengraf 2006; Roulston 2010). For example, questions were asked using phrases such as “tell me about”; “describe for me” or “what is important to you”. To demonstrate this, data extract 1 shows some examples of the questions asked by the interviewer during the initial interviews.

Just thinking about the kind of current services that you provide within your role in third sector care, can you just describe a little bit for me about the services that you provide for people with HIV now?

Interviewer extract from Interview 1 with healthcare professional

Thinking about the current service that you provide for people with HIV, tell me a little bit about that

Interviewer extract from Interview 3 with healthcare professional

Tell me a little bit about your appointments here, how often you attend, who you see

Interviewer extract from Interview 4 with patient participant

Data extract 1: Examples of interviewer questioning

A reflexive approach was taken to the interview questions throughout the duration of the research to explore the language used by the researcher and how the phrasing of the questions may have influenced the response of the participant (Charmaz 2002; Wengraf 2006; Kvale and Brinkmann 2009; Roulston

2010). In this context, the application of the “why-interview”, as described by Maso (2003), was utilised by exploring the concepts in the interview questions and the assumptions underlying particular interview questions. This was methodically included in the researcher’s reflexive diary following each interview interaction and incorporated into the data analysis (Charmaz 2002; Gough 2003; Roulston 2010). The reflexive approach was utilised to review the construction of the interview questions, the interview dynamic and the ability of the researcher to work with participants to construct meaning during the interview process. In this way, the reflexive diary was used as a dynamic tool to develop the interviews in the following areas:

- Exploring the questions that were asked and assumptions underlying those questions
- Reflexively exploring interviewer positioning as a researcher
- Exploring the interviewer’s skill in asking open-ended questions
- Ability to conduct interviews as conversations
- Ability to work with participants to elicit meaning during the interview interaction

During the recruitment phase, the researcher introduced herself as a research student and briefly outlined her clinical background so that participants were aware of her familiarity with the research topic (Charmaz 2002; Roulston 2010). For the purpose of the interview, the researcher dressed in semi-casual clothes to distinguish herself from the professional, uniformed staff although in some

environments was required to adhere to the local dress code particularly with regard to infection control policies. For face to face interviews, rooms were booked in advance at a pre-arranged time. These interviews were conducted in either clinical, research or administrative areas depending on participant preference and room availability. This minimised the rate of interruptions in a busy clinical environment, increased confidentiality and optimised the recording quality of the interviews (Wengraf 2006). Eight interviews were carried out by telephone. Four of these were with healthcare professionals that had previously met the researcher on site. Four were follow-up interviews with patient participants.

Baseline demographics of the participants were recorded on *Microsoft Excel 2010* spreadsheets. For patient participants, this included age, ethnicity, risk group, year of diagnosis and if taking antiretroviral therapy, how many regimes to date. For healthcare worker participants, this included age, main job role and length of time working in HIV.

Interviews were conducted from a relatively passive position where the interviewer asked questions, guided the conversation, provided prompts or probes but where most of the speaking was undertaken by the participant (Schatzman and Strauss 1973; Holstein and Gubrium 1998; Roulston 2010). However, to maximise the opportunities to elicit meaning from the interview, an 'active' interviewing approach was adopted (Holstein and Gubrium 1995, 1998). This involved moving the interview beyond the description of experience and

working with participants to derive meaning from their responses (Ibid). For example, the data extract below shows how the researcher moved the patient participant response from description of her preferred healthcare provider towards how she viewed her preferred provider in relation to her perception of her HIV.

Extract from Interview 5

Interviewer: so you would see them (HIV services and GP) working together having a liaison role. Who do you think should take charge of that?

Interviewee: HIV

Interviewer: Why do you think that?

Interviewee: Because why do I, I don't know (laughs)

Interviewer: I'm interested in why you think that

Interviewee: yeah because that is the illness that is with me now and is going to be with me for the rest of my life. I think for them (HIV services) to take control just to rule it out that it's not HIV related I'd feel more comfortable than the GP being in charge. If they find out that it's not HIV related they can then lose the control and put it onto who should be in control

Data extract 2: Eliciting meaning during an interview

The use of 'active' interviewing techniques also included presenting alternative viewpoints to participants to further develop understanding of their responses. Data extract 3 shows how the interviewer questioned the interviewee's response by posing another perspective on the issue of free prescriptions for patients in general practice.

Extract from Interview 1

Interviewee: there has certainly been a change in [...] what people are able to be prescribed via the clinics or elsewhere [this is a] cost implication to patients because [if] they would have previously been prescribed from GUM it would have been free if it's through the GP it's not

Interviewer: Is that an issue that patients bring up?

Interviewee: No. Do you know what? People don't really, very rarely, say that to me

Data extract 3: Presenting an alternative viewpoint during interviews

The use of an 'active' interview approach therefore created opportunity for the shared construction of knowledge in relation to HIV healthcare delivery.

The interviews were up to 60 minutes in length to encourage the flow of conversation (Schatzman and Strauss 1973; Holstein and Gubrium 1998; Kvale and Brinkmann 2009) and a selection of participants were invited for a second interview based on the theoretical questions that arose from the data analysis. Each interview intentionally concluded with a 'blue skies' question in order to finish on a positive note (Charmaz 2002). Participants were asked about their interview experience and if there were issues raised as a result of the interview, follow-up support was offered.

Evolving interview style

The initial interview agenda was devised as a starting point to generate data concepts based on the original research goals. As concepts emerged from the data, the interview questions evolved in order to pursue concepts and working hypotheses (Schatzman and Strauss 1973; Charmaz 2002; Kvale and Brinkmann 2009).

There are two examples of how this was operationalized in practice. The initial interviews with non-HIV healthcare workers generated concepts of HIV patients being perceived as different from those in other disease areas; more expert and better supported by services. This concept of difference was further examined with patient participants in relation to how they viewed non-HIV healthcare services. Likewise, the concept of HIV as an all pervading condition arose early in the interview data and generated questions about how HIV was viewed by participants. In working with these early concepts, the researcher was able to steer subsequent interviews to explore these ideas further (Glaser and Strauss 1967; Schatzman and Strauss 1973; Strauss and Corbin 1990; Charmaz 2006a; Kvale and Brinkmann 2009). This approach facilitated the use of multiple perspectives in interpreting and analysing the data.

Transcribing approach

Forty interviews were conducted for this research and transcribed using a digital recording device and immediately downloaded to a secure laptop protected with *TrueCrypt* software. The initial fifteen were transcribed verbatim by the

researcher and for pragmatic reasons subsequent interviews were transcribed selectively based on consistency with the emergent themes. The overall aim of the transcripts was to portray the spoken word as closely as possible and to preserve the meaning of the original speaker (Powers 2005). For this reason, the insertion of punctuation was kept to a minimum in the transcripts and data extracts as this can inadvertently alter the intended meaning (Poland 2002; Roulston 2010). The exception to this was where punctuation was added to capture the inflection of the spoken word or to enhance readability of the data extracts. In addition, to preserve confidentiality, references to regional language were removed and replaced with more neutral language. For example, when one participant spoke of “me grandma” this was changed to “my Grandma”. There were several participants for whom English was not their first language and some sentences were reworded for readability and to further protect identity and deductive disclosure. Likewise, all references to places and names were removed and referred to in square brackets as [name] or [name of place] (Kaiser 2009).

Square brackets [...] were used throughout the transcripts to demonstrate where the researcher had added or omitted text to increase explanatory power and to portray the extent of researcher interference with the original text (Powers 2005). Finally, where data quotes were used, the original text was ‘cleaned’ for pauses, hesitation and phrases such as ‘you know’ to improve readability of the text. The transcripts were therefore altered from their original form, but with the intention of preserving the spoken words of participants as closely as possible.

Finally, the data transcripts were not shared with participants to confirm their accuracy. This was intentional, given the number of interviews and to avoid participant concerns about their individual transcripts (Houghton, Casey and Shaw et al. 2010). As an alternative, the concepts in the data were explored and compared across participants and a number of theory verification strategies were employed that will be covered later in the chapter.

3.4.3 Number of site visits

The number of site visits was dictated by recruitment progress, interview schedules and theoretical sampling. A small budget was available for travel and accommodation and where possible individual site visits were co-ordinated to include recruitment, interviews or meeting with the local research hosts.

There was a minimum of six site visits to each centre and the duration of each visit ranged from one day to four days on site, depending on the stage of recruitment and the interview arrangements. The site visits followed the sampling strategy and were accessed simultaneously where this was indicated in order to explore working hypotheses or theoretical concepts (Schatzman and Strauss 1973: Glaser 1978). Each site was also contacted by telephone and e-mail to report the progress of the study and to inform the site leads of any follow-up interviews that were arranged independently by telephone.

3.4.4 Use of other data sources

As stated in the introduction, a multi-method approach was taken to this research and this included the use of other data sources alongside passive observation and semi-structured interviews. This is a common approach in grounded theory research to increase the validity of the findings (Glaser 2002) and to assist with conceptual distance when analysing data and building theory (Schatzman and Strauss 1973; Strauss and Corbin 1990). In addition, alternative data sources were utilised to address gaps in the literature on certain aspects of the research topic such as the roles of HIV nurses. This approach to including other data sources enabled the inclusion of new health policy or guidance documents that were relevant to HIV services where they fitted into the wider healthcare climate.

Literature and policy documents

Literature and research from other chronic disease areas was used to situate the concepts and categories of HIV care from the data within a chronic disease paradigm and to compare different models of care. Where the use of literature was integral to the interpretation of the research data, this has been included in the presentation of the findings in Section 3 of this thesis.

HIV specific policy documents were also analysed for consistency with the research findings and to explore and compare macro concepts of HIV as a disease area. These documents included:

- HIV Outpatient Clinical Care Pathway developed for a payment by results tariff for HIV (Department of Health 2011a, 2011b, 2011c, 2012b)
- *No vaccine, no cure: HIV and AIDS in the UK; Report* (House of Lords 2011b)
- *Clinical Advisory Group for Prescribed Services* (Department of Health 2011)
- British HIV Association Standards of care for people living with HIV (British HIV Association 2012)

The use of these documents as data assisted in keeping the research relevant to the constantly evolving healthcare climate as considerable structural changes in the National Health Service were introduced over the duration of this thesis.

Site activity reports

Site questionnaires were used at the study set-up visits to obtain information on the number and type of clinics, staff roles and liaison with community and voluntary services (see Appendix 5). While the main purpose of this was to access information to inform staff recruitment, this questionnaire also provided valuable insight into the breadth of roles and services in place in each site. Where possible, local site data was used as evidence, for example data on the numbers of patients attending nurse-led clinics and using virtual results services such as e-mail or telephone clinics. There were logistical challenges in obtaining this information, either because it was not recorded or there were delays in receiving requested information. However, the information obtained was useful in understanding service utilisation to situate the data findings within some context.

HIV conferences and study days

A grounded theory approach was also adopted when attending subject specific conferences or study days. This enabled further conceptualisation of the issues pertinent to HIV care at national and global levels. For example, attending the XVIII International Aids Conference in Vienna in 2010 highlighted the human rights issues for people with HIV and how different models of care were evolving to respond to the needs of people with HIV at national and local levels. At a World AIDS Day education event in London, held on December 1st 2011, invited speakers celebrated the successes of HIV treatment since the first case of AIDS was reported in San Francisco 30 years previously. At this event, the overriding theme was the 'miracle' of HIV treatment and this discourse emphasised the pioneering approach to managing HIV and working in partnership with patients to develop treatment and care options.

Annual HIV Nursing Conferences offered the researcher insight into nursing care concepts such as managing patients who are lost to follow-up and role innovations. As an invited speaker at an advanced practice study day for HIV nurses, the researcher collected data on perceptions of advanced practice roles through anonymous keypad voting following permission from the attendees. The results from this voting and the ensuing discussions helped to inform the interview agenda with regard to nursing roles and levels of practice in HIV care. In 2011, feedback gathered at a further invited lecture on models of HIV nursing contributed to the conceptualisation of components of HIV nursing. The

preparation for this lecture included an informal survey of HIV nursing roles across the UK and this was utilised to contribute to the findings of this research.

Survey of HIV nursing roles

The aim of this snapshot survey was to provide baseline information on the role of nurses in HIV care and to gain a greater understanding of the diversity of roles in place. The survey was carried out by telephone in May/June 2011 with a convenience sample of nurses working in HIV care across seven geographical areas in the UK. The locations and nurses were chosen by a snowball technique and to reflect the different cohort sizes and settings of care found in the UK. Potential participants were telephoned or e-mailed and asked if they would like to participate in a survey to inform a lecture on nursing roles. They were then given the option to speak on the phone if they were interested or to make contact with the researcher at a later date. Out of twelve participants approached, one did not make contact with the researcher. Participants were asked to talk about the following areas:

- Size of HIV caseload
- Nursing services for stable HIV patients
- Nursing services for complex HIV patients
- Other nursing roles
- Challenges with nursing practice issues

Further details of the locations surveyed and the participants involved are outlined in Appendix 7; participants verbally consented to sharing their names with a wider audience and at a national presentation. There were 11 participants from 7 locations, of which 7 were nurse specialists, 2 nurse consultants, 1 was a lead nurse and 1 a primary care nurse practitioner.

This supplementary survey showed a very mixed approach to the utilisation of nursing roles in the care of patients with HIV. Role development seemed sporadic and there was no evident career progression structure in the clinics surveyed. Nurse-led roles were often linked to the addressing of appointment capacity, particularly in the care of medically stable patients. There was a variety of models of care for stable patients that included nurse-led, e-mail and telephone clinics.

Although this informal survey was not specifically part of the original research design, it served as an additional data source in developing the concepts in relation to nursing roles. Where this was the case, the use of the survey as a data source has been made explicit.

This section on the data collection methods used for the research has included discussion on passive observation, semi-structured interviews and the use of secondary data sources to inform or situate the research. The next section will present the processes involved in data analysis.

3.5 Analysing the data

The main analytical strategy used to examine the data was dimensional analysis that involved coding and developing properties and dimensions that were grounded in the data. This strategy was utilised alongside constant comparative analysis across participant groups and sites. The next section will detail how the elements of dimensional analysis and the constant comparative method were systematically applied to the data.

3.5.1 Developing dimensions and properties

The construction of dimensions and properties is the foundation of using dimensional analysis. Kools, McCarthy and Durham et al. (1996, 316) defined a dimension as

“An abstract concept with associated properties that provide quantitative or qualitative parameters or modifiers for the purpose of description. Each dimension is a component of the phenomenon under study”

In order to develop dimensions from the data, initial coding was undertaken by naming chunks of data. This was done by viewing the data for “what ‘all’ is involved here” (Schatzman 1991, 310) and identifying the component parts of what was ‘involved’ in the data transcripts. For example, where patients spoke of their experiences with HIV care, this was initially named as trust and friendship as shown in the coding extract below.

Coding extract from Interview 9

I do find the doctors all of the doctors here and all the staff here to be extremely helpful and more importantly extremely friendly and that is a big issue as well because there is no possible way that you can have an intimate discussion with someone about this sort of thing unless you have a very friendly arrangement with them and should the Dr be that sort of person who wasn't a friendly person it just wouldn't work because people would not open up

INITIAL NAMING OF DATA: TRUST / FRIENDSHIP

Coding extract 1: Naming data chunks

This naming of data is known as the designation phase of dimensional analysis (Kools, McCarthy and Durham et al. 1996). This process was repeated throughout the initial transcripts and as concepts were developed, these were further explored in subsequent interviews. Transcripts were coded using *Microsoft Word 2010* comment balloons within the document review facility. Constant comparative analysis was also utilised in forming the concepts by comparing impressions from the data across the transcripts.²⁷ As more concepts were developed through this naming or designation of data, the dimensions and properties began to take shape. For example, trust began to emerge as a key concept across the data and was then conceptualised as a dimension with the properties shown in coding extract 2.

²⁷ The use of constant comparative analysis will be discussed in more depth in the next subsection, 3.5.2.

DIMENSION	Properties						3 rd August 2011
TRUST	Comfort	Familiarity	Feeling cared for	Quality	Friendship	Open	

Coding extract 2: The dimension of trust with associated properties

A dimension was viewed as an abstract concept as described by Kools, McCarthy and Durham et al. (1996) at the beginning of this section. The abstract concepts were developed through the use of an online thesaurus, visual thesaurus and concept thesaurus (dictionary.reference.com). This assisted in highlighting linkages between initial codes and distinguishing abstract from concrete concepts.

The dimensions and their properties increased with data collection and were re-conceptualised as more data was available (Schatzman 1991; Kools, McCarthy and Durham et al. 1996). As these dimensions and properties were developed, tables were constructed in word documents to explore linkages between the concepts and comparisons across patient and staff groups. This method was utilised to organise the data in preference to a software package in order to assist in directly comparing, analysing and visualising the concepts as they emerged. In addition, analytical memos were used alongside the transcripts to inform the ongoing development and redefining of dimensions and properties. For example, the dimension of trust was further examined as shown in coding extract 3.

Is 'trust' a property of relationships between patients and health care professionals?

Is familiarity about knowing and feeling known?

How do healthcare workers perceive 'friendship' with patients and is this perhaps more about rapport?

Coding extract 3: Analytical memo exploring trust as a dimension 3rd November 2011

In this way, each interview was transcribed, coded, compared and conceptualised as a dimension or property. These dimensions or properties were then re-examined through analytical memos and re-conceptualised to reflect the emerging picture within the data and the relationship between the assembled concepts (Schatzman 1991). As a result of this process, the concept of trust moved from being a designated code to a dimension and then to a sub-property of another dimension that was called relationships (see coding extract 4).

DIMENSION	Properties 3rd November 2011		
RELATIONSHIPS	Nurturing Sub-properties Trust / Knowing / Rapport / Security	Supportive	Functional

Coding extract 4: Re-conceptualisation of dimensions and properties

This differentiation of the data enabled further abstraction from the data (Kools, McCarthy and Durham et al. 1996) and assisted in identifying the more salient dimensions and relevant properties. The differentiation stage of the data analysis reduced the mass of dimensions from ten to four and properties from forty-four to twelve. The concept of trust was finally designated a sub-property of supportive relationships that was a property of the dimension of engaging with care (see coding extract 5).

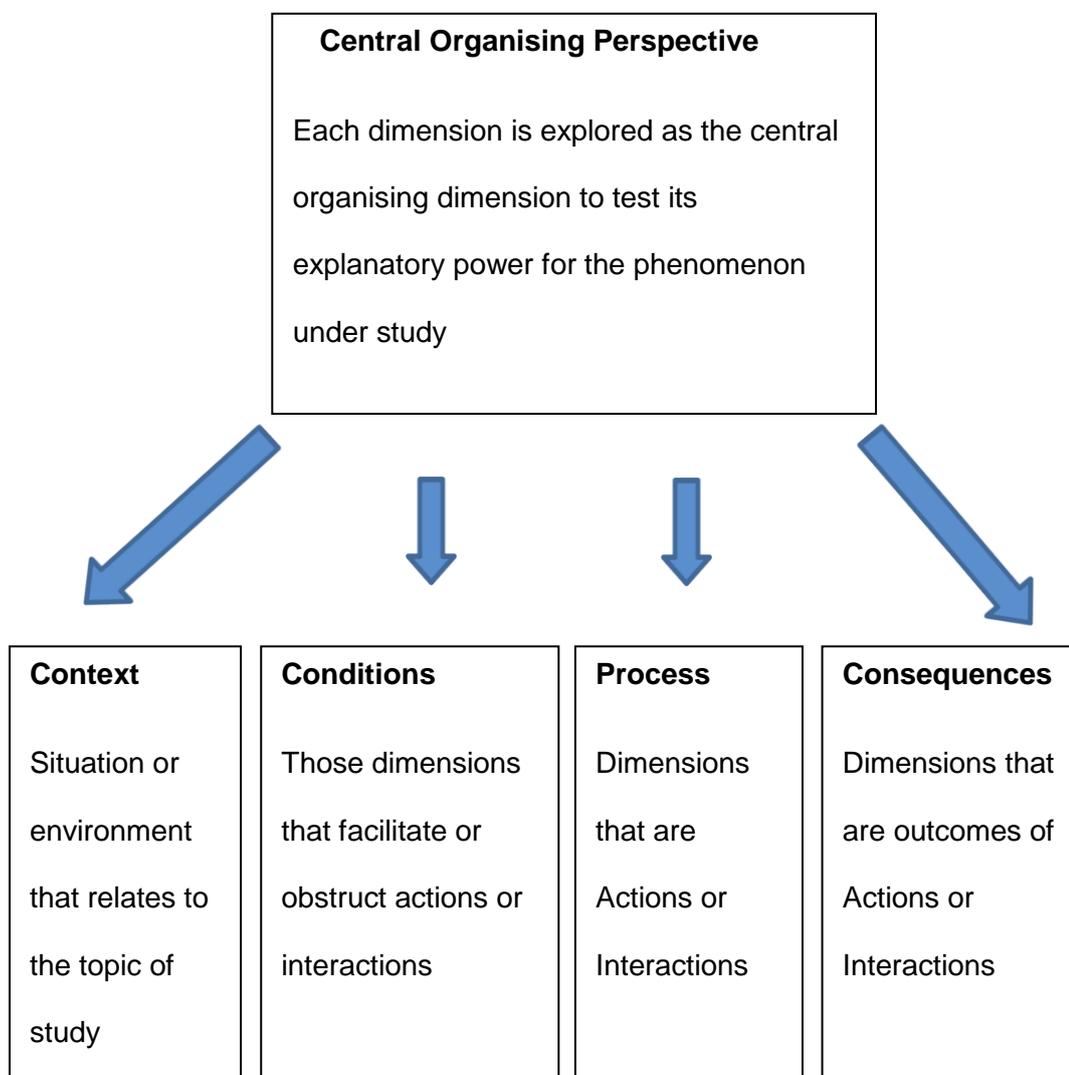
DIMENSION	Properties	Sub-properties
Engaging with care	Supportive relationships	Security; trust; knowing; rapport; attachment
	Feeling accepted	Approval; disclosure, felt and enacted stigma
	Participation	Responsibility; partnership; support

Coding extract 5: Final placement of the concept of trust, a sub-property

In addition, the use of an audit trail of dimensions, properties and sub-properties was instrumental in tracking the emergence of the data findings and in the theoretical development of the thesis.

Once the dimensions and properties reached a plausible point, they were then placed into an explanatory matrix that is described as the cornerstone of

dimensional analysis (Robrecht 1995; Kools, McCarthy and Durham et al. 1996). The aim of the explanatory matrix is to identify which dimension holds the greatest explanatory power for what is occurring in the data and can be utilised to develop a theory on the topic of research (Schatzman 1991). Therefore, each dimension was placed as the central organising perspective in relation to the other dimensions that were considered as either context, conditions, process or consequences. This stage in the analysis was based on a template adapted from Kools, McCarthy and Durham et al. (1996) as shown in Figure 3.9 below.



Adapted from: Kools, McCarthy and Durham et al. 1996

Figure 3.9: Diagram of explanatory matrix used for dimensional analysis

This process of exploring perspectives within the explanatory matrix was mapped out using *Microsoft Word 2010* and at times supported by the sorting of handwritten cards for the dimensions and properties. As each dimension was explored, this provided a different perspective on the data and further illuminated the connections and linkages between the dimensions (Schatzman and Strauss 1973; Schatzman 1991; Robrect 1995). For example, the dimension of engaging with care was tested as the central organising perspective and was not able to theoretically account for what was occurring in the data. Instead this was perceived as an outcome of the way that people with HIV viewed their condition. This method also assisted in exploring different perspectives in the data thus therefore moving it further from the individual researcher perspective (Schatzman 1991).

This procedure was repeated at several stages during the analysis as different theories were explored. Initially, the concept of HIV services as an evolutionary phenomenon was explored for its theoretical plausibility and perspective in explaining the other dimensions and properties. At a later stage, identity was examined for explanatory power in relation to the other data concepts. When these concepts were rejected for their central organising perspective, other theories were explored and dimensions and properties re-conceptualised. This cycle of inductive and deductive analysis using the explanatory matrix enabled the identification of a central perspective that formed the basis of the substantive theory.

3.5.2 Constant comparative method

Throughout the naming of data and development of dimensions and properties, constant comparative analysis was undertaken. This method was used to explore and compare concepts from the data across the case study sites and between participant groups (Glaser and Strauss 1967; Strauss and Corbin 1990; McCann and Clark 2003b; Charmaz 2006a). Although constant comparative analysis was utilised to support the development of dimensions and properties, this subsection focuses on the specific application of this method in data analysis.

The constant comparative method commenced after several interviews had taken place and after initial coding had started (Schatzman and Strauss 1973; Morse 2009). This involved a continual process of going back to the data to further explore similarities and differences and to build on the analysis of the findings (Emerson 2004; Hoare, Mills and Francis 2012). Data concepts from patient groups in the sites were compared across all interviews both within each site and across the sites to explore context and to investigate whether differences existed in age, length of HIV diagnosis and current illness status (Strauss and Corbin 1990). Likewise, healthcare worker concepts were compared by discipline, length of service and role within and across the sites to explore commonality and differences.

As concepts emerged from the data, the literature was then used to explore these further to confirm their relevance to the research topic (Strauss and Corbin

1990; Charmaz 2006a; Walls, Parahoo and Fleming 2010). For example, when relationships were seen as a key concept in patient interviews, this was compared with patient interviews across both sites and then compared with data from healthcare worker interviews. This comparison helped the researcher to understand how these relationships were viewed from different perspectives and to reshape the concepts to integrate with the raw data across the groups and sites. The literature was then examined to explore patient-provider relationships in other disease areas and how these may relate to the on-going interactions within healthcare settings. Figure 3.10 shows an illustration of how the concepts within the participant groups and research sites were compared with relevant literature.

Constant Comparative Analysis of Concepts

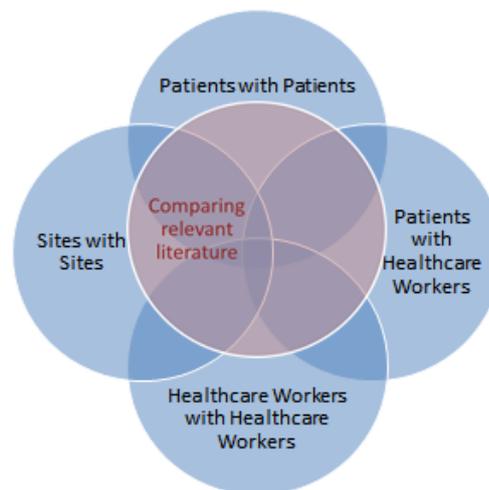


Figure 3.10: Using literature to compare with data concepts

The constant comparative method was also used to explore working hypotheses and to interrogate the data further to test those hypotheses. The memo extract below shows how this approach was used to interrogate the data in relation to the deployment of nursing roles in the care of people with HIV.

Working Hypothesis: Nursing roles are driven by the structure of a service and medical approval.

Data interrogation: Constant comparison analysis of medical and nursing interview data within and across sites with regard to the concepts involved in utilising nursing roles and nursing skills.

Memo extract 1: Example of how constant comparative analysis was used to test a working hypothesis.

The use of the constant comparative method alongside the naming of data and the development of dimensions and properties enabled the researcher to focus on the main concerns of the participants and reduce the potential for researcher bias (Glaser 2002; Strauss and Corbin 1998; Charmaz 2006a, 2006b). In this way there was an on-going relationship with the data and the process of moving between the data, data concepts, literature, and back continued until theoretical plausibility was reached.

The study design included healthcare workers and people with HIV in order to address the goals of the research and gaps in knowledge. Although each

dimension was derived through robust comparative analysis across participant groups, the presentation of the findings has conceptually separated the perceptions of healthcare workers and patients in Chapters 7 and 8. This approach is intended to demonstrate the connections between the dimensions and the relationship with the substantive theory and not imply that participants were analysed in distinct groups.

The final section of this chapter will outline the additional strategies used to develop the substantive theory.

3.6 Building the theory

The development of a substantive theory began when the first wave of dimensions were placed in the explanatory matrix (see Figure 3.9). This involved the ability of the researcher to think on a theoretical level while remaining grounded in the data. There were several strategies used to assist this process.

3.6.1 Conceptual levers

Firstly, conceptual levers were utilised as a tool to open up the data and provide a different way of thinking about the emergent data concepts. Schatzman and Strauss (1973, 118) define a conceptual lever as “any thinking device that both distances the analyst from his data and provides a new perspective on them”. Initially common theoretical classes were used to gain entry into the data and to view the data from a theoretical perspective (Schatzman and Strauss 1973;

Glaser 2004). This assisted with exploring the density of connections between the dimensions and searching for the grounded key in the data.

One conceptual lever used was the interrogation of the data using the following questions:

- What is this study about?
- What is the main concern of the participants?
- How are they resolving that concern?

This approach enabled further abstraction from the minutia of the data and exploration of “what ‘all’ is involved here” (Schatzman 1991; Robrect 1995; Kools, McCarthy and Durham et al. 1996; Glaser 2002). Other healthcare phenomena were used for comparison, such as other chronic disease areas, to situate HIV healthcare within a wider context (Strauss and Corbin 1990). At times, far out comparisons were made, such as exploring disruptive technology in relation to the transferability of the principles of HIV healthcare delivery within a sustainable healthcare context (Ibid).

The use of a theoretical lens to approach the development of theory and to view the data was another strategy in building theory. Although the lens changed as the perspective of the researcher evolved, the data was largely viewed through a chronic disease lens and with regard to long-term sustainability of HIV healthcare provision. Charts and tables were also to explore the occurrence of phenomena for each participant. For example, the concept of ‘fragility’ among patient

participants was further explored by mapping patient demographics against presence of symptoms, expressed uncertainty and perceived stigma.

The theoretical concepts of identity and transition were explored in relation to the data findings, but did not have the fit, grab and relevance that reflected what was occurring in the data. The substantive theory of healthy-illness representation emerged from the central organising perspective of illness representation of HIV. This was discovered through the use of the conceptual levers identified above and the adaptation of received theory (Schatzman 1991). This was further verified for fit, grab and relevance in the field of HIV healthcare (see Section 3.6.3 for verification strategies).

3.6.2 Use of reflexive diary and memos

A reflexive diary was utilised to maximise the trustworthiness of the data by exploring the perspective of the researcher and the potential impact on the data (Willig 2001). This tool was used to examine the researcher's interpretations and to balance her experience in the field with her perspective (Schatzman and Strauss 1973; Charmaz 2006a).

For example, following the initial interviews, the researcher explored how she had distanced herself during the interpretation of the interview (see diary extract 1).

Reflection on interview 12

At times, I referred to my own clinical practice in this interview. Was this because I was interviewing a non-HIV specialist healthcare worker? Does this help me to review the research from another perspective? How much more neutral can I become? How well did I use my lens of sustainability or chronic disease lens?

8th June 2011

Diary extract 1: Reflection on sociological distance during an interview

A further reflection was then undertaken exploring the first reflection as shown in diary extract 2.

Reflection on the reflection for interview 12

Although I continue to have a specialist hat on, my interview questioning is broadening my perspective and becoming more exploratory. I am starting to situate HIV healthcare workers alongside their non-HIV peers. I used my own clinical practice as a reference point in this interview but it seemed to serve to illuminate the differences from other healthcare fields.

8th June 2011

Diary extract 2: Reflecting on the reflection

In addition, to manage the ambiguity in identity as a nurse consultant and researcher, a scoring system was devised to self-assess and monitor the level of sociological distance from a nurse consultant role. The use of a reflexive diary

also assisted in managing the relationship with some healthcare worker participants who were known to the researcher in a professional capacity.

Interview 21

I knew this participant well professionally and had previously engaged in some discussions with them on aspects of the research topic and worked with them at a national level. I found that actively using my working hypotheses and theoretical lens helped to distance this relationship and helped me to keep the conversation focussed around the research goals. I (further) distanced myself by asking questions about (patient) needs and not nursing role development and this was a helpful strategy in not aligning myself with the participant.

17th August 2011

Diary extract 3: Managing the researcher/participant relationship

The reflexive diary was therefore a dynamic tool with which to manage the researcher perspective throughout the duration of data collection. In addition, memos were written after each interview and at key stages in the development of the theory (Ghezeljeh and Emami 2009). These memos served to develop working hypotheses and to track the analytical thinking as the data concepts emerged and theory started to develop.

For example, the concept of disease representation emerged about half-way through data collection. This was first recorded in an analytical memo (see memo extract 2).

The changing spectrum of HIV disease appears to be a local concept. Neither patients nor healthcare worker participants talk about disease complexity on the Springfield site. Is this because the epidemic is younger in Springfield and does this only fit into the illness trajectory in some settings? 2nd August 2011

Memo extract 2: Is the concept of disease complexity site specific?

As more data was collected and analysed and concepts were explored through theoretical sampling, it became evident that healthcare workers had different approaches to delivering services for stable patients. Memo extract 3 shows how the researcher's thinking was progressing in terms of exploring healthcare worker conceptions of HIV as a condition.

There appears to be a range of healthcare worker views on how to provide care for stable HIV patients. It is not clear if this is linked to casemix or length of time working in the speciality. The larger clinics are more inclined to diversify. Is this because they can? Or perhaps because they have to? What is underpinning these approaches? 20th November 2011

Memo extract 3: What underpins the different approaches to stable patient care?

The memos continued after initial data collection and influenced further data interrogation. This process assisted in exploring the data further to uncover the main concerns of participants (see memo extract 4)

There seem to be some factors that influence how patients view the role of HIV services. It is not clear if this is related to certain characteristics, such as length of diagnosis or experience of being unwell with HIV. There is an underlying anxiety or perhaps fragility in the narratives of patients that suggest it goes beyond the fact that they like their healthcare workers and the standard of care they receive. Map this out further against the patient data

9th January 2012

Memo extract 4: Factors influencing how HIV service are utilised

In this way, analytical memos were also utilised to develop new working hypotheses and to produce concepts from the data (Glaser 2004). They also served as an audit trail for the dimensions and properties and to track the evolving theory throughout the thesis.

Finally, supervisory sessions were also used as a way of enhancing data quality by examining the methods used and by introducing new methods where required.

3.6.3 Verification strategies

During the development of theory, a number of verification strategies were used to test the theoretical constructs for fit, grab and relevance (Glaser 1978; Kools, McCarthy and Durham 1996; Strauss and Corbin 1998; Charmaz 2006a). Firstly, opportunities were utilised to present the emerging findings at academic and subject specific conferences and feedback was considered and fed into the theoretical production. For example, the interim findings were presented at a National HIV Nurses' conference in June 2012 in a 15 minute presentation. On reflection, this forum may not have been the most suitable environment in which to present interim results as the focus of the conference was on concrete nursing practice issues and not on developing theories for service provision. However, this verification exercise prompted a re-conceptualisation of the findings that contributed to theory development. During the latter stages of theory development and writing the thesis, presentations were given to a wide audience to generate discussion and test the relevance of the theory for healthcare delivery. These presentations were delivered to the following forums:

- The annual doctoral conference
- To 25 nurses at two of the research sites
- To the Chair of the Clinical Reference Group for HIV
- At a National HIV Nurses' Conference 2013
- At a Departmental academic meeting
- At several research workshops

These forums created opportunities to articulate and reflect the emerging theory and incorporate the views of a wide range of healthcare professionals.

Patient participants were central to verification of the emerging theory and second interviews were undertaken with a selection of patient participants to further explore and test it. Throughout the thesis development there were also many conversations with the members of the Patient Advisory Group. In addition, a large number of critical friends were involved with the research and were valuable resources in verifying the findings in relation to clinical practice in a number of settings. Informal conversations with staff at the research sites were also instrumental in forming and confirming theoretical constructs. Finally, the use of extant literature from other settings was pivotal in verifying what was particular to HIV from other chronic disease areas.

3.7 Chapter Summary

This chapter has presented the specific grounded theory methods that were used to conduct this research. It has shown examples of the recruitment and sampling strategy and the interview style adopted. The chapter has included how concepts were derived from the data and developed into dimensions and properties. The mechanics of building theory have been explained and included examples from the research diary. The following section will present the findings and substantive theory of this thesis.

Section 3: Findings and Substantive Theory

This section will present the findings and the substantive theory that were developed from the data concepts in this research. Throughout this section, HIV healthcare has been viewed as a spectrum of related concepts that incorporate the narratives of people with HIV and healthcare workers. This spectrum embodies the interactions and processes involved in HIV healthcare from patient and healthcare worker perspectives in order to address the research aims (Section 1.4).

This section will present an adapted theory of illness representation that accounts for the way that HIV is viewed as a chronic stable condition and how this affects the way that services are delivered and utilised. Established theories of illness representation are based on the cognitive and emotional perceptions of illness that influence patient responses to symptoms and subsequent coping behaviours. The adapted theory of this thesis has been named healthy-illness representation of HIV that is based on a spectrum of disease representation along a health-illness continuum and incorporates the cognitive and emotional experiences of both patients and healthcare workers. This substantive theory explains how HIV is represented as a long-term condition based on how patients and staff think and feel about the experience of having HIV infection.

The first chapter of this section, Chapter 4, will present the sample characteristics to provide some context for the research findings. Chapter 5, 6, 7 and 8 will examine the evidence within four dimensions of HIV healthcare with references to the linkages and connections between them and the theoretical concepts. These dimensions with their properties and sub-properties are shown in Figure S3.1 below.

Dimension	Properties	Sub-properties
Benchmarking	Expectations	Standards; norm; approach to care
	Identity	Exceptionalism; Uniqueness; Specialist
Engaging with Care	Supportive relationships	Security; trust; knowing; rapport
	Feeling accepted	Approval; felt and enacted stigma
	Participation	Responsibility; partnership; support
Adapting HIV healthcare	Counterpoising	Transforming stability; extending parameters of HIV
	Healthcare worker constructions of HIV	The well patient; the patient requiring on-going engagement in care; the holistically complex patient; job role
	Delegating	Substitution; complementarity
Illness Representation	Symptom identity	Cause, physical and psychological
	Consequences on self	Uncertainty, controllability, timelines
	Consequences on social integration	Stigma as a social process
	Spectrum of needs	Symptom experience; impact of HIV on self; impact on social integration

Figure S.3.1: Summary of Dimensions and Properties

This section will conclude with Chapter 9 and will present the substantive theory based on the central organising perspective that emerged through integration of the theory. Figure S3.2 introduces the substantive theory of healthy-illness representation of HIV and shows the connections between the dimensions. The corresponding chapters have been included in this figure.

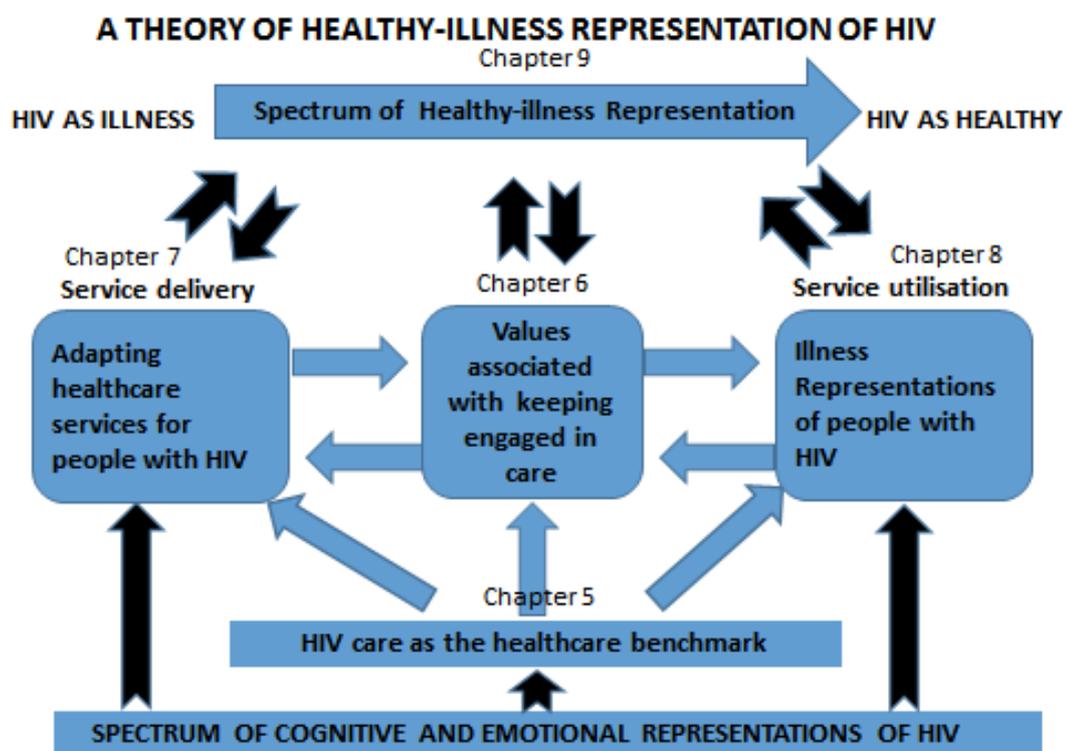


Figure S3.2: Illustration of the theory of healthy-illness representation of HIV

The first chapter of this section will begin with a bridging chapter that describes the research sample and context of the research sites.

Chapter 4: Context and sample characteristics

4.0 Introduction to chapter

To assist in interpreting the data, an understanding of the context of the field setting and sample characteristics is required (Schatzman and Strauss 1973). This chapter will present an overview of the study sites and sample demographics in order to situate the findings presented in the rest of this section.

4.1 Research sites

The three research sites were situated between the North Midlands and the South of England. These locations served very different populations ranging from an urban centre to a smaller rural population and had diverse HIV prevalence rates. The sites were given the pseudonyms of fictitious towns and were named Metropolis, South Park and Springfield.

The caseload demographics across the sites were a mixture of the dominant HIV risk groups that included men who have sex with men and heterosexuals from countries of high HIV prevalence (Health Protection Agency 2012). The total number of HIV patients attending these three clinics was approximately 5000.

4.1.1 Service specification

The research sites included one HIV Unit and two HIV centres, two of which had clinical network structures in place (See Section 3.3.1). Two of the clinics had full time HIV sessions.

There was a wide range of different services and roles across the research sites. In some areas there were virtual results clinics for patients who were considered to be medically stable. This involved patients attending for blood tests and receiving their results either by e-mail or by telephone. Nurse-led activities ranged from no service at all to fully developed nurse-led services that in some cases included advanced practice roles. There was patient access to different multidisciplinary roles, such as psychology, mental health and pharmacy across the three service sites. In addition, two of the clinics had established links with allied specialities, such as renal medicine, cardiology and oncology and some participated in joint clinics. All service sites had links with general practice, although these links were more formal in one of the service sites. Two of the clinics worked alongside HIV community nursing teams and a different two services worked alongside the voluntary sector and provided clinics space for voluntary sector workers to see patients.

The relevance of specific site characteristics to the construction of the substantive theory will be discussed in detail in the following chapters of this section.

4.1.2 Interviews by site

There have been 40 semi-structured interviews with 34 individuals across the three research sites. Of the 34 participants interviewed, 13 were patient participants and 21 were healthcare professionals. Of the 40 interviews, 17 were with patients and 23 with healthcare worker. Figure 4.1 shows the distribution of patient participants across Springfield and Metropolis and the distribution of healthcare worker participants across all three case sites (see Section 3.3.2 for rationale for participant sampling across sites).

Site	Springfield	Metropolis	South Park	National	Total
Patient Participants	5	8	0	0	13
Healthcare workers	6	6	5	1	18
3rd sector	2	0	1		3
	Total 13	Total 14	Total 6	Total 1	Total 34
Second Interviews	2	4		Total Interviews	40

Figure 4.1: Participant distribution by site

4.2 Sample characteristics

The patient participant sample characteristics included in this subsection give specific details of gender, age, ethnicity, length of diagnosis and treatment history. Again, where these demographic factors were believed to influence the concepts in the data, this has been made explicit in throughout the forthcoming findings chapters.

Of the 13 patient participants the majority were male and 7 of these 9 were males were men who have sex with men. There were two Black Africans, 1 Black Caribbean, 1 White European and the remainder were White UK. While the nature of this research was not to recruit a representative sample of patients, these demographics were reflective of the spread of HIV across these groups nationally (Health Protection Agency 2012). Figure 4.2 illustrates gender, risk group and ethnicity in the two sites where patients were recruited.

	Springfield	Metropolis	Total
Male	4	5	9
Female	1	3	4
MSM	4	3	7
Heterosexual	1	5	6
White UK	5	4	9
Black African	0	2	2
Black Caribbean	0	1	1
White European	0	1	1

Figure 4.2: Patient participant by gender, risk group and ethnicity

The age profile of patient participants was different across the recruiting sites with participants in Metropolis having a median age 13 years higher than Springfield as shown in Figure 4.3.

Age range over both sites	27-70yrs	Mean 47.3yrs Median 52yrs
Metropolis	34-70yrs	Mean 50.5yrs Median 52yrs
Springfield	27-56yrs	Mean 42.4yrs Median 39yrs

Figure 4.3: Age profile of patient participants

In comparison with the age distribution across the UK, over half of the sample was over 50 years of age as opposed to just over 20% of people with HIV in 2010.

Although comparative statistical analysis was not undertaken as part of this study, there was an observed difference in the length of time since diagnosis across both sites where patients were recruited. In Springfield, the median time since diagnosis was 4 years compared with 14 years in Metropolis as shown in Figure 4.4:

Time since diagnosis over both sites (range)	3yrs-20yrs	Mean 9.7yrs Median 9yrs
Metropolis	4yrs-20yrs	Mean 12.6yrs Median 14yrs
Springfield	3yrs-10yrs	Mean 5.2yrs Median 4yrs

Figure 4.4: Length of diagnosis of patient participants

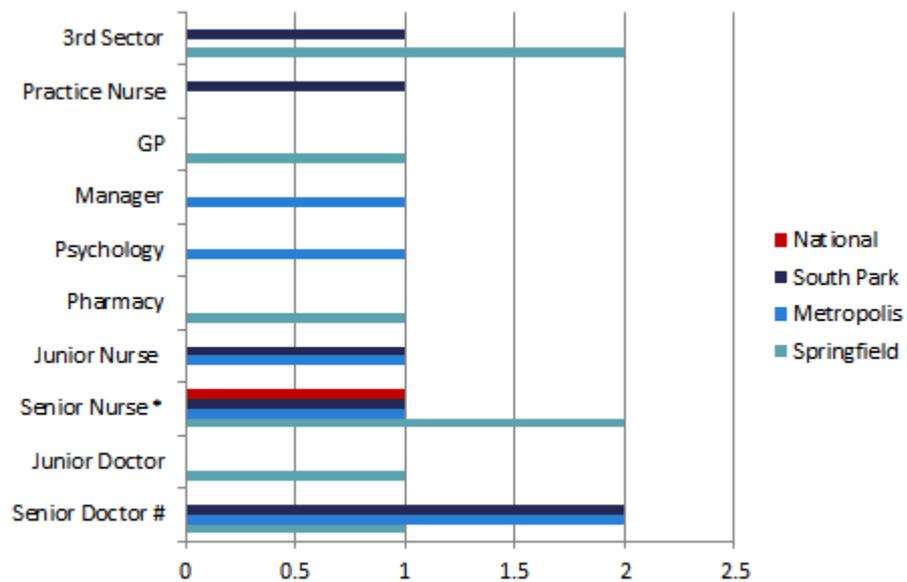
The majority of patients were on antiretroviral therapy or HAART (see terms and abbreviations) and only one participant was not on treatment at the time of the study. For the 12 patients on treatment, two were on their third drug combination. 10 of the 13 patients were attending their clinics 3-4 monthly for routine

monitoring indicating that their HIV condition was medically stable. Of the total patient participant sample 4 were attending research clinics and participating in clinical trials at the time of the study. A different 10 patient participants were registered and using general practice services to some extent. These characteristics are illustrated in Figure 4.5 below.

	Springfield	Metropolis	Total
Diagnosis pre-HAART	0/5	4/8	4/13
On ART	5/5	7/8	12/13
1st HAART	5/5	2/7	7/12
>3 HAART	0/5	2/12	2/12
3-4 month clinic appts	5/5	5/8 (inc 1 tel)	10/13
Uses GP	5/5	5/8	10/13

Figure 4.5: Antiretroviral therapy and service use

There were a range of healthcare workers recruited to the study that covered a number of disciplines and who represented several service settings. The spread of healthcare workers by discipline is shown in Figure 4.6.



* Include one nurse from allied speciality. # Includes 2 doctors from allied specialities

Figure 4.6: Healthcare worker participants by discipline

Two staff were based in the community and two had previously been in community posts. Three were in paid roles in the non-statutory sector and three were from allied specialities that worked alongside HIV services (see Figure 4.7).

	Doctor	Nurse	Allied HCW	Total
HIV Clinic	4	5	1 Manager 1 Psychologist 1 Pharmacy	12
Allied Specialist	2	1	-	3
Community	1	1	-	2
Voluntary Sector	-	-	1 Social Work 1 Mental Health 1 Palliative Care	3
Independent	-	1	-	1
Total	7	8	6	21

Figure 4.7: Healthcare workers by workplace setting

4.3 Chapter Summary

This chapter has presented the demographics and sample characteristics to provide some context for the research findings and analysis. The following chapter is the first of four chapters that present the evidence for the substantive theory of healthy- illness representation of HIV.

Chapter 5: The legacy of HIV healthcare

5.0 Introduction to the chapter

The social history of HIV in the UK spans three decades since the initial reports in 1981 (Owen and Catalan 2011). The first decade was associated with significant mortality rates until the introduction of Highly Active Antiretroviral Therapy (HAART)²⁸ in 1996 (Hammer 1996; Palella, Baker, Moorman et al. 2006). This gave rise to a new discourse on HIV as a chronic treatable infection that has continued since the mid-1990s until the present day as HIV enters its fourth decade (Kylam, Vehvilainen-Julkunen and Lahdevirta 2001; Bravo, Edwards and Rollnick et al. 2010; Owen and Catalan 2011; Perrett and Biley 2012). During this transformation, HIV treatment and care in the UK has predominantly been provided by specialist HIV services (Department of Health 2001; British HIV Association 2007; Independent Advisory Group on Sexual Health and HIV 2009; House of Lords 2011b; British HIV Association 2012).

This chapter will present the evidence on how the current identity of HIV services has influenced the expectations of patients in relation to their healthcare

²⁸ See terms and abbreviations.

provision and how this is linked with the way they cognitively and emotionally represent their HIV condition.

5.1 HIV care as the touchstone

The data analysis indicated that HIV healthcare services were viewed by all participants as different from other healthcare services in terms of the approach and quality of care provided. Patient participants perceived that their HIV care was of a very high standard and 12 of the 13 patient participants expressed high levels of satisfaction with their care, irrespective of the length of time since diagnosis, age, ethnicity or which research site they attended. This satisfaction appeared to be related to several elements of care. For some this was about the processes and delivery of care and for others it was about how healthcare workers in HIV acted towards them.

When I sit down on a one-to-one basis and I talk, I always come away assured or feeling assured that they are doing everything in the background possible to ensure that my health is fine and is maintained at an acceptable level

Sebastian, Age 38

It's like they begin to feel what you feel and as such they are much more understanding. When they approach you and they ask you what you are going through and it's like they are so much willing to see you well and up on your feet. It's like they don't like you suffering, they don't want to see you being isolated or segregated because of this [HIV]. They want you to feel more like a normal human being

Malcolm, Age 55

I'm quite happy with my HIV healthcare yeah I wouldn't change it. It's just sometimes I go into the doctor [GP] and say that I've come here and I've wanted to speak about something and it's not like one of the normal [HIV] doctors

Sally, Age 27

The concept that the HIV doctor was viewed by Sally as the 'normal' doctor was not uncommon among participants and this did not seem to be linked to how long ago people were diagnosed. Typically HIV patients are monitored every 3-6 months after diagnosis and it appeared that the approach and standard of care in HIV had become the 'norm' for patient participants. However, this seemed to create expectations for patients of how their healthcare should be provided in the future. Some patients believed that specialist knowledge was important and others that communication was a key issue in future care provision.

You have to feel confident that the person you are talking to knows exactly what they're talking about and that they can 100% reassure you that what they are feeding you, that the information is correct and there's nothing worse than dealing with people and myself, being in business, dealing with people in my business who cannot, who don't have the right information in front of them and they feed you the wrong information all the time

Simon, Age 56

I'd like to feel comfortable talking to them [healthcare workers] and feel that they are comfortable talking to me and I get that here [HIV clinic]. I do get that here

Scott, Age 52

A number of patients were anxious that their care would change and that this would constitute substandard care for them and present risks to their health.

I worry sometimes that all this is going to disappear and that I'll be in a situation where I'll have suboptimal care which may be good care for somebody who is newly diagnosed and is maybe the sort of care that they feel happy with and it will keep them healthy [but] which I think would be suboptimal for me. I find that very worrying because I obviously want to stay healthy for as long as possible

Michele, Age 52

I'm quite happy with the way it's [my care] structured at the moment. I see the staff here every three months. For example this morning with the [increase in] the viral load, if that had been six months or 12 months or two years then I might not have been aware of that for a longer period of time so I certainly hope that [the monitoring] will continue into the future

Stewart, Age 39

Those patients who expressed satisfaction with care and concerns about the future standards of care were all taking antiretroviral therapy. Although most patients described recent changes to the way their care was provided in the HIV clinics, their 'norm' still appeared to be rooted in a standard and approach to care they had come to expect. These expectations were often not fulfilled in other healthcare encounters and this presented difficulties at times for patient participants when they accessed healthcare outside the HIV setting. For example, those who had first-hand experience of other services were often disappointed with their care in comparison to their experiences of HIV care. Two patients described their experience when accessing GP care.

She [new GP] asked me a couple of times how did you catch it [HIV], because she didn't remember specifically my face. When it came up on the screen and it showed HIV-positive she asks how did you get it [...] yeah once [or] twice [but] three times you start to wonder

Martha, Age 40

And when he finalised this letter he said could you please help this poor HIV-positive man [...] and that sort of stuck with me. It made me angry yes I'm HIV-positive but I'm not poor [...]. So everywhere I go even when I go and see the GP this is the way they see me, a poor HIV-positive person who might die any time who has got no answer or no other medication

Malcolm, Age 55

These experiences had led both of these patients to disengage from their general practice and only to attend when they felt they had no choice. In addition this reinforced their faith in HIV services which provided the different standard

and approach to care that they had come to expect. While the majority of patient participants continued to access their GP, there were concerns expressed about the ability of GPs to meet their specialist healthcare needs.

I think the drive to allow people the drive to make GPs take more responsibility for chronic condition management is good but [it's] a blanket policy [that] I think risks endangering those people who are obviously in stable care from specialist clinics

Morgan, Age 45

I know that I read things about GPs sometimes and worry because I have a complex health issue that needs a lot of caring for [I worry] that maybe I would fall into the category of patients who are too demanding for a GP surgery

Michele, Age 52

The use of general practice for their healthcare needs was further complicated by how patients viewed the cause of symptoms. Michael spoke of the difficulty in deciding which service to access if he had a health problem.

You have to take minor illness to your GP or non-HIV related illness to your GP and you have to take HIV related illnesses to your clinic but two things come to mind on that. How do you tell the difference? And the second is who is best able to deal with my problems. And I think the [HIV clinic] is best placed to deal with my problems, because they know the underlying condition, they are aware of HIV and everything involved with HIV so they don't treat something just as an illness, they treat it as a threat

Michael, Age 70

This indicates that patients view their condition within a specialist paradigm and that this influenced the way they perceived the role of non-HIV healthcare services. Patient perceptions of their condition will be explored in more detail in Chapter 8. However, HIV services as specialist entity was saturated in the patient participant data.

They [the HIV clinic] are more specialised to deal with HIV people so you know they are going to treat you like anybody else

Martha, Age 40

When it comes to HIV, I'd much more come to an HIV specialist doctor than a GP

Sally, Age 27

I mean the world in general is becoming, people are becoming more specialised in everything aren't they? Whether that's in schools, with hospitals or in law, the move is towards more specialism. As things become more complicated and move back to a local family doctor, while it has its advantages, apart from cost of course, it doesn't seem logical

Morris, Age 52

This expressed need for specialist HIV care seems to be connected to the standard and approach to care that had become the 'norm' for patient participants in this study. This may be explained by the biographical relationship that HIV patients had with HIV services. This implies that patients were viewing HIV care as a medium to meet all their healthcare needs and that this formed the way that they viewed HIV as a condition.

Healthcare workers in HIV acknowledged difficulties in encouraging patients to access GP services. One senior doctor summarised the historical factors that contributed to the uptake of GP care.

I think the big gap is that general practice has been left behind in HIV care not through their own fault. Some of it was a lot the fault of the speciality holding onto HIV and doctors, doing every single thing for the patient because many patients wouldn't disclose their HIV status to their GP. So doctors felt obliged to manage all of the routine care for that individual for the rest of their life and I think that has been a mistake which we are slowly redressing

Seth, Senior Doctor

Many other healthcare workers in HIV recognised that the way HIV healthcare services had been provided could have contributed to a specific culture or identity within HIV services that set it apart from other healthcare settings. One medical registrar believed that emphasis on supporting patients to manage their life-long HIV treatment may have contributed to developing the approach and identity of HIV care.

We are involved with our patients quite considerably for a considerable period of time and as adherence [to antiretroviral therapy] is a significant feature. I would think we are probably less directive than in other medical specialties so if patients want to bring up their own concerns to us I'd like to think that there is a space for that to happen

Spencer, Specialist Trainee Doctor

Other staff acknowledged the role of HIV services in intensifying the barriers to accessing GP care.

One of the problems is about patients being empowered to get the most out of primary care. I think that we have created some problems in keeping people within HIV clinics and they know how to get the best out of us and they haven't necessarily figured out how to get the best out of a GP

Mason, Senior Doctor

We as staff find it difficult triaging patients and saying to them actually we shouldn't be seeing you, you should be seeing your GP [and] we won't be providing a clinic appointment for you. I think is very difficult it's hard to move from - we look after you to actually we [only] do a certain amount for you

Marcus, Senior Nurse

This indicates that HIV care has evolved as a specialist service that provided for all the healthcare needs of patients and that both staff and patients are challenged by integrating with mainstream healthcare services. This creates a complex picture where the legacy of HIV care continued to pervade the

perceptions of patients and staff on the role of non-HIV healthcare services and in particular primary care.

The findings above are consistent with previous studies on the role of general practice in HIV (Benn, Miller and Evans et al. 2009; Munir, Edwards and Richards et al. 2009; Namiba, Anderson and Tolowinska 2010; Defty, Smith and Kennedy et al. 2010). In comparing concepts of primary care devolvement in other chronic disease areas, patient readiness for discharge from specialist care, expectations of relationships with primary care providers and access to multidisciplinary services were factors that influenced successful transition in diabetes management (Brez, Rowan and Malcolm et al. 2009). Wilson, Brooks and Proctor et al. (2012) also identified that secondary (specialist) care was perceived as having the “monopoly of expertise” by patients with a range of different chronic diseases. HIV patients in this study do not appear to differ in these respects. However, non-HIV healthcare workers who were interviewed for this thesis believed that HIV patients had different expectations of healthcare services from other patients in their care.

I would say they [HIV patients] probably expect more because I think they get provided for very well in comparison to other conditions, maybe stroke patients in the past. I know that's improving now, I don't know if it's a good comparison but then when they [HIV patients] come into another part of the hospital I think they do expect high standards

Pam, Senior Nurse, Allied Speciality

They [HIV patients] need to feel that you're an important part of their care and not a second class addition. I am aware that they have had a very intensive medical experience. They are used to not seeing the NHS at its worst they have seen the NHS at its best. So those two things I suppose, I won't say it makes me nervous, but I am aware of it

Paula, Senior Doctor, Allied Speciality

The concept that HIV patients have been *provided for very well* and come from an *intensive medical experience* suggests that they have had different and perhaps better experiences than other patients in the NHS. This appeared to create some tensions when HIV patients accessed other healthcare settings. One community nurse believed that the expectations of HIV patients were sometimes unrealistic and very different from patients in other disease areas.

If you look at the service that [HIV] patients get - I remember talking to somebody who had a headache and they think I can go and get a scan within a couple of weeks and go and see the [HIV] specialist. No other service gets that

Penelope, Community Nurse

This highlights that the expectations of HIV patients may also be related to the responsiveness of services and to the reassurance that new symptoms would be investigated promptly. This seemed to be more of an issue for patients who had been diagnosed for longer and who were patients at a time when considerably less was known about HIV. Nowadays, many patients are relatively stable and much less at risk of life threatening infections. It is possible that there is a biographical component that currently pervades the expectations of HIV patients who have been diagnosed for some time. This concept has also been found in a study on gay men ageing with HIV where the biographical relationship with the HIV epidemic was shown to impact on expectations of service delivery (Owen and Catalan 2011). Nevertheless, in this study on HIV healthcare, expectations of services were predominantly driven by the perceived 'norm' or standard of care irrespective of age or length of HIV diagnosis. These findings indicate that there is a connection between the way that HIV services have been provided and how patient participants viewed their specific needs as a person with HIV.

There were mixed views among some HIV healthcare workers on the underlying factors that influenced patients accessing other healthcare services. One senior nurse believed that some HIV patients preferred to access HIV services because they were vulnerable and anxious about what would happen if they accessed other services.

We have a cohort of patients who are vulnerable, a cohort of patients that are not necessarily good at accessing healthcare anywhere else

Marcus, Senior Nurse

In contrast, a senior doctor thought that many HIV patients who were articulate and well informed about their care demanded the same standard of care from other services.

They [the patients] do push at the boundaries in other specialities which sometimes does cause a bit of resentment

Seth, Senior Doctor

There was evidence of both these factors across the narratives of patients that implied a spectrum of need when accessing non-HIV healthcare services. This included vulnerability at one end and assertiveness at the other. Although some non-HIV healthcare workers were mindful of the expectations of HIV patients (as discussed earlier in this section), others welcomed the challenge of caring for patients who were articulate and well informed.

It's always nice to be at the cutting edge of a service. I think that again is a privilege that doctors really shouldn't take for granted. I mean I've worked in other parts of the UK where the level of self-education amongst patients is relatively low for all sorts of understandable reasons and as a doctor you become quite paternalistic. It's kind of easy medicine that way, you say go and do this and they go and do it. It's much more of a challenge if you've got people coming in to see you and say, well actually, I don't think we should do that because and then they produce a sheet of paper

Pascal, Senior Doctor, Allied Speciality

The allied specialists interviewed for this study all had experience of looking after people with HIV to some extent and were based at the sites with higher HIV prevalence. It is possible that in areas of lower HIV prevalence, healthcare workers from other disease areas may not have encountered people with HIV and are perhaps unprepared for the expectations that patients may have.

Overall, patient participants perceived high standards of care within HIV services that many had perceived as the 'norm' and within a 'specialist' paradigm. This appeared to occur at a conceptual level with regard to how they perceived their needs and at an emotional level in relation to how they felt about HIV services. This resulted in expectations of non-HIV services such as general practice and allied specialities. In this way patients were benchmarking their healthcare experiences in these settings against the care they received in their HIV clinic and many found them inconsistent with how they viewed their needs.

5.2 Distinctiveness

The narratives of healthcare workers in HIV also referred to the high standards and specific approaches to care that had become inherent to the model of HIV healthcare delivery. This included national targets to improve access and a team approach to caring for the physical and psychological needs of patients.

We must be the only service in the country if not in Europe to have demanded a 48 hour access target²⁹

Seth, Senior Doctor

HIV was at the forefront of really embedding holistic³⁰ care into the service model

Melissa, Psychologist

These elements of care were spoken of with pride and were viewed as important achievements in relation to the wider healthcare environment. Indeed, many healthcare workers in HIV perceived that they were different from other healthcare workers.

We are different I think, if you work in sexual health [including HIV] we're not better than anybody else. But I think we are different

Shirley, Senior Nurse

Sometimes I wonder if GUM [including HIV] attracts the mavericks [...]. The rest of medicine is quite conservative

Spencer, Specialist Trainee Doctor

This concept of difference seemed to underpin the way healthcare workers viewed HIV services. One senior nurse spoke of the concept of HIV healthcare as a 'club' and summed up her motivation for working in HIV based on her beliefs that people with HIV were being treated unfairly by other healthcare services.

²⁹ National performance target to improve access in Genito-Urinary Medicine clinics that specified that people should be able to be seen within 48 hours for sexual health issues. While this doesn't specifically relate to HIV care, many HIV healthcare workers are based within a sexual health service that includes HIV testing.

³⁰ Holistic care refers to a whole system approach to healthcare that includes the physical, psychological, spiritual and social aspects of health.

Working in HIV has a sense of belonging to a club, a society, a community of like-minded people who have chosen to work in the field. Because you all think similarly, you all feel that the stigma is unjust and unfair and you want to contribute to doing something about that just by putting yourself forward and working in that field. And if I ever got asked why I ended up in HIV in the first place, that was why I think I found it appealing as an area to work in. Because I wanted to say, look I don't think that these judgements you are making and the stigma is fair and just, so I'm going to go and work in it to almost prove that

Nancy, Senior Nurse

This political aspect of HIV care was also reflected by some staff and patients who were involved in the development of services for people with HIV. Some believed that what was unique about HIV services was the patient activism that occurred early in the HIV epidemic.

To some degree the services being as good as they are is due, in some large measure, to patient pressure in the early days

Seth, Senior Doctor

I think with HIV, we won the battle for people with HIV to be treated as people. Whereas in cancer it's still very much - we're treating the cancer, it just happens to be a person

Morgan, Age 45

It's a fantastic disease in terms of the way it has activated social and [political] response which is great. I don't think we have many other examples of how the gay community for example were gathered together to ask for rights, to fight for discrimination in the workplace and in society. It's a catalyser of social energies

Matthew, Staff Nurse

There were elements of a shared identity between some staff and patients in relation to the role of activism in shaping HIV healthcare. While a minority of patient participants spoke of the role of patient activism in the developing services, the legacy of patient activism was evident in the partnership approach to care within the current service model. This will be explored in more detail in the next chapter.

The concept of the difference and uniqueness of HIV care was saturated throughout many of the healthcare worker transcripts and was largely irrespective of the length of time in the speciality. This seemed to be related to the way that HIV services and evolved and the staff that chose to work with people with HIV. Many healthcare workers spoke of HIV 'exceptionalism'³¹ in different ways. The term HIV 'exceptionalism' first emerged in the late 1980s (Oppenheimer and Bayer 2009) and referred to the unique response to HIV at a global level. This 'exceptionalism' was associated with a response to HIV that was considered over and above the standard public health approach (Smith and Whiteside 2010). This latterly became linked with a liberalist moral theory that places the rights of the individual over the greater good (April 2010). HIV was therefore considered to be treated differently from other infectious conditions through the provision of exclusively specialist services.

Some healthcare workers participants questioned whether 'exceptionalism' was still relevant in the current era of HIV therapy.

I think our job is to exceptionalise where it is needed and recognise that we need to provide oversight of the care and make sure we negotiate difficulties at PCTs and primary care providers and other members of the hospital if necessary, so that we don't entrench patients in exceptionalism, which is actually not beneficial and not relevant in 2011. You know we can become part of the problem and part of the reason we become part of the problem is [that] we still invest in what we have achieved [and] in what we have done for the patient

Mary, Senior Doctor

³¹ Exceptionalism in HIV has been described as the exceptional healthcare response that was initially required when HIV/AIDS first emerged and later from a global perspective to increase universal access to antiretroviral therapy. Exceptionalism implies something extraordinary and not mainstream.

I think some patients who were diagnosed a long time ago in the years of HIV exceptionalism - which there were good reasons for HIV exceptionalism because of the stigma that was perceived and existed. And those patients would find it quite hard to change if they have been used to having their other needs dealt with so they feel their HIV clinician is their carer, so I can see how that would be difficult to adjust

Spencer, Specialist Trainee Doctor

These views were more evident in younger healthcare workers but were not necessarily reflective of length of time working in the speciality. This perspective represented a move away from the earlier 'exceptionalist' models of HIV healthcare where complete packages of care were provided for people with HIV and were not integrated with other mainstream healthcare services. This model was perceived by some as potentially fostering patient dependency on HIV services that was no longer relevant in the era of antiretroviral therapy nor as the spectrum of HIV disease changed and there was a need to engage with other services. Most healthcare workers acknowledged that the 'exceptionalist' model was a potential barrier to managing change and patient expectations of services. One senior nurse talked about the challenges in redressing this, particularly for staff who had worked in HIV for a considerable time.

I do think that exceptionalism still exists and I [wonder] do we still cultivate that? I can't hand on my heart say we are not guilty of that. I think newer nurses find it easier not to do that. I would say a lot of older nurses probably are able to do that as well. I'm not sure about doctors too much but I do think we still do cultivate it on some levels

Marcus, Senior Nurse

This implies that some staff also have a biographical relationship with the HIV epidemic that influences their approach to managing HIV care. This 'exceptionalism' seemed to be an inherent part of the identity of HIV healthcare services and was linked to the way that staff benchmarked how they thought and

felt that care should be provided. In a similar way to patients, there was a spectrum of 'exceptionalist' approaches across individual healthcare workers that may reflect the way they view HIV as a condition and subsequently the way services were delivered.

Disease 'exceptionalism' in HIV has been the subject of much debate over the duration of the epidemic. Initially exceptionalism in HIV/AIDS manifested in the approach and procedures for HIV testing when written consent was required and obtained by highly trained healthcare professionals. Confidentiality was paramount in the provision of care that was delivered exclusively through specialist units. Many authors acknowledge that this approach was the required response as the epidemic was unfolding when mortality rates were high and there were considerable fears around HIV/AIDS (Hanssens 1998; De Cock and Johnson 1998; Bayer and Edington 2009; Smith and Whiteside 2010). Over the past decade there have been proposals to end HIV 'exceptionalism' in order to normalise HIV testing and to integrate HIV services with other healthcare systems (De Cock, Mbori-Ngacha and Marum 2002). These authors were in favour of a public health and social justice approach to HIV testing as a way of normalising or mainstreaming HIV as a condition (Ibid.). Other criticisms of 'exceptionalism' are based on the negative impact for other disease areas due to the prioritisation of HIV/AIDS financially and politically (Bayer and Edington 2009; Smith and Whiteside 2010). While a more public health approach to HIV testing is now established (British HIV Association, British Association of Sexual Health and HIV and British Infection Society 2008), there remain concerns that the end of HIV 'exceptionalism' in service delivery will result in health inequalities and

substandard care (Smith and Whiteside 2010; Sherer 2011). These debates within the literature reflect the ambiguity on the place of disease exceptionalism in delivering HIV healthcare that was found within the data in this study.

The concept of HIV 'exceptionalism' in the narrative of participants in this study suggests that the identity of HIV services was still rooted to some extent in an 'exceptionalist' philosophy. There were, however, some tensions in how to balance this within the current model of specialist HIV healthcare and promote a more integrated approach across other healthcare services.

5.3 Summary on the legacy of HIV healthcare

The legacy of HIV healthcare appears to be embedded in the perceived difference from other disease areas in terms of **standards** and approach to care. For many patients, their HIV care had become the '**norm**' and appeared to drive **expectations** of what was acceptable for future care delivery. The way that services had historically been provided within the HIV clinics seemed to reinforce the **specialist identity** of HIV services and how patients viewed their HIV as a condition. This was further influenced by the extent to which patients had a biographical relationship with HIV services and how this influenced their perceptions of their healthcare needs. Patient participants were therefore **benchmarking** future healthcare services against what they had learned to expect from HIV services.

For healthcare workers in HIV this **benchmarking of HIV care** was linked to individual approaches to the disease **exceptionalism** of HIV that influenced the way care was organised. There was a pervading perception of the **uniqueness** of HIV services that underpinned the **identity** of HIV as a **specialist** service.

For both staff and patients, the concept of **benchmarking** HIV care in relation to HIV healthcare delivery was based on both conceptual and emotional perceptions of the current needs of people with HIV. This benchmarking influenced how services were delivered by staff and utilised by patients and contributed to how both patients and healthcare workers represented HIV as a long-term condition. Figure 5.1 is an illustration of how these concepts are linked.

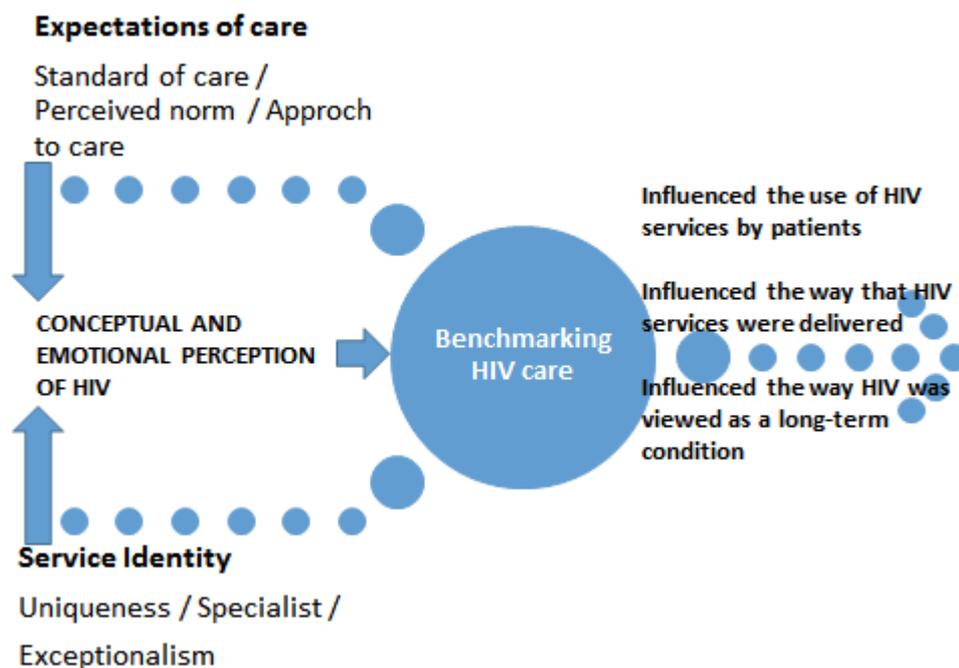


Figure 5.1: Concepts in the benchmarking of HIV healthcare

The way that HIV care was benchmarked by patients and staff was underpinned by key values that were highly evident across the data. Chapter 6 will present these values and how they relate to the substantive theory.

Chapter 6: The values of HIV healthcare

6.0 Introduction to the chapter

It became evident early in the data collection that some aspects of HIV healthcare held an overriding significance for patients and that seemed to relate to the model of specialist care delivery that has been discussed in Chapter 5. These aspects of care were conceptualised as the values of HIV healthcare as they were perceived by participants as highly desirable and non-negotiable in the planning of future services. These values were largely derived from the interview data of patients and then compared with the perceptions of HIV healthcare workers. The dominant values that will be discussed in this chapter are relationships, non-judgemental approach to care and working in partnership.

These values have been viewed as a significant emotional component in the way HIV was viewed by participants and they have been considered to be a consequence of the way that HIV is represented as a health condition.

6.1 Relationships

When patient participants were asked about their HIV healthcare, almost all of them spoke spontaneously of their relationships with healthcare workers in terms of feeling safe and secure within the HIV clinic setting.

We rely on them [Healthcare workers in HIV]. I rely a lot on them morally and for the medication

Martha, Age 40

She [my doctor] always gives me that impression that she is genuinely concerned about you as a person and your healthcare and I say that about [my doctor] but it's the same with all of them. I always leave here thinking well they do care

Stewart, Age 39

I get very very well looked after by everyone who I have contact with. They are kind of looking out for me so if they note anything wrong they phone me straight away and I know that they are there in the background

Michele, Age 52

If you are comfortable with your care provider and if you are comfortable with the arrangements for that care then you are much more trusting and more confident about what you are being told

Morgan, Age 45

I'm on this medication if it was to fail where do I go from here? And then the anguish comes in again and with the anguish comes the need for reassurance. And this is where I was saying we're back with the reassurance again and the reassurance is very very important. You have to walk out of this clinic feeling that you have hope

Simon, Age 56

This perception of trust and security in relationships with healthcare staff in the HIV clinics was reflected throughout most of the patient participant interviews irrespective of their length of diagnosis, perceived health status or clinic size. For some patients this was the most important element in their care and was based on the personal nature of those relationships as well as the perceived knowledge

of their healthcare workers. When Morris was asked what was important to him about his HIV healthcare, he responded:

Personal relationships with I guess in the first instance, the nurses, they're the people that see you most of all. But personal relationships and I think because of the fact that I have a huge amount of trust because you know they know everything here. I'm sure they do

Morris, Age 52

Although this patient specifically mentioned nurses as his main healthcare providers, there was no perceived difference in how relationships were viewed according to the discipline of the healthcare worker. For the 13 patients in the study, the primary HIV healthcare providers were doctors (7), nurses (4) and a combination of both doctors and nurses (2). The feeling of security and trust that patients associated with their HIV healthcare workers also seemed to be based on the reassurance that their health was being monitored and that problems would be identified swiftly.

The appointments here [HIV clinic] I'm very pleased with. I'm very pleased with the level of care the level of attention I get. If anything is the least bit untoward, a consultant will be pulled in

Scott, Age 52

This feeling of security made it hard for some patients to conceive of different models of care that they felt might put their health at risk. On the surface, this seemed to be irrespective of length of diagnosis or perceived health status although the intensity of these patient-provider relationships was influenced by how patients perceived their HIV condition.

In addition to the security and trust that patient participants spoke of, being 'known' by their healthcare providers was also important. For patient participants, this constituted the healthcare professional knowing their medical history and also knowing the patient as an individual.

If I go to someone that doesn't know me it's like starting all over again from the beginning. You've got to go over your story again and lahdedahdedah. I just feel comfortable here so I've got a good relationship there's no way I'd want to move

Sally, Age 27

I feel that they know me as an individual. They also know me as a patient and I think they are very empathetic, they are always aware of what my condition is. And yet they don't sort of put me aside because as a person who is HIV-positive. You find that isolation if people know

Malcolm, Age 55

I don't cry wolf. I've never rushed into the clinic because I've had a spot on my leg or a spot on my face. I wait until it becomes a problem before I really say I'd better do something about this or it's not gone away or it's something I can't deal with. I think people in the [HIV] clinic have to know you for that so they don't say he's making a fuss about nothing, so they know if I come into the clinic that there is a problem

Michael, Age 70

This feeling of being 'known' was therefore viewed as adding something to their care and as a factor in assessing new symptoms. Seeing the same healthcare professional was also valued by patient participants across the main study sites in terms of building rapport and maintaining continuity of care.

Seeing the same doctor and [having a] close relationship over the year so she can monitor me better and see what's wrong and use the appropriate medication for me. Then you can build a link between your doctor and the patient which is very important because there are things that you don't want to say, I mean things that are personal to you, that you find it hard to say to a person that you are not confident with

Martha, Age 40

It is nice to see the same people I will say that because you build up a relationship with that particular doctor or nurse and you do feel more comfortable if you're dealing with the same person

Simon, Age 56

However, continuity of carer was not explicitly an issue for all patient participants but this was generally within the context of being looked after or 'known' by a team who were familiar with their case and with whom they felt comfortable.

I don't have any issue with seeing the same person every time. It doesn't really bother me if I see somebody new no that's okay

Stewart, Age 39

For Stewart, there was a team of people in the clinic that he knew and who were familiar with his case and continuity of care seemed to be maintained in this way. This was similar to the experience of patients who were on clinical trials where the nursing team often provided the continuity of care through a team approach as well as through a named nurse system. There was no apparent difference in the demographics of patients who expressed a preference for seeing the same healthcare professional and those who did not as long as there was a collective 'knowing' about their individual case. The nature of these patient-provider relationships was also built on rapport that was at times described almost in terms of friendship.

I do find the doctors, all of the doctors here and all the staff here, to be extremely helpful and more importantly, extremely friendly and that is a big issue as well. Because there is no possible way that you can have an intimate discussion with someone about this sort of thing unless you have a very friendly arrangement with them. And should the Dr be that sort of person who wasn't a friendly person, it just wouldn't work because people would not open up

Simon, Age 56

I've seen staff come and go and they have all been brilliant you know. They are friendly, you do get to know them and they get to know you and whatnot. So it is quite chatty, sort of how you like coming to see your friends kind of thing

Sebastian, Age 38

Its nice talking to a department where, even if people don't know your name, they say hello to you. And it's obvious that they recognise you as they are very friendly, they're very obliging, nothing is too much trouble

Morris, Age 52

They create an atmosphere of friendliness, you know something like, you are in good hands. The way they talk to you, they are so friendly

Malcolm, Age 55

These references to friendliness seemed to reflect the connection between patients and their healthcare workers in HIV and this did not appear to differ across gender, ethnicity, research site or length of diagnosis. This perception of friendship or friendliness may have related more to the approachability of the HIV clinic staff and the therapeutic rapport that developed through the way HIV services had evolved. Healthcare workers in HIV believed that these relationships may have developed as a result of the way that services were organised or through the therapeutic interactions over time.

The friendly atmosphere that pervades this clinic I think is largely due to the well-structured organisation of the clinic

Seth, Senior Doctor

We have great longevity of relationship with patients and you may have seen them through various sick periods when they are very unwell and they may have seen you as a saviour or integral to their health

Mary, Senior Doctor

This reinforces the connection between the legacy of care discussed in Chapter 5 and the value associated with patient-provider relationships in HIV care. Indeed there were some references from patient participants to forming attachments with healthcare workers in HIV at the time of their HIV diagnosis.

Although patients were not specifically asked about their experience of diagnosis, they spontaneously spoke of that time and the intensive role of healthcare workers in HIV in supporting them. However, overall, these attachments reported by patient participants appeared to be equally related with how they currently perceived their HIV as a chronic condition as well as how the relationships had evolved.

Other healthcare staff acknowledged the intimacy of relationships with HIV patients but were conscious that the nature of these relationships may pose challenges for providing HIV care in a different way in the future.

It's very like a family in some places and the patient feedback to me is that they adore the consultant and the consultant has saved their lives

Miles, Manager

I think that's just not in HIV but in any form of chronic health there's a certain amount of patient/clinician relationship that becomes, no I wouldn't say friendship because that's too far down the boundary side. But it's more than a normal patient/clinician relationship, you learn more about the patient, you learn more intimate stuff about the patient and I think it's then difficult 1 for the patient to move from that and 2 for the clinician to let go of that

Marcus, Senior Nurse

Ultimately a person needs from a psychological element safety, attachment and sense of belonging. It can be projected on a national health service centre or projected on a 3rd sector agency

Matthew, Staff Nurse

There were different views among healthcare workers about how patient-provider relationships should be managed and this seemed to relate to how they constructed HIV as a long-term condition.

In comparing these findings with other data sources, the importance of patient-provider relationships in HIV has been linked with maintaining engagement or retention in HIV care (Roberts 2002; Mallinson, Rajabuin and Coleman 2007; Rajabuin, Mallinson and McCoy et al. 2007). Likewise, the concept of 'harmony' between patients and their HIV healthcare providers has been considered a positive factor in maintaining long-term adherence to antiretroviral therapy (Roberts 2002). One study of HIV patients from the Netherlands showed an association between insecure attachments in therapeutic relationships and the occurrence of depressive symptoms (Hinnen, Schreuder and Jong et al. 2012). The feelings of security and trust expressed by participants in this thesis may suggest a secure attachment relationship that contributed to maintaining the goal of long-term engagement with HIV healthcare.

In other disease areas, such as cancer and diabetes, relationships with specialist healthcare workers have been described in similar terms to these findings and this has presented challenges for the devolvement or discharge of patients from secondary to primary care (Brez, Rowan and Malcolm et al. 2009; Lewis, Neal and Hendry et al. 2009; Wilson, Brooks and Proctor et al. 2011). In Taiwan, the statistical analysis of 285 general outpatients found an association between trust and interpersonal relationships with patient satisfaction and service quality and the authors suggested that this may give services a competitive edge (Chang, Chen and Lan 2013). This suggests that the value of supportive therapeutic relationships is not unique to HIV care although there are additional public health benefits in minimising on-going transmission of HIV through supporting adherence and maintaining psychological health.

The **trust, security, rapport** and **'knowing'** that were evident in the data indicated that **supportive relationships** were highly valued by patients and staff and formed part of the identity of HIV healthcare. These factors may make it difficult to replicate HIV healthcare in other settings although there were degrees to which individual patients and staff viewed the role of relationships as paramount. While these **supportive relationships** reinforced the way patients viewed themselves, they were also perceived as a response to the actual or expressed needs of people with HIV.

6.2 Non-judgemental care

Another significant value that emerged from the data analysis was the non-judgemental approach to care that patient participants perceived in the current model of HIV healthcare delivery. When patients were asked about their appointments in the HIV clinic, many spoke of how they felt when they accessed HIV services.

Whenever I come here to attend by appointments, I actually forget that I'm HIV-positive and this is the truth I don't perceive myself as one because of the way I'm treated. I feel very normal

Malcolm, Age 55

I think coming here has made me feel much more at ease because of this kind of matter of factness about coming here

Morris, Age 52

It's completely different from going to your doctor [GP], you've got more of a relationship. It's like an HIV family

Sally, Age 27

This *matter of factness* and *feeling normal* seemed to translate into feeling accepted and that patients had the approval of their healthcare providers as a person with HIV. The concept of an *HIV family* captures the essence of being accepted for whom they were and perhaps in a way that differed from the reception they received from other healthcare professionals. This need for acceptance and approval was summed up by one patient.

A lot of people are angry with themselves for becoming positive and I think that has an impact on how they respond to treatment and care and how they view treatment and care

Morgan, Age 45

For other patients this feeling of approval appeared to be linked to being able to be open about their HIV and to be accepted as a person with HIV. For this reason, some viewed HIV services as a place they could go where they could openly talk about all aspects of their HIV and receive support from the people involved in their clinical care. Although these feelings were expressed by most patient participants, this was more apparent in patients who were isolated with their HIV diagnosis and had smaller personal support networks.

I do feel that coming here does give me some support as and when I need the support which hopefully is not too often. But occasionally, with this sort of thing, you do need support and it is important to have somebody in the background who you feel you can come and talk to

Simon, Age 56

I guess they're [HIV Healthcare workers] only here to make sure that I'm okay medically but as I said before we do tend to chat and if I have questions I feel comfortable enough to be able to ask them. And you know I recently asked a question about whether or not having HIV would stop me from getting buried or whether I'd have to be cremated

Stewart, Age 39

This openness and approval was in contrast to how the patient participants often felt in other healthcare settings and particularly in other areas of their lives. When patient participants were asked about their HIV healthcare, many spoke of the secrecy surrounding their HIV diagnosis and the lack of freedom to speak openly about being HIV positive. This had implications for individuals across many aspects of their lives from family relationships, to community integration, employment issues and personal relationships.

It's like a dirty secret and it shouldn't be a dirty secret. It's horrible! I can't tell [my] Grandma or no one but it's like my Mum said, she's getting too old now. Why upset her [because] she'll be dead before I am. So I can understand that but sometimes you know when you just want to talk to someone else within the family and you can't, that's when you think oh it's a dirty little secret

Sally, Age 27

The community in which you live, you always have this secret. It's like your life is not free anymore, you cannot open up, you're always careful and you're always worried and concerned. Like I have children and I'm always worried about them although we have told them, but sometimes I suspect that they are fearful of maybe me passing it over to them

Malcolm, Age 55

I have a possible relationship at the moment which could be going to start shortly. I don't know how I would deal with telling that person. I don't know how anybody ever deals with telling someone because there are a lot of people who are so frightened of this sort of thing

Simon, Age 56

While the management know about my condition and close friends do and it's not an issue and they're very supportive. But I don't go around telling everybody because I realise there would be people even in my school who would question my ability to work with kids and if I were to be exposed to being hit or whatever. So the emotional rollercoaster is not particularly about what might happen in the future because I think these changes will set out very slowly

Morris, Age 52

The secrecy and anticipated disapproval of their HIV status in other aspects of their lives seemed to reinforced their feeling of security and approval from within

the HIV clinic. This perceived stigma also extended to accessing other healthcare facilities where confidentiality was an issue for some patients.

I had a big problem with it because you go down to collect your medication and I'm on obviously what I call a repeat prescription. So I just go and give my name in and then they say who's sent you and what clinic have you come from. And I actually a few years ago stood at the reception and said I know which clinic that's referred me down here to collect my repeat prescription, however I don't think the 20 people sat waiting to collect their prescriptions need to know which clinic has sent me down

Sebastian, Age 38

Another patient spoke of going to a beauty salon and filling out the health form then observing that the form with her HIV diagnosis on the front was visible to anyone at the reception desk. Other patients spoke of their concerns about disclosing their HIV status to healthcare professionals who did not work in the HIV field.

Each disclosure does bring with it some difficulties and some dangers and some concerns

Morgan, Age 45

I had looked into other dentists which were private but that's all there appears to be. I was going to go and sign up but then you see I got this KS [Kaposi's Sarcoma] in the mouth and I thought I don't know if I should go. [I'm] a bit wary I should say of putting myself forward for that and what they might say

Scott, Age 52

One psychologist believed this was due to the possibility of discrimination by other healthcare workers and that this was perhaps underestimated by referring clinicians.

If you think about personal disclosure it's always predicated on trust. So I think knowing that it's not going to be met with discrimination or adversely affect your care is really important and I don't know that is necessarily the case

Melissa, Psychologist

For two of the patients, this discrimination was a reality when they accessed non-HIV healthcare services.

For example I went to physio to have a massage I had the massage with latex gloves which I found horrible

Martha, Age 40

This incident occurred about eighteen months prior to the interview and compounded Martha's feeling of having a 'dirty' disease and not being physically touched by healthcare workers when it was clinically required. Malcolm, who visited his GP for genital pain was told to expect this pain as he had HIV and that there was no available treatment for him.

I go to my GP and I say I have this pain in my [perineum]. And I said to my GP I keep feeling this pain and he said it's because you're HIV-positive and then you don't get anything [for it] you must understand because you are HIV-positive

Malcolm, Age 55

Perineal pain is not a recognised manifestation of HIV and, whether this response was based on lack of knowledge or not, Malcolm perceived this as dismissive and unsupportive due to him being HIV positive. Other patients described the responses from some non-HIV healthcare professionals when they became aware that the patient was HIV positive.

There was one occasion and I don't know if it was [a locum doctor] [...] who did say something like you have a very serious illness. And I did think when he said that, I'm not ill, I don't feel ill. I might have an infection and there's the potential there to be ill. And that just grated with me at the time but I don't know whether it was just sort of a bit of a shock to him to actually be confronted with somebody with HIV

Scott, Age 52

I went to a dentist who was working really well and when I mentioned that I was HIV positive he almost fainted although he had already started work, he put the tools down

Max, Age 56

These responses from within the mainstream healthcare setting were very different from the positive approval, acceptance, security and rapport that participants experienced with their healthcare workers in the HIV setting. Two patients described being involved in an occupational exposure incident where healthcare workers were exposed to their blood during a medical procedure.

Michael describes his experience of this:

During the operation apparently one of the people concerned cut his hand on the splinter of bone of mine and they had to send someone up to me [for me] to explain what they needed to do about PEP [post-exposure prophylaxis] treatment [...]. You're aware enough to tell them you are HIV positive and they should be aware of what that means

Michael, Age 70

These events fuelled the patients' perceptions of being potentially infectious and the reported reactions of the healthcare workers reinforced this for them. Notably, the majority of these negative experiences with healthcare services happened to participants from the larger urban clinic. This may be explained by the longer average length of diagnosis of patients within the urban clinic who were accessing a wider range of non-HIV health facilities than those in the smaller HIV Unit. In addition, all the patients who experienced perceived or enacted stigma in healthcare facilities belonged to minority groups such as black Africans, non-UK citizens or gay men, but this reflected the demographics of the majority of study participants.

The expressed need to feel accepted and supported by healthcare providers in HIV was linked to the felt and enacted stigma or potential disapproval that patients experienced outside the HIV clinic in healthcare settings and the wider community. So, in addition to the benchmarking other services with HIV care, participants were also measuring their healthcare experiences based on anticipated or enacted stigma. This implies that patient participants in this study were sensitised to the possibility of disapproval and that this was integral to how they perceived their needs as a person with HIV. This again was more evident in people who were more socially isolated or secretive about their diagnosis and indicates a spectrum of perceptions across the study group.

Healthcare workers in HIV also perceived stigma as a potential obstacle to patients accessing non-HIV services and this was particularly evident in the narratives of healthcare workers in psychosocial roles.

People with HIV need to come somewhere and to know that they are going to be ok

Polly, Mental Health Worker

I think it's for whoever is providing the healthcare needs to be trained and understand what HIV means and I don't mean just from a medical point of view about what the virus does in the body without understanding I suppose the history of HIV the impact of stigma and discrimination and how that impacts on an individual

Shaun, Social Worker

Stigma is probably the theme that goes across it [...] because it covers sex and relationships and transmission it might resonate in all those things like feeling you wouldn't be in a successful relationship ever and that might resonate with something from their past or feeling like you're worthless or marked in some way

Melissa, Psychology

Feelings of guilt and shame in HIV patients were commonly identified by this group of healthcare professionals.

Some of the patients I see as a counselling therapist are people that are very lonely mainly as they are not free to speak about certain areas of their life because of shame and guilt. HIV still carries shame and guilt especially in certain ethnic communities

Matthew, Staff Nurse

A lot of people that I see feel shame although they might not use that word [shame]

Polly, Mental Health Worker

Although guilt and shame were not overtly expressed by the patient participants in the study, the need to feel accepted as a person with HIV suggests that stigma formed part of their identity as a person with HIV.

In comparing these findings with the literature, stigma associated with HIV had been well documented since the beginning of the epidemic and remains evident in the UK today (The People Living with HIV Stigma Index 2009; National Aids Trust 2011). There are many other health conditions that have been stigmatised by society including diabetes, lung cancer, multiple sclerosis, mental health and leprosy that are now integrated with mainstream healthcare services (Shiu, Kwan and Wong 2003; Chapple, Ziebland and McPherson 2004; Grytten and Maseide 2006; McDaid 2008; van Brakel, Sihombing and Djarir et al. 2012). However, research comparing stigma in different health conditions has shown that it is consistently higher in HIV as illustrated in Figure 6.1.

Author and study aims	Study findings in relation to HIV stigma
<p>Stevelink, van Brakel and Augustine 2011</p> <p>Questionnaire-based study measuring internalised stigma, perceived stigma and social participation in people with leprosy and HIV in India.</p>	<p>Internalised stigma notably higher and reduced social participation in people with HIV compared with leprosy. 75% of people with HIV reported feelings of guilt and shame.</p>
<p>Daftary 2012</p> <p>Modified grounded theory study on the construction and management of dual stigma in HIV and Tuberculosis in South Africa.</p>	<p>More negative identity and stigma associated with HIV.</p> <p>Dual infection made HIV more visible.</p>
<p>Fernandes, Salgado and Noronha et al. 2007</p> <p>Structured interviews with general public and people with epilepsy to compare stigma perception of epilepsy to HIV and diabetes in Brazil.</p>	<p>HIV/AIDS had highest level of stigma in comparison to epilepsy or diabetes. The perceptions of the general public and people with epilepsy were the same.</p>

Figure 6.1: Summary of research comparing stigma in HIV to other health conditions

Although these studies have been carried out in different contexts, their findings above appear consistent with recent UK studies mentioned previously (The People Living with HIV Stigma Index 2009; National Aids Trust 2011) and with the experiences of people with HIV in this thesis research. For most patients in this study on HIV healthcare, feeling accepted and to an extent ‘normal’ in the HIV clinic was almost a stigma free refuge from other areas of their lives with

HIV. This is likely to be a significant factor in maintaining patient engagement in HIV care in the longer-term and in successfully integrating HIV patients into non-specialist healthcare settings. This is also consistent with the theory of symbolic interactionism that views the concept of 'self' on two levels. The first level is based on introspective views of the 'self' with the second level focussing on how the individual interacts within society (Blumer 1969). Therefore, meaning is derived from how individuals judge themselves in relation to their interactions with others (Blumer 1969; Chenitz and Swanson 1986; Benzies and Allen 2001; Klunklin and Greenwood 2006). The findings of this thesis indicate that people with HIV see their interactions with mainstream society as potentially threatening and this shapes their views of themselves and the way they construct or represent their HIV condition.

This point is further illustrated by one patient in the study group who did not feel that she was accepted or approved of by her HIV healthcare providers. This patient, with the pseudonym Mabel, had chosen not to take antiretrovirals to treat her HIV and this presented a problem for her in terms of her relationship with her healthcare workers in the HIV clinic.

It's been a difficult experience because I haven't taken ARVs [antiretrovirals] and they don't know what do to with me

Mabel, Age 34

Mabel was the only patient who came forward for the study who was unhappy with her care and the only patient who was not taking antiretrovirals. When asked what would improve her experience as a patient, she responded:

I'd like a conversation for one thing with someone who can actually look at the individual rather than the HIV

Mabel, Age 34

For Mabel, antiretrovirals were not an overriding priority in her care and this seemed to create tensions in her relationships with the clinic staff. This suggests a difference in treatment philosophy between Mabel and her healthcare workers. Her opposition to taking treatment did not, in her view, resonate with the treatment philosophy of her healthcare workers in the HIV clinic. Mabel felt she was perceived as a 'difficult patient' for not complying with the views of healthcare workers and did not feel that her opinions were accepted or approved of by clinic staff. All other patient participants were taking HIV treatment and their narratives reflected their appreciation of having access to treatment. Although the aim of this research was not to evaluate the specifics of HIV care, the dialogues of many healthcare workers in HIV were focussed around the logistics of monitoring people with HIV on treatment in the longer term. Likewise, the contemporary discourse of HIV care concentrates upon access and maintenance of HIV treatment (Hammer 1997; Van Sighem, Gras and Reiss et al. 2010; Joint United Nations Programme on AIDS 2011). It is possible that Mabel was not perceived as compliant in the same way as other patients who were taking HIV treatment. This may indicate that some discrimination also exists within the HIV healthcare setting where there is a discrepancy in treatment philosophy.

What was significant about Mabel's case was that in spite of her feelings of disapproval, she continued to access HIV care. She explained that this was

because it was the only place she could access healthcare as she had not disclosed her HIV diagnosis to her GP.

Well if I don't go [to the HIV clinic] they withhold care because of the diagnosis. I haven't told my GP so I have made them [HIV clinic] the first port of call. And because I've made them my first port of call if I want to go to a gynaecologist I make them do it rather than my GP because it's so much easier to keep my care in one place

Mabel, Age 34

This suggests that HIV services were filling a need on some level for Mabel but perhaps only because she perceived that she had nowhere else to go due to her HIV status and her reluctance to disclose to her GP. Although she perceived that the HIV clinic viewed her as a “difficult patient”, it was the one place she could access healthcare and be open about her HIV diagnosis. However, her access was sporadic and driven by physical problems and in the absence of these she was at risk of becoming completely disengaged from all care.

In another grounded theory study Mallinson, Rajabiun and Coleman (2007) found that relationships and validation or approval were central to keeping people with HIV engaged and retained in HIV care. The example of Mabel illustrates the importance of these factors in delivering HIV care and how they shape the way patients view themselves in relation to the people with whom they come into contact. For the majority of patient participants, the need for **approval** was a significant factor in their HIV care. Overall, **feeling accepted** was a central value for patients and to some extent compensated for the **perceived or enacted stigma** experienced in other healthcare or community settings. It may also be the case that the values of HIV healthcare have emerged as a

consequence of how people with HIV perceive themselves and have evolved in response to this.

6.3 Working together

In contrast to the experiences of Mabel, the majority of patient participants valued the nature of working together alongside their healthcare professionals in HIV. Some patients felt that they had a responsibility to look after themselves and participate in their own healthcare.

Somewhere along the line I got myself into this situation and so I have to take some responsibility for that and I think it would be very remiss of me if I took the approach that, well, I'm not going to look after myself

Stewart, Age 39

For this patient, responsibility was based on his perception of how he acquired HIV and his subsequent role in looking after his own health. For others, there was almost a reciprocal responsibility for how they could contribute to their own health.

I suppose I can go away feeling positive that well they're looking after me so now I want to look after myself because they're doing their bit so I've got to do my bit. If I thought they were very lackadaisical and didn't really care then I might have that same attitude about, well, what shall I bother for then

Sebastian, Age 38

The concept of *doing my bit* seemed to be linked to the perception of high standards of HIV healthcare and the trust and feelings of security associated with their HIV healthcare workers. This suggests that the way services are organised

and patient-provider relationships are linked to active involvement of patients in their own care. Being an active partner in care was a common theme throughout the interview data and there were no perceived differences across gender, age, risk group, ethnicity, length of HIV diagnosis or stage of HIV infection.

You've got to feel like you can have a say and I think people when they come to places like this [HIV clinic], they do have a say

Sally, Age 27

I think that we should be honest enough with our clinicians here to explain how our life is. They always ask so we shouldn't be hiding anything with them we should actually be open because they really are very understanding

Malcolm, Age 55

This concept of partnership in care seemed to relate to having a say in their care and also in actively participating by being honest about any problem relating to their HIV. Another patient gave an example of how a partnership worked in a consultation and used the word “we” to describe how he and his HIV doctor tackled a new health problem.

So I took advice from the [HIV] Dr on that and he said to put myself on a low cholesterol diet for the next four months just so that I could try and assess myself where the problems [were] coming from and that in turn on the next visit did produce different results which again we were able to analyse and the conclusions we've come to now is that although the medication is affecting my cholesterol levels slightly, my diet is also affecting the cholesterol level

Simon, Age 56

This example highlights the joint responsibility in tackling a health problem and how the patient viewed his role in addressing his high cholesterol alongside the role of his doctor. Another patient spoke of the need for healthcare staff and patients to learn from each other about HIV together as it was still a relatively new disease area.

We have to learn. And vice versa the staff as well

Martha, Age 40

This concept of working together as partners in care seemed to form part of the identity of HIV services and again this was often not replicated in other areas of healthcare.

There was an equivalence between the treating clinicians and the patient which meant there was a degree of mutual respect and often still in other areas of disease treatment that's not the case

Morgan, Age 45

Partnership in care seemed to be integral to the identity and expectations of HIV services and how patients perceived themselves in relation to their HIV clinic. There was also evidence in the data of patients being involved in decisions about how services were delivered therefore reinforcing their involvement and consultation in aspects of service provision. For example, patients were consulted on changes to their appointment system in one research site, and the larger services provided opportunities for patients to be involved in forums where they could discuss service delivery issues or provide feedback and input on service development.

Alongside these partnerships in care, participating in their care was inherent in the language of most patients who included their own approaches to maintaining their health and well-being. These included recognising when they were becoming unwell and utilising strategies to sustain and maintain their health. Many of the patients undertook a self-assessment, if they had a new problem, before deciding whether to access HIV services or general practice. These self-

assessments appeared to be based on a mixture of the severity of the problem and whether it was thought to be related to HIV.

I would always assess myself. I try to assess myself for what I think I'm dealing with and then would act accordingly and either to go to my own doctor if I didn't think it was severe enough or I didn't think it was a sexual health issue. Or if I did think it was a possible sexual issue of some description or it was related to my medication or something, then I would try to come here

Simon, Age 56

If it's pretty routine, on the odd occasion I've had diarrhoea or something I've rung the GP because I'm pretty sure it's nothing either sexually related otherwise I could come here or related to the medicine because I've only been taking that for two and a bit years

Morris, Age 52

I didn't think it [the symptom] was related to my HIV. I'm not very good at working out when something is really serious and so I chose to go to my GP for that reason - I thought it wasn't serious

Michele, Age 52

It was a bit with depression as well so it wasn't just HIV. But so you know it was half and half like I was feeling really tired which I relate to fatigue with HIV only because I've read about it [...] because it was a bit of both that's why I decided to go to the GP rather than come here [HIV clinic]

Sally, Age 27

This indicated that patients had developed their own systems for assessing new problems and deciding where to go for help or advice. Although many patients expressed concerns about using their GP for unscheduled care (See Chapter 5), they were actively participating in accessing their GP when they thought this was expected of them. This did not necessarily reflect their preferred place of care in these circumstances and appeared to be driven more by complying with clinic policies to use their GPs as opposed to how patients viewed the cause of their symptoms. This indicates that the value of working together and the subsequent responsibility that patients developed as a result had benefits from a service delivery perspective. However, this was reliant on support from the HIV clinics to

help them to make the decisions about which service to access for unscheduled care.

I mean I suppose if I didn't know what the answer was then I would definitely phone here and check with someone here what they felt I should do

Michele, Age 52

I have been known to ring in though for clarification of what might be the problem. I would explain my symptoms over the phone so as not to come down and maybe waste my own time and the doctor's time and take guidance from that having then spoken to possibly one of the nurses

Simon, Age 56

So, **participation** in care was comprised of **partnership** working that involved patients taking **responsibility** for some aspects of their care and HIV services providing **support** for other aspects when this was required. This value was therefore beneficial for both patients and healthcare workers and in terms of service utilisation.

The values of participation in care and working partnerships described by most patients in this study are in keeping with current healthcare policy on shared decision-making in the NHS (The Health Foundation 2012). Decision-making tools are in the process of being introduced into different disease areas, such as, kidney disease and cataracts and for specific procedures, such as breast surgery and prostate specific antigen testing (National Health Service 2012). However, these appear to be in the early stages of implementation across the rest of the National Health Service (Edwards, Elwyn and Wood et al. 2005; The Health Foundation 2012) and this may have an impact on the way that people with HIV engage with non-HIV healthcare services. For example, a study of shared

decision-making in general practice following a training intervention suggested that GPs felt their consultations had improved and patients were more empowered when they used a shared decision-making approach (Edwards, Elwyn and Wood et al. 2005). However, concerns were raised by GPs about the length of consultation time required to undertake shared decision-making with patients (Ibid.). Another study of 2,965 patient ratings of shared decision-making in 29 general practices indicated that shared decision-making was in place in 75% of practices on average but with a range between 61%-97% (Fullwood, Kennedy and Rogers et al. 2012). However, 50% of participants in the same study were over 65 years of age and had lower expectations of shared decision-making than younger patients (Ibid.). This suggests that expectations of shared decision-making may have played a role in the patient ratings and that the presence or absence of shared decision-making may be open to individual interpretation. It is not clear how the participation and partnership in HIV healthcare may translate to a non-HIV setting where shared decision-making may be less established or integrated into service delivery. An association has also been made between healthcare professional uncertainty and decreased use of shared decision-making with patients (Politi and Legare 2010) and this may be an additional barrier for non-HIV healthcare staff to work in partnership with people with HIV.

In other chronic disease areas, involving patients in their care has been a central factor in the strategic management of long-term conditions (Department of Health 2005a). However, in a case study review of chronic disease models, The King's Fund (2007) reported that 42% of patients had a self-management plan.

In the recent *State of the Nation 2012* report, only 36% of diabetic patients had received structured self-management support (Diabetes UK 2012). Likewise, there have been national recommendations for healthcare staff and diabetic patients to work in partnership in order to reach minimum treatment targets (Health and Social Care Information Centre 2012). In comparison, the data from this study on HIV healthcare indicates that the current disease model incorporates partnership working and this may be linked to the high levels of HIV disease outcomes referred to in Section 1.2.3.

These values in HIV healthcare were based on the concepts of supportive relationships, feeling accepted and participation and these appeared to be integral components in successfully interacting with people with HIV in specialist healthcare settings. These elements seem to link with the concept of engaging in care (see footnotes 2 and 3 in Section 1.2.3 for definitions of retention in care as a measure and engagement in care as a process).

Engagement in HIV care was initially an *in vivo* concept³² that arose early in data analysis. Further interrogation of the data and theoretical sampling identified the relationship between engaging in care and how staff and patients viewed HIV on a healthy-illness spectrum. For example, some healthcare workers believed that engagement was central to keeping patients well and supporting them to manage their condition.

³² An *in vivo* concept is a concept taken directly from the data and explored for its relationship with the emerging dimensions and properties in the data. See also Chapter 3, Method, for how *in vivo* concepts were treated.

What I see in most HIV clinics is staff who are really engaged with the people they are working with. They are not just seen as another patient. In a way it's more the clinical staff have an interest most of the time in their clients and want the best for them rather than just having a quick consultation oh your bloods are ok today, here's your pills, off you go

Shaun, Social Worker

The care is actually quite straightforward but the patients need to be engaged. They need to feel that the doctor cares about them and that the treatment is important and will work

Seth, Senior Doctor

Throughout the data patient participants spoke of the importance of interactions with their healthcare professionals to enable them to raise sensitive issues and participate in their care. This appeared to be linked to the standard and approach to care that had evolved.

I think the key thing through this has to be to ensure people who are HIV-positive received good care such that they can manage themselves

Morgan, Age 45

The narratives of patients and staff in HIV healthcare highlighted how these components of engaging in care were central to supporting them as individuals with HIV and in responding to the way they viewed their HIV as a condition. Some healthcare professionals warned of the detrimental effect of patients not being retained or engaged in care in terms of health outcomes and public health consequences.

I see that all the time people who have just not been in care, not been taking tablets and have then got an opportunistic infection³³

Mason, Senior Doctor

³³ See terms and abbreviations.

People are very good at just not telling and I think if we get the service models wrong it may not look like we're missing stuff because it will just go underground. And [there] are all kinds of issues there in terms of people's adherence, people's resistance, public health issues, disclosure. And I think particularly with HIV and wanting to minimise obviously the prevalence and incidence those things need to be sorted out very carefully

Melissa, Psychologist

In comparing the concept of engagement in care with the literature, non-engagement in HIV care has been associated with increased transmission, non-adherence and increased healthcare costs (Bakken, Holzemer and Brown et al. 2000; Roberts 2002; Rajabiun, Mallinson and McCoy et al. 2007; Mugavero, Davila and Nevin et al. 2010; Gardner, McLees and Steiner et al. 2011). These elements of engaging in HIV care that have emerged from the study participants are supported by another grounded theory study on hard to reach groups with HIV in the US (Mallinson, Rajabiun and Coleman 2007). In this thesis on HIV healthcare in the UK, the sample was largely medically stable and yet similar concepts emerged from the data. This suggests that the fundamental principles of HIV care need to be built on **supportive relationships**, ensuring patients feel **accepted** and working in **partnership** with patients irrespective of where this care is provided. Figure 6.2 illustrates the relationship between the properties of **engaging with care** and how people with HIV feel about their condition.

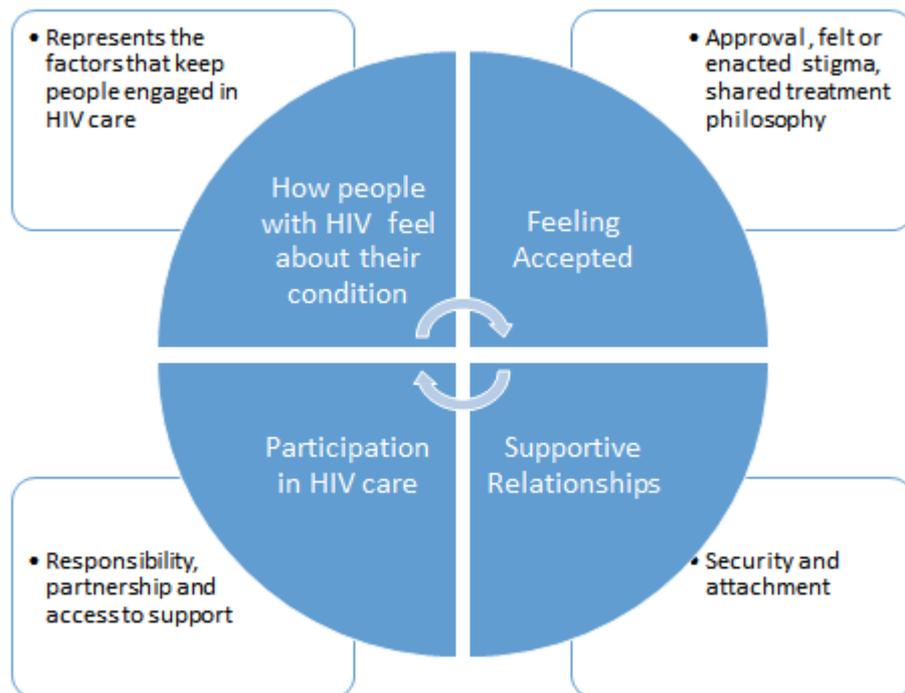


Figure 6.2: The properties of engaging with care and emotional representation of HIV

6.4 Summary on the values in HIV care

In the UK, keeping people engaged and retained in care is a quality of care measure and national data reports indicate that 96% of people with HIV were retained in care between the years 2010 and 2011 (Health Protection Agency 2012). This suggests that the current model of HIV specialist secondary care is instrumental in keeping people with HIV engaged and retained in care. In comparison, in the US, population studies have shown that between 45-55% of people with HIV had not received care over the previous year (Gardner, McLees and Steiner et al. 2011). This is believed to be a key factor in fuelling the HIV epidemic in the US. Data from this research has further illustrated the components involved in engaging people in care.

The dimension of **engaging in care** has been viewed mostly as a consequence of the emotional representation of HIV as a health condition and is therefore closely linked with the way that HIV healthcare services are currently provided. The way that HIV healthcare is organised and delivered in response to stigma and patient perceptions of themselves as a person with HIV is likely to be instrumental in influencing levels of engagement as a health outcome.

The following chapter will focus on the processes of HIV healthcare delivery and how this is informed by the way that HIV healthcare workers conceptualise HIV as a health condition.

Chapter 7: Evolving service delivery

7.0 Introduction to the chapter

The previous two chapters have presented how HIV was viewed emotionally and cognitively by participants and the way this influenced the values in HIV care and how this care was benchmarked against other services. This chapter will focus on the conceptions of healthcare workers in HIV and show the relationship with how services are adapted to respond to the perceived needs of people with HIV. It will include how care is organised based the prevailing representations of HIV and present how the processes of care that emerged from the data relate to a healthy-illness continuum.

The current healthcare climate in the UK is undergoing considerable change due to political drivers, re-organisation and financial constraints (Department of Health 2010; Department of Health 2012a; NHS Commissioning Board 2013). In this environment of change, HIV services had also evolved to reflect the changing needs of HIV patients as discussed in Chapter 1. Throughout the data collection period, patients and healthcare workers were asked about changes in the way that HIV services were provided in order to explore concepts in future care delivery. The key findings were conceptualised as, redefining services, interpreting HIV wellness and devolving HIV care. Where relevant, secondary

data sources have been used for comparison to situate the findings and explore HIV as a chronic long-term condition.

7.1 Redefining services

There was evidence from the interview data across the services of recent changes to the structure or frequency of appointments. Patients in Metropolis and Springfield spoke of changes to the appointments services they were receiving.

I'm on a four-month appointment system now. Because I used to go on a three-month appointment system and I was given the option to increase it to 4 months because my results were pretty well okay on the three months

Simon, Age 56

I think that probably the biggest change is previously you used to come and see the doctor and then they'd take the blood after the appointment and then it would be three months before I had those results unless I want to phone beforehand. But now they've swapped it around so you can have your bloods taken two weeks before you see the doctor so that they've got those results when you come on the three monthly visit

Stewart, Age 39

I come three times a year. One time I see the doctor, the other two times [they] take blood and the nurses call me to give me the results. I used to come three times a year and each time I would see the doctor

Max, Age 56

My appointments now have been cut down, not cut down, naturally reduced from a maximum of at one time of 3 appointments a week down to 1 every 3 months. I now attend something called the ageing clinic on the view that I'm considered elderly

Michael, Age 70

The above data show a range of service adaptations from less frequent face-to-face appointments, to new blood appointments, telephone clinics and specific services for those patients ageing with HIV. This suggests a constantly shifting

healthcare environment may be reflective of the changing needs of people with HIV. Many patients who identified themselves as stable spoke of changes to the frequency of their routine appointments that they believed reflected a positive change in their stable health status.

From a healthcare worker perspective, adaptation of services was perceived as inevitable as the number of patients increased and as more patients became medically stable. One junior doctor summarised the rationale for changing the way that services were provided within HIV clinics.

Because we are going to have more and more patients on our books, more and more patients on therapy, the older models of seeing people every couple of months and giving the full works, it's just not going to work

Spencer, Specialist Trainee Doctor

So, demand from increasing numbers of patients appeared to play a significant role in redefining services. This was particularly relevant in the larger sites where stable patient services were introduced that included nurse-led clinics, telephone and e-mail clinics.

I wanted the virtual model. The nurses had their stable model but I wanted a more remote model because I felt that there wasn't enough capacity. I felt the nurses needed to see more of the stable patients and they couldn't do it if they were physically seeing every single person. So I thought there was a need for capacity in terms of capacity for complex patients

Mary, Senior Doctor

There was also evidence of financial drivers in reconfiguring service delivery.

I think all the time there is pressure to have really efficient streamlined services and I think stable patients [services] are one part of that because the cohorts are increasing but the money isn't so services recognise that they've got to start having those kinds of clinics

Miles, Manager

The introduction of e-mail clinics was relatively new in the larger centres where two out of three clinic appointments a year were replaced by a virtual e-mail results service. This seemed to represent a service innovation as these virtual services were not common in the snapshot survey that was utilised as secondary data for this research (see Appendix 7). In relation to the main research sites in this study, one of the larger centres undertook an internal service review of their e-mail clinics. They estimated that approximately 1,000 face-to-face appointments per year were being released through the provision of e-mail clinics (sourced from local site audit documents). In this way, the larger clinics seemed to be balancing the needs of the most stable group of patients through the provision of virtual services with the increased demand for clinic appointments for patients with more complex problems.

Releasing appointment capacity was much less of an issue for Springfield that had approximately 20% of the caseload size of the other two clinics. In this setting, there was much less demand for clinic appointments and as one senior doctor pointed out, small modifications to the service were currently sufficient to maintain an equilibrium in meeting the need for appointments.

There's no sign of exponential growth. It's a steady growth so as long as the service is increased in personnel and the physical space to take that into account [...] I think it's relatively easy to plan for that. There's no sudden crisis looming, it just requires a bit of forward planning but nothing major

Seth, Senior Doctor

In this clinic setting, service adaptation focussed more on modifying the frequency of appointments for patients who were medically stable as opposed to more radical service innovations. This implies that demand on services plays a role in how healthcare delivery evolves.

In conjunction with the changing structure of appointments for stable patients, the larger clinics were introducing new services for patients with more complex health problems. This was evident from the site questionnaires from Metropolis and South Park where joint services such as renal, oncology and ageing clinics had been or were in the process of being introduced. As fewer stable patients were accessing clinic appointments, more clinics for complex patients were emerging. This again reflected a continual movement or balancing of services between those who were designated as stable and those perceived to have more complex needs.

The rationale for these joint clinics was described by two medical consultants.

I don't want people who don't know about the conditions, who aren't well read on the data to see patients and make mistakes because they just don't know what they are doing and no one ever picks it up. I want the best person who knows about the stuff to see those patients who have a complexity and I want the person to develop more expertise by concentrating the patients in one place

Mary, Senior Doctor

I think what you really need is two specialists. You need an HIV specialist and [allied specialist]. You need to be able to have the other members of the team which is specific to [the allied speciality]

Paula, Senior Doctor, Allied Speciality

This concept of joint clinics seemed to involve joint learning and developing joint expertise in managing co-morbidities and co-infections. Although these clinics had not been formally evaluated, they represented the emergence of HIV sub-specialities that reflected the demographics of each caseload. In this way, HIV as a condition was being redefined as the parameters extended beyond the expertise of HIV physicians to include gerontology, hepatology, endocrinology and oncology.

However, not all allied specialists believed that joint clinics were the way forward.

A regular joint [allied speciality] and HIV clinic I suspect wouldn't be particularly helpful because what would happen at that? I know there's some joint clinics with some other specialties which we then decided wasn't that beneficial. As the [allied specialist] you would sit and do your bit and then stop and then the HIV person [would do] their bit. And you just think this is interesting for us from an education point of view and the patient is getting one consultation instead of coming up for two, but apart from that maybe not much else

Pascal, Senior Doctor, Allied Speciality

This consultant had been involved in HIV as a clinician for many years and did not see the added benefit of operating a joint clinic session to develop expertise. So, joint clinics may not be the sole way forward in extending the parameters of

HIV. Nonetheless, the patient perspective supported joint working particularly where co-morbidities and co-infections were present. Several patients commented on the experience of friends who had co-infections and raised concerns about the difficulty of managing several health problems.

And my experience with my friend who is HIV-positive and hepatitis C positive has been that they are disjointed. The care is disjointed in some ways and it requires an individual or people supporting an individual to be able to help them and support them, sometimes to the degree that might be difficult for people who are not well accustomed to navigating the way in which care is provided

Morgan, Age 45

It's the people that are co-infected that need a little bit more support and guidance with HIV and another [infection], emotionally with the medication [and] with the side-effects. Because you don't have to deal with only one disease, it's two or three because it's more difficult it's much more difficult

Martha, Age 40

This suggests that collaboration may also serve to support patients to manage several conditions. This is consistent with patient views on developing relationships with healthcare workers outside the HIV setting and managing disclosure issues. Although the focus of this thesis is on people who are stable with HIV, it is not yet clear how long people will remain stable and if they will develop more complex needs over time. With this in mind, healthcare worker participants were asked who they believed had overall responsibility for the care of patients with multiple health needs.

I think you'd have to be clear who actually owns the patient, whose the patient was. And now I think that still should remain with the HIV consultant for now because it feels as though we are adding on. We are another multidisciplinary worker who is coming to support that patient who has a history because of the relationship they have with the HIV team. That is their home, so to speak

Paula, Senior Doctor, Allied Speciality

We often see patients quite frequently as well, so I suppose by default we are felt to be the primary carer

Spencer, Specialist Trainee Doctor

The reference to the HIV team as *home* really highlights the perceived role of HIV services in the care of complex patients and this was reflected in the narratives of other allied specialists. From a patient perspective, there were only two patients in the study attending a joint clinic. However, most patient participants viewed their HIV healthcare worker as their primary provider irrespective of their stable state of health. So, although the condition of HIV was being redefined by the extending parameters of HIV associated healthcare, there remained a central focus on HIV services in terms of care co-ordination.

It seemed that a critical mass of patients was required in order for joint clinics to happen.

We don't really have enough numbers to have a shared clinic with anybody.

Spencer, Specialist Trainee Doctor

Thus the size and casemix of services appeared to play a role in the development of new clinics and in the extending parameters of HIV infection.

In relation to the way HIV services were evolving, there was evidence in the data that services were continually being redefined. This involved a process of **counterpoising** the perceived needs of HIV patients with clinical, financial and operational considerations. For stable patients, this was achieved through modifying appointment structures or by service innovation. In addition, services

were evolving for those with more complex needs through collaboration with allied specialists. As a result, healthcare workers appeared to be **transforming stability** at the same time as **extending the parameters** of HIV as a disease area. HIV services were therefore redefining HIV as a disease area through the organisation and delivery of care. Figure 7.1 is an illustration of this process.

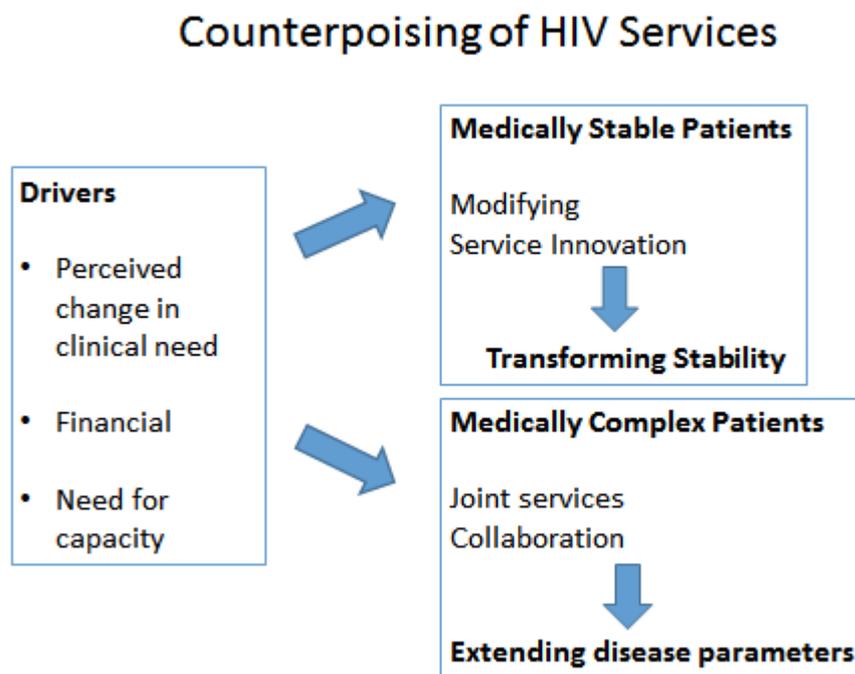


Figure 7.1: Illustration of the drivers, processes and effects of counterpoising

However, there were other issues in the process of adapting services that determined how services were redefined. The next section will present the underlying factors that influence how healthcare workers perceived HIV as a stable condition and how this impacted on the way that services were organised.

7.2 Interpreting HIV wellness

The majority of patients that came forward for this study perceived themselves as medically stable. However, perceived medical stability did not necessarily determine the type of service that was suitable for patients at an individual level.

Where virtual clinics were in place, they were designed for those who were designated medically stable. However, the numbers of patients actually recruited to virtual clinics at Metropolis and South Park was between 20-25% of the total clinic populations (sourced with permission from local site data). Although approximately 15% of these patients were temporarily discontinued for clinical reasons (sourced with permission from local site data), the uptake suggests that this service innovation was suitable for some patients some of the time. Secondary data analysis of the eligibility criteria for virtual clinics showed that the profile of patients opting for these clinics was similar to the stable health status reported by the majority of the research sample. However, most patient participants on both research sites had concerns about reducing face-to-face contact with the clinics.

At my stage of the game to be honest there's probably not a great need to come and sit physically with a consultant and take up their time and have a chat, as long as I know the figures that I'm after are OK, I suppose the problem is if I ever got e-mails or got over the phone that my CD4 and viral load is this and my viral load wasn't non-detectable. And then I [would] go into sheer melt down and panic over it that I'm not there with somebody who can calm me down from a medical point of view and tell me the information that I might need to know at that point in time

Sebastian, Age 38

I'd understand why they'd want to do it because it's probably easier and you get more time. But no, no. What if something is seriously [wrong] you can't write all your feelings in a letter in an e-mail. No I'd hate it, I'd completely hate it

Sally, Age 27

I think if I had the comfort [of knowing] that things were okay, [that] they were on an even keel and they felt that I didn't need to come into the Department quite so regularly and that they could deal with it over the phone and by e-mail, I don't think that would worry me too much provided that at some point there would still be that hands-on person, that personal contact

Stewart, Age 39

Sebastian and Sally explicitly preferred personal face-to-face contact, particularly where they anticipated problems with their physical or psychological health. On the other hand, Stewart appeared open to the idea of less frequent visits to the department, but still felt that personal contact was a key factor and this was reflected throughout his interview. As only one patient was in a telephone clinic, it is possible that patient participants may have been influenced by their current model of face-to-face appointments. However, another patient, Morgan, was keen to explore virtual models for his future care.

I think if you are that stable patient model actually what tends to annoy you more is the fact that you are forced into these regular appointments. That's when you start to focus your energies about can we do something to make these appointments more useful, can we do something to make these appointments fit into my lifestyle?

Morgan, Age 45

This suggests that there is a range of views among patients about their stable status and how their care should be provided. Although most patient participants in the study identified themselves as being medically stable, it was only a small minority who were prepared to consider virtual clinics as an option. This was

consistent with the uptake of virtual clinics reported by Metropolis and South Park as mentioned at the beginning of this section.

There was also a range of views among healthcare workers about how stable patients should be managed. For example, one senior doctor believed that patients who were 'well' required different models of care from the traditional face-to-face appointments with their regular doctor.

We have to let them go if they are well. And that is difficult. Sometimes they don't want to let us go and they hold on tight. But it's about telling them with compassion that they are well and that we believe they are well and if they are not well they can always rebook. They are always our patient

Mary, Senior Doctor

There were other disciplines who shared this view that many stable patients were essentially 'well' and that services needed to reflect this.

I've got people that don't want to treat HIV as a special thing they just want to get on with their lives and it's just part of their life

Penelope, Community Nurse

A lot of the time they are doing well occasionally they have some health issues that come to the fore

Phyllis, Staff Nurse

From a service planning perspective, healthcare workers who shared these perceptions of need were more likely to instigate or support models of care that proactively facilitated patient independence. This was conceptualised as interpreting **the stable patient as 'well'**.

Another perspective that emerged from the healthcare worker data was that patients needed to be actively engaged in their care on an ongoing basis. This appeared to influence the introduction of virtual services such as e-mail or telephone clinics.

I think you are losing something called the therapeutic consultation, the relationship between the patient and the physician they are seeing is actually therapeutic and important. And I don't think the patients would feel the service actually cares that much if it's just an e-mail or telephone

Seth, Senior Doctor

This perspective highlighted the belief in the role of face-to-face relationships in maintaining long-term engagement in care. Again this view was shared by some other healthcare workers. One senior nurse spoke of the importance of maintaining these relationships to support patients when they encountered new problems.

We've got patients here that on the face of it are very strong characters. You see them regularly and they cope with it and they're fine and then that patient will amaze you because they'll have an issue that they will come to you with and you wouldn't have thought it so

Samuel, Senior Nurse

This suggests that longevity of relationship with a team was perceived as playing a role in active engagement. In addition, those providing face-to-face stable patient clinics believed that their service provided an alternative for those who were essentially medically stable.

We provide stable patient clinics for patients who don't, for whatever reasons, want to be, or fit into a virtual clinic process. So that might be patients who have some element of co-morbidity

Marcus, Senior Nurse

This included patients who chose not to opt for virtual clinics as well as those who required monitoring of other health problems. This perspective was conceptualised as interpreting **the stable patient as requiring active on-going engagement.**

Finally, a third perspective in the healthcare worker data viewed some stable patients as having complex psychosocial needs.

I think the thing especially around HIV, not just HIV, but probably lots of other medical issues, it's not just solely about someone's medical or physical health. There are a lot of other factors that impact on someone's physical health. If you don't look at the social, emotional, and psychological support needs or mental health, then I think people are less likely to do well

Shaun, Social Worker

Other healthcare workers felt that the concept of complexity in HIV should not be confined to people with specific co-morbidities, but that people who were bio-medically stable could also have complex issues around their diagnosis and vice versa.

I think that idea about what complexity is, is really important because you can be healthwise, tick, tick, tick, but actually in terms of adjustment or what an HIV diagnosis means to you [is] very complex. And the other way round, people who have hordes of medical problems and complexity and TB as well and actually they are sort of managing within their resources [...] So you've got to look at it in a different way to see that complexity

Melissa, Psychologist

I think we need to try and figure out this definition of complexity. That's the main problem because I think what's happened is that people have used the word complexity and then put a whole bunch of diagnoses under it. But that doesn't mean that people with those diagnoses are complicated

Mason, Senior Doctor

This perspective raised concerns about categorising patients into complex and stable groups and suggested that people with HIV had a range of individual needs. Mason expands on the types of issues that he experiences with some of his stable patients.

We see ourselves much more as specialising in the different kind of complexity because of the particular patient population having major problems around the social side of things, housing insecurity, financial insecurity, psychological distress. And we would see ourselves as providing more of a specialist services for those patients who are harder to reach and to engage in ordinary services. So it's providing a less complex outpatient care for very complex patients

Mason, Senior Doctor

This third perspective on the management of stable patients has been conceptualised as interpreting **the stable patient as holistically complex**.

These conceptualised perspectives were intended to reflect the dominant perceptions of stable patients that emerged from the data of healthcare workers. These were therefore viewed as disease labelling behaviours as opposed to individual healthcare worker constructions of HIV. These perspectives appeared to be linked to the size of the clinic and caseload. For example, in Metropolis and South Park, staff were more likely to conceptualise **the stable patients as 'well'** and in these clinics there was more diversity of services and service innovation for stable patients. These services, however, had significantly higher numbers of patients and it may be that the perception of 'wellness' was relative to those patients with more complex health problems. In contrast, staff at Springfield generally did not conceptualise patients as either stable or complex, instead they were viewed according to individual needs. In this setting, healthcare workers

were more inclined to view medically stable patients as **the stable patient as requiring active on-going engagement**. Those staff that had individual caseloads with a high burden of psychosocial issues appeared more likely to interpret **the stable patient as holistically complex**. The organisation of services for stable patients within these two healthcare worker constructions seemed to be more geared towards preserving continuity of care where they felt this was indicated.

So, there was a link between how healthcare workers perceived HIV and how services were adapted. Although this was influenced by demand for services and financial factors, the conceptual and to some extent the emotional representation of HIV as a condition was embedded in the approach to service delivery.

Another factor in the construction of HIV by healthcare workers was job role which functioned in a similar way to casemix in influencing views on how services should be provided in the future. For example, those in psychosocial roles were more likely to focus on the vulnerability that some people with HIV experienced.

We know that in the first six months there is an adjustment period. But for most people that's a kind of a limited period and they kind of get on with it [...] But then there's a proportion of people for whom it's very life changing and I think there is also huge amounts of social isolation and secrecy that come with that

Melissa, Psychologist

Depression, panic and anxiety issues are extremely common in people with [HIV]. Body dysmorphia type issues to psychosexual issues after diagnosis. There are also issues around drug and alcohol use with someone's psychological health [...] But a huge percentage I would say of HIV positive people that I work with have some sort of psychological issue. And I would suggest that for a lot of them, a lot of it is related to their HIV diagnosis from and the impact it has had on them. Their life has changed since their diagnosis and they will try to keep themselves at home. The fear of disclosure, the fear of not having a partner, the fear of being kicked out by their family or isolated from their family

Shaun, Social Worker

There is this sense, in my opinion that [people with] HIV project anger and frustration towards themselves. HIV people have got a kind of internal agony

Matthew, Staff Nurse

I think if the [patient belief in medications] is handled well [and] supported, then they are going to do better because the shame they pour into the medication, these shameful feelings or these unhelpful ways of being in the world, they don't feel they do deserve the drugs

Polly, Mental Health Worker

These views were perhaps formed by the nature of patient contact experienced of these healthcare workers. Likewise, the narratives of nurses generally focussed more on the social aspects of care.

It would be silly to separate antiretroviral therapy care [from] the clinical management of that and everything else that the patient presents with. It almost feels like there are two separate channels they could go down. They could go down one to be seen for their medicines management and then everything else under another umbrella. But you can't do that because clearly it is all interlinked in reality with adherence to medicines

Nancy, Senior Nurse

And certainly from the people that I have seen, some of the hardest bits now are the expectations that they are going back to work, the expectation now that they are going to be treated like everybody else

Penelope, Community Nurse

There is not a day goes by without getting a call whether that's medication housing a problem with a family member

Samuel, Senior Nurse

In contrast those healthcare workers whose job remit was to address capacity had a different view on how services might be provided in the future.

Certainly in [this clinic] you are going to have to show you have an expertise to provide. But I think, ultimately, that clinics that are poorly differentiated are going to run into difficulties

Mary, Senior Doctor

HIV centres are about complex management and releasing capacity so [there is a] wider diversity of roles

Marcus, Senior Nurse

So, the perceptions of staff were also linked with their individual job roles and formed part of the way that healthcare workers construct HIV as a condition. Figure 7.2 illustrates the relationship between job roles, healthcare workers constructions of stable patients with HIV and the way services were delivered.

Healthcare workers constructions of HIV as a stable condition and service delivery

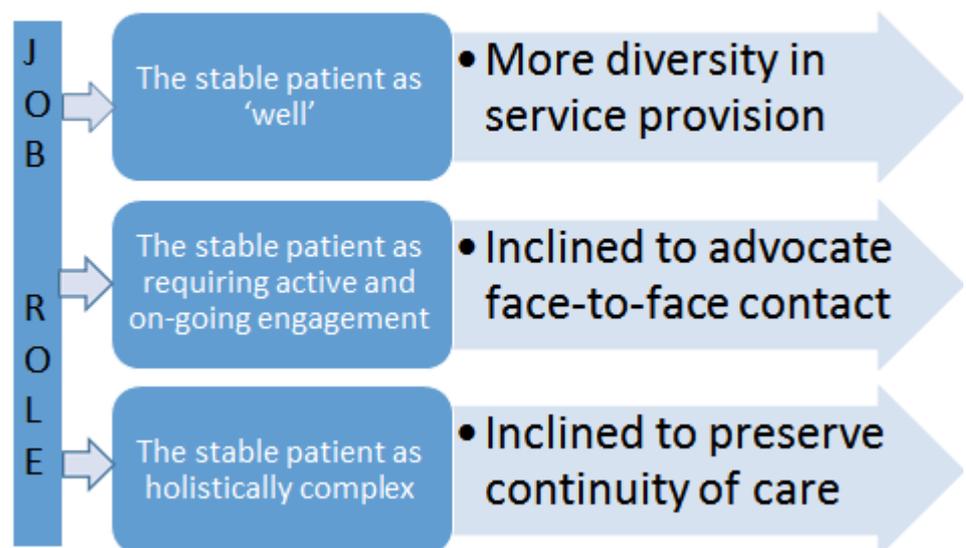


Figure 7.2: Healthcare worker constructions of HIV and service delivery

Therefore, for healthcare workers in HIV, the interpretation of HIV wellness occurred along a spectrum of health and illness that was related to the **construction of HIV as a stable condition**. This seemed to be linked to **job roles** and to an extent casemix. These disease labelling behaviours were strongly related to the way services were planned and delivered and to the how they were adapted to respond to the perceived needs of stable patients.

7.3 Devolving HIV care

In other countries, devolving HIV care to nurses and to primary care is a common strategy in tackling demand on specialist HIV services and in the organisation of HIV healthcare (Wilson, Landon and Hirschhorn et al. 2005; Hekkink, Wigersma and Yzermans et al. 2005; Sanne, Orrell and Fox et al. 2010). This section will present how HIV nurses were deployed in the care of stable HIV patients and how this is influenced by healthcare workers' perception of their roles and the needs of patients. This has been conceptualised as part of the process of adapting HIV care services to respond to the changing needs of people with the virus.

The final dataset that informed the development of the national HIV Care Pathway and Payment by Results tariff for HIV Outpatients showed that, for 6,543 stable patients, 81% were seen by doctors, 23% by nurses and 29% by pharmacists (Department of Health 2011c; see also Section 1.3.1 for details of the data collection for the HIV Care Pathway). This implies that stable patients were being seen by more than one healthcare professional in HIV clinics,

although doctor activity may have included some virtual clinic data. Specific data on the breakdown of healthcare professional activity within the HIV clinics was not collected for this study. Alternatively, the underlying factors that informed the roles of healthcare workers in the HIV clinic in the care of stable patients were explored and compared with modernisation in other healthcare areas.

The clinics for stable patients ranged across the sites from being completely medically-led towards wholly nurse-led services. For those services that were more medically-led, doctors viewed their role in terms of monitoring the routine needs of patients.

Basically they come here for their routine HIV care

Seth, Senior Doctor

A lot of it is quite a chronic disease management model. We cover routine screening tests that are encompassing national guidelines for outpatient monitoring of HIV, some kind of rapport regarding adherence particularly for those who are finding it more difficult to have successful treatment. And I suppose there comes an opportunity for concerns to arise as brought to you by the patient

Spencer, Specialist Trainee Doctor

These medical staff were asked about how they perceived the role of nurses in caring for stable patients as part of redefining HIV services.

There's very little difference between a nurse-led follow-up clinic and a doctor follow-up clinic. Again it's down to the personality. If you've a good nurse who understands the condition and has worked in that area for some time, they're every bit as good as even the senior junior doctors

Seth, Senior Doctor

I don't necessarily think that all HIV care has necessarily to be delivered by a doctor

Spencer, Specialist Trainee Doctor

However, in this clinic setting, getting organisational approval for new nursing roles was perceived as a challenge due to nursing shortages and financial constraints. Seth also commented that he had initially needed to prioritise medical posts when he was developing clinic services and that this may have impacted on the current skill mix. Nevertheless, a future role for nurses was being considered as part of expanding the number of HIV clinics.

If we do have to set up (another) HIV clinic (session) we would probably try and make that nurse-led

Seth, Senior Doctor

This represents a hypothetical shift towards the inclusion of nursing roles in keeping with a more chronic disease management approach. There was no immediate pressure in this clinic to release medical appointment capacity by the use of nurse clinics. This implies that the introduction of nursing roles as part of the process of counterpoising HIV services may be viewed as complementary to the medical role in this setting. In other disease areas, approval by medical staff has been considered as pivotal to the introduction of nurse-led roles (Read 2001) and this may reflect the start of a multidisciplinary model in the monitoring of people with HIV in this clinic.

In contrast with the smaller HIV clinic, services for stable patients in the larger clinics were more differentiated.

Some patients who are stable are seen by doctors. Most are seen by nurses within stable patient models which would either be a physical clinic if the patient needs it or it would be a telephone clinic or an [e-mail] clinic [...]. Then once a year they come for an annual review with a doctor

Mary, Senior Doctor

We have a stable patient thing and it works flexibly. So if you want to come and get your bloods done beforehand and see the nurse you can. Or if you want to just come in and get your results by e-mail then that's also possible. And she [the nurse] just does it either way

Mason, Senior Doctor

In these settings, there were established services for stable patients across a spectrum of face-to-face, telephone and e-mail clinics that appeared to be delivered mostly by nurses with additional input from pharmacists. One senior doctor, Mary, spoke about how this change in services was presented to patients in her clinic.

If patients understand they are being de-medicalised because they are well and they are still going to have a proper review annually, that the British guidelines say that is enough, they accept that is fine and there is evidence behind it

Mary, Senior Doctor

This reference to the *de-medicalisation* of HIV in this context suggests a shift from a biomedical approach to managing stable patients towards a more diverse multidisciplinary model. This view was supported by other healthcare workers. One community nurse spoke of the implications of a purely medical model in HIV.

You have to really probe to find what their [the patients] responsibility is [...] and they are not responsible for taking any actions on improving their health. So it is kind of like it has become very medicalised

Penelope, Community Nurse

Another medical consultant commented on his workload and thought this may partly relate to seeing patients who do not have specific medical needs.

I do feel a slight pressure on my time at the moment. I am probably the most overbooked and some of that is because I am seeing people that don't really need to see me

Mason, Senior Doctor

This notion of de-medicalisation was often linked with the introduction of nursing roles in the care of stable patients that were again perhaps viewed as complementary to medical roles.

However, the narratives of nurses providing stable patient clinics indicated that not all doctors were comfortable in utilising nurse-led services for this group of patients. For example, in South Park, referrals for nurse-led clinics increased when there were shortages in the medical team and decreased when there were sufficient doctors. Likewise data from the snapshot survey indicated that in some areas nurse-led clinics that were established for stable patients were more commonly utilised for appointment capacity. There was also evidence of some tension between nursing and medical teams during the establishment of nurse-led clinics for stable patients.

It took a long time to negotiate that [nurse-led clinics]. It was very much a case of trying to allay the fears of the doctors that we weren't suddenly going to steal their patients

Marcus, Senior Nurse

This suggests that nurse-led clinics were viewed by some as a substitution for medical clinics. While Mason was in support of deploying nursing roles, he pointed out the undesirable aspects of stable patients moving from his caseload into nurse-led clinics.

To some extent I am forced to lose some of those [stable] patients if you like. I am also aware that if I lose all these patients that other people can look after then my job in some ways becomes increasingly unattractive because I have to focus on the people that are just really hard

Mason, Senior Doctor

For Mason, this substitution meant that, firstly, there was a sense of loss of his stable patients and, secondly, the balance of his caseload would become more intense. In Chapter 6, patients and staff spoke of the value of supportive relationships and this may also be a factor for doctors considering the deployment of stable patients to nurses. However, while patient-provider relationships were important for all patient participants, for many continuity of care across a known team was equally valued.

There were other doctors who believed that relinquishing these long-standing relationships was part of responding to the changing needs of people with HIV.

We can become part of the problem and part of the reason we become part of the problem is [that] we still invest in what we've achieved, in what we have done for the patient

Mary, Senior Doctor

This sentiment was re-enforced by a diabetic specialist who was part of the study group but whose coded name has been withheld for this data quote to prevent deductive disclosure.

I think the lessons from diabetes would be let go. Because back in the 80s that was the attitude. It was they must all stay with us. And ultimately it's not in the patient's best interests for that. They shouldn't be coming to see you about problems that they really should be seeing someone else [for]

Interview 3 (coded name withheld to prevent deductive disclosure)

In diabetes care, devolvement to nurses has become an established part of service provision. In one study of 159 diabetic services, there were nurse-led clinics in 90% of health facilities (James, Gosden and Winocourt et al. 2009). However, there were specific roles reported for diabetic nurses that included education, blood glucose monitoring and administration of insulin. These roles differed considerably from traditional medical roles and were perhaps for this reason more acceptable.

In relation to the care of stable HIV patients, nursing roles were providing elements of routine monitoring that had been previously undertaken by doctors working in HIV, many of whom were medical consultants. This may help to explain why the concept of substitution was evident in the data. The referral criteria for the nurse-led face-to-face clinics were focused around disease markers and the absence of active health conditions as shown in Figure 7.3.

Blended referral criteria for nurse-led face-to-face clinics for stable patients
Stable on ART with HIV viral load <40 for 6 months
Stable off ART with CD4 count >350 cells/mm
No active co-morbidities at time of referral
Declined or not eligible for e-mail clinics
Additional support needs such as adherence or psychosocial
Annual review by medical consultant

Figure 7.3: Broad referral criteria for nurse-led clinics for stable patients

These criteria for nurse-led clinics for stable patients reflect a majority of stable patients as defined in the national HIV Care Pathway (Department of Health 2011c). Nonetheless, many patients who met these criteria remained engaged in medical clinics. Marcus explains the ongoing challenge of moving stable patients from doctor clinics into nurse-led clinics.

I don't think we have won the argument yet. I would still argue there is some level of anxiety that still exists. I don't think we have completely solved and won that argument and I think we operate a very mutually respectful service in the sense that they [doctors] accept the service as long as they don't feel too threatened by the service. And I think if we suddenly went actually lets go down the line of identifying where all the stable patients are and making sure those stable patients were converted into the [nurse-led] stable patient clinic, I think we would then have a lot of trouble

Marcus, Senior Nurse

From the previous evidence presented, this reluctance to devolve stable patient care to nurses seemed to be linked to losing patients and change in intensity of

workload. As the nurse clinics were in effect replacing the care that was delivered by medical consultants, this was conceptualised as a substitution role. The concept of substitution was drawn from previous work exploring new nursing roles. In this national evaluation (Exploring New Roles in Practice³⁴), substitution roles arose where medical tasks were delegated to nurses. Likewise, Scholes and Vaughan (2001), who were part of the same study group, identified that tensions across teams were greater if there was a perceived threat to existing therapeutic relationships. As both these elements were present in the data, it suggests that HIV nurse-led face- to-face clinics were viewed as substitution by some medical staff. Where doctors spoke of the *de-medicalisation* of HIV, they were more likely to view these roles as complementary. This concept of complementarity was also derived from the ENRiP project (see footnote 33) where these roles were generally more successful and acceptable to the multidisciplinary team. This implies that, within the HIV sites studied, the deployment of nursing in the care of stable patients was viewed either as the creation of substitution roles or complementary roles. This seemed to be dependent on the perceived loss of medical role and therapeutic relationship in the case of substitution or a perceived change in the medical needs of HIV patients in the case of complementary roles. Figure 7.4 shows the relationships between the perceived roles of doctors and how nursing roles were deployed.

³⁴ Exploring New Roles in Practice: Final Report. University of Sheffield, University of Bristol, Kings Fund Nursing Development Programme 2001. This report undertook a mapping exercise of new roles in the NHS and a grounded theory approach on case studies to identify the experience of new roles in practice.

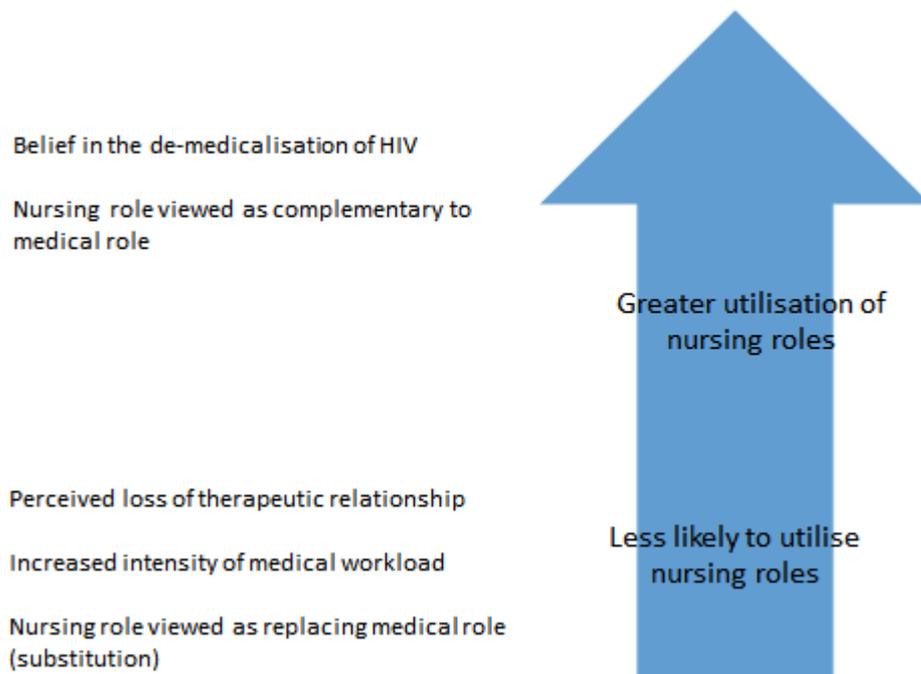


Figure 7.4: Medical factors associated with deployment of HIV nursing roles

However, most nurses interviewed believed that nurse-led services for HIV stable patients were more commonly driven by the need to release capacity for medical appointments than by identifying who was best placed to provide this aspect of care.

Capacity I think is something that has driven nurse-led care in HIV. Perhaps it developed because of capacity issues

Marcus, Senior Nurse

Doctors can't cover everything in big centres. I think it [nursing role] does depend on the numbers of patients you've got and the skill mix in your department

Shirley, Senior Nurse

Nonetheless, nurses also believed that looking after stable patients gave them the opportunity to utilise their nursing skills in addition to routine monitoring.

We know perfectly [that] the CD4 and the viral load are the aspects that we would look at [...]. I think it is assessing and monitoring [...] and the psychological support and the assessment is part of the nursing

Matthew, Staff Nurse

I am a nurse and not a doctor so the extent to which I use my nursing skills certainly there is stuff there around education, there is stuff there around the social psychological aspects which I think I do provide from a very nursing background style [...] So when I am thinking about the patient, what I am doing for the patient, I think about his lifestyle which then places it clearly within nursing

Marcus, Senior Nurse

In this way, those who were providing nurse-led clinics for stable patients viewed their role as complementary as they believed their skills were adding a nursing perspective to care of stable patients. The narratives of nurses throughout the interviews and this thesis were much more focussed around vulnerability, psychosocial needs and advice for non-routine problems irrespective of the perceived medical stability of patients. In comparing this with other data sources, these findings on the role of nurses were consistent with audit data on 50 patients in nurse-led stable clinics at the HIV unit at Chelsea and Westminster Hospital (McPeake 2010). This audit showed that 40% of patients in these clinics had psychosocial issues, 16% adherence issues and 28% were referred to other medical specialties. In addition, there were similar findings in other disease areas, where the evolution of nurse-led roles highlighted unanticipated need in cancer and diabetes patients attending nurse-led services (Gee 2004; Woodward, Wallymahmed and Wilding et al. 2006). This suggests that there is potential for HIV nursing roles in addressing the non-medical needs of stable HIV patients.

So, in terms of devolving HIV care the need to release capacity for appointments was found to be a main driver in a similar way to the redefining of HIV services. The utilisation of nursing roles was influenced by medical perceptions of what nurses could contribute and how this might impact on the roles of doctors. Subsequently, the **delegation** of stable patient care to nurses was viewed either as **substitution** or as **complementary**. Where medical staff believed in the de-medicalisation of HIV, nursing roles were more likely to thrive. This indicates a relationship between how medical staff view and **construct HIV as a condition** and the way in which nursing services evolve with regard to the care of people with HIV.

7.4 Summary on evolving service delivery

This chapter has shown HIV services as a constantly evolving healthcare environment that was continually being **adapted** in response to the perceived needs of people with HIV. This process of adapting involved the cognitive representation of HIV as a stable condition and there was an evident spectrum of views in the way that **constructed HIV as a long-term condition**. These disease labelling behaviours were linked to how services were redefined and how the needs of stable patients were **counterpoised** against those perceived to have more complex healthcare needs. The prevailing medical conceptions of HIV as a stable condition were also a factor in the **delegation** of care to nurses and whether this was viewed as **substitution** or **complementary** care. The

process of planning HIV healthcare therefore was embedded in how healthcare workers in HIV cognitively and emotionally perceived HIV as a stable condition.

The organisation and delivery of healthcare services has previously been shown to contribute to how illness is represented or constructed by patients (Leventhal, Neretz and Steele 1984; Green 2009). There were elements of this in the way that patients viewed their needs within a specialist domain and their expectations of other services in responding to their needs. There was also evidence of this in the values associated with engaging in care and how this was linked with how patients viewed themselves as a person with HIV. The next chapter will specifically explore how HIV patients construct their illness experience and how this informs the way they perceive and utilise HIV services to meet their holistic needs.

Chapter 8: Illness experience

8.0 Introduction to the chapter

One of the unexpected findings of this research and its contribution to future healthcare planning was that most patients did not view their healthcare in isolation from their whole experience of living with HIV, irrespective of their perceived health status. When patient participants were asked about their healthcare, they spoke of relationships, feeling accepted and the secrecy of having an HIV diagnosis. There was no apparent compartmentalisation of healthcare provision from each individual's personal story of HIV; they seemed to be inextricably linked. This chapter will present the cognitive and emotional factors that influence the way patients view and interact with HIV services and their perception of the role of HIV services in their care.

8.1 Pervasiveness

Although the majority of patient participants perceived their health to be currently stable, most patients in the study perceived HIV as a pervasive condition that affected every aspect of their physical and psychological health.

I think with HIV one of the biggest problems is not the illness itself but the depressions that go with it. They are really depressions. You really do go into a deep decline

Michael, Age 70

However happy you might seem today I think I'm quite aware that you're never far away from the edge, where you might start to feel low or despondent or whatever. That's not just about medication or physical health, that's about the fact that very often if you meet someone and you start a relationship and you start going out with them at some stage you obviously disclose your status. And it's you toss a coin, you're totally accepted or you're rejected out of hand, or any number of things can happen. That's taken a long time to come to terms with

Morris, Age 52

I recently asked a question about whether or not having HIV would stop me from getting buried or whether I'd have to be cremated. It's just one of those things that you think about when you lose somebody close so you know it's just a stupid thought that came into my mind. But it was one I couldn't get out of my head

Stewart, Age 39

For example, sometimes I feel so exhausted and I do nothing. This depresses me

Martha, Age 40

This illness perception, while very individual, appeared to be constructed on both physical and psychological levels for most patient participants. This perceived pervasiveness of HIV as a condition moved the patient representation of illness beyond clinical disease markers and current perceived physical health status. As such, many symptoms appeared to be viewed as integral to the experience of having HIV irrespective to how patients described their health status. These are similar concepts to those mentioned in previous research into illness representation models (Leventhal, Nerenz and Steele 1984; Theunissen, De Ridder and Bensing et al. 2003; Hagger and Orbell 2003). Theories of illness representation are based on how patients view their symptoms, or experience illness, on both cognitive and emotional levels and that coping strategies are

centred on the individual's interpretation of a symptom or illness (Leventhal, Nerenz and Steele 1984; Kemp, Morley and Anderson 1999; Moss-Morris, Weinman and Petrie et al. 2002). The pervasiveness that patient participants spoke of suggests that HIV was often viewed as the cause of physical and psychological changes in their health and perhaps contributed to constructing their illness identity as a person with HIV.

In relation specifically to physical symptoms, some patient participants perceived that HIV was linked to any physical health issues they may have as HIV infection was seen as being related to immune function.

HIV is more your immune system isn't it. So it's to do with everything anyway

Sally, Age 27

Any other illness that the body can get can be caused by HIV or can be caused because you have HIV. It [HIV] won't tell you what's going on. It attacks all sorts of different parts of your body at different times for different reasons

Michael, Age 70

I suppose in some sense I guess everything from now on is going to be related in some way because it affects my immune system

Stewart, Age 39

This perception may explain the reticence of some patients to use their GPs and the belief that HIV services would be better placed to deal with any new symptoms if they were believed to be related to HIV. This provides some insight into what informs some patient decisions to access services for non-routine health problems. As discussed in Chapter 5, historically all healthcare problems were dealt with by HIV services and the way services had been organised in the past seemed to reinforce patient perceptions that all things related to HIV. In

Section 6.3, some evidence was presented on how patients undertook a self-assessment when they had new symptoms to help them to decide which service to access. It is possible that this self-assessment was influenced by how patients viewed their symptoms and whether they perceived HIV to be the cause. This may subsequently impact on whether they choose to access HIV services or general practice. These perceptions may also influence their expectations of non-HIV specialist healthcare workers in relation to their knowledge of HIV.

So, with regard to physical symptoms, the illness identity of patient participants appeared to be linked to their conceptual attribution of the cause of symptoms in keeping with other theories of illness representation. While it was beyond the scope of this research to explore perceptions of specific symptoms, the presence or absence of symptoms and previous or current illness did appear to play a part in how people with HIV constructed their condition and how they subsequently viewed the role of HIV healthcare services.

Overall, patients referred to a range of health conditions, physical and psychological symptoms in their interviews. All but two patients described previous or current health issues or made reference to specific symptoms throughout their interviews, of which the majority were psychological in nature. Data analysis extract 1 shows the list of the conditions and symptoms from the transcripts of patient participants including the number of patients that spoke of these experiences.

Previous conditions declared	Current conditions declared	Symptom experience declared (ever experienced)
Kaposi Sarcoma	Cerebral oedema	Diarrhoea x3
Pneumocystis Jirovecii Pneumonia (PCP) x3	Virological blip	Fatigue x4
Skin infections x2	Gynaecological problems	Flu-like symptoms x2
Shingles		Depression x6
Treatment failure		Anxiety x6
Hospitalised for abdominal pain		Roller coaster of emotions x2
Irritable bowel syndrome		

Data analysis extract 1: List of symptoms/conditions declared in the patient participant interviews

Other symptoms/illness experiences, such as back pain, orthopaedic surgery or dental problems have been excluded from this list as there was no evidence that these cognitively formed part of the way that patients constructed their HIV condition or viewed the role of HIV services. The purpose of this research did not include specific questions about symptom or illness experience and is therefore not intended to accurately reflect the overall symptom experience of the participants.

There was no obvious connection with the age of participants in relation to their symptom/illness experience, although over half of the sample was over 50 years of age. Likewise, length of diagnosis did not appear to influence this. However, overall the experience of previous ill health and/or the experience of symptoms that patients attributed to their HIV were dominant factors in how they viewed the role of HIV services. Further reference to the symptom experience of participants in this thesis includes the previous and current health conditions described.

Patients also had different perceptions of their biological disease markers and did not necessarily use the language of their healthcare workers. For example, Sebastian speaks about his view of HIV viral load³⁵ before he started treatment.

I went from being up in the 20,000s sort of viral load figure which I was told wasn't high. But to me 20,000 is a high sum of money so it seems like a high figure. So within two months to go non-detectable and stay non-detectable for four years, to me that's important

Sebastian, Age 38

This highlights the individual approach to interpreting numerical measures of disease and how this may differ from the perceptions of healthcare workers. This is of particular relevance as NHS funding for HIV care is soon to be based on biomedical disease markers and not on the individual illness experience of people with HIV. The pervasiveness of HIV that patient participants perceived was integral to their illness **identity** or representation and seemed to be linked to the relationship between the perceived **cause** of **physical and psychological symptoms**.

8.2 Anticipation

In addition to the perceived pervasiveness of HIV with regard to physical and psychological health, many of the patients also spoke of uncertainty and concern that their physical health would not remain stable. This uncertainty manifested as anticipation of a change in blood results or of pending health deterioration.

³⁵ See terms and abbreviations for definition of viral load.

I think when you've got this you're always conscious that something at some point is going to go wrong I come in anticipation that the results will be good but always with a very slight heavy head maybe if that's the word there's always a chance that this might be the one where the results aren't quite what I want them to be

Simon, Age 56

While you feel well you don't feel vulnerable. I suppose you're walking very close to the edge. I think were it to change, I would feel vulnerable again very quickly. It's not just your physical health, it's your emotional health that is quite close to the edge as well

Morris, Age 52

You are always hoping you go to one appointment and they say I've got something for you that's going to [cure]. And it never comes. Or the opposite, that they tell you that your results today show that your immune system is devastated. You always hope for to go back to how you used to be without [HIV]

Martha, Age 40

Other patients spoke of an inevitability that their health would deteriorate and were in essence waiting for this to happen.

I suppose looking at my blood counts I feel safe, but there's always the worry that things may go wrong

Michele, Age 52

At least the way that I've interpreted it, HIV doesn't always necessarily follow on into full blown AIDS or anything like that provided that you look after yourself and you take the medication. But I do still worry about it

Stewart, Age 39

I'm not yet really sick anyway

Max, Age 56

I seem to recall there was maybe as many as five or six possible options so for me that means I have five or six possible lives left out of my nine lives as a cat. So because I've had this one for 10 years and the medication has worked so far for the 10 years that is brilliant. But I do believe that at some point in the future this medication may well fail

Simon, Age 56

Conceptually, patients were assuming an 'inevitable' change in health status and although there was evidence that their health was biologically stable, there was

an emotional component to their illness perception that translated into concern about their future health. This may also explain why all the patients in the study had utilised HIV services at some point for advice and reassurance when new problems arose for them. This uncertainty is consistent with studies on illness representation where perceived controllability of a health condition influences coping strategies (Hagger and Orbell 2003; Lowe, Porter and Snooks 2011). In the context of this research, this perceived controllability of future health may have influenced how patients viewed their healthcare needs and the consequences of HIV for themselves. In addition, there appeared to be a conceptual timeline for patients that antiretroviral therapy may not continue to be effective in the longer-term.

Some other patients had concerns about long-term access to antiretroviral therapy in the current healthcare climate and whether this would always be available to them.

I guess if I'm honest I've got no real idea how much the cost of me having those drugs is to the health service. I imagine it's quite high. But I think the bottom line for me was if at some point in the future they turn round and say you've got to start paying for that, well I'd have to start paying for it, because my life depends on taking those drugs

Stewart, Age 39

It worries me about the whole NHS and the availability of free drugs

Sebastian, Age 38

The only niggle I have, the only uncertainty I have, I think is the availability of new drugs. Because you know that again I've been lucky. I seem to have been lucky throughout this whole diagnosis you know. I got onto a new drug, trialled a new drug that was supposed to have very very few side-effects if any and that's proved to be the case. But I was lucky enough to continue that but maybe that wouldn't be available to other people and maybe new drugs won't be available to me in the future because of cost-cutting or whatever happens. So the budget restrictions might mean fewer choices in the future

Morris, Age 52

While this may not specifically relate to HIV as a condition, this may add to the feeling of uncertainty and lack of permanence around health service provision for people with HIV. The concept of uncertainty in HIV is not new and has been found in a number of other studies (Kylam, Vehvilainen-Julkunen and Lahdevirta 2001; Brashers, Neidig and Russell et al. 2003; Bravo, Edwards and Rollnick et al. 2010; Perrett and Biley 2012). Likewise uncertainty in other chronic illness is well described in the health literature (Bury 1982; Charmaz 1994; Bailey, Barroso and Muir et al. 2010) and people with HIV did not appear to differ in this respect. However, the uncertainty found in this thesis was strongly linked with the way that people with HIV represented their HIV health condition and subsequently with how they perceived the role of HIV services. This is further supported by Brashers, Neidig and Goldsmith (2004) who found that the inclusion of social support in the care of people with HIV assisted in proactively managing uncertainty. This again reinforces the role of healthcare services in influencing patient perceptions of their illness.

Some patients specifically requested that discussions about their future health were incorporated into their care package and included advice on what to be

aware of in terms of future health problems. This included advice on self-monitoring and long-term prognosis.

Perhaps if we move to the once a year model that is being proposed in some areas for HIV care, built into that approach is a discussion or talks about the ageing process, signs and symptoms of other things and other care needs

Morgan, Age 45

Maybe a bit more guidance for me, I would need a little bit more guidance because of my survival instinct. [I need to know] things to watch out for that are related to the disease to the HIV illness. I need more information and as well maybe they prepare us a little bit more for towards the end [of life]

Martha, Age 40

Although a couple of patients mentioned end of life care, in general patients were reassured by the on-going monitoring within HIV services of potential complications. This is similar to the experiences of cancer patients who felt more secure when being monitored for disease recurrence by cancer services, and current cancer survivorship models are being developed in response to this (Department of Health, Macmillan Cancer Support and NHS Improvement 2010). Models of healthcare therefore seem to have a role in moderating uncertainty.

The **uncertainty** experienced by patient participants in this research appeared to be based on concerns about long-term **controllability** of their HIV and conceptual **timelines** for how long their antiretroviral therapy may remain effective. These factors were integral to how patients represented HIV as a condition and how they viewed HIV in terms of the **consequences for the 'self'**.

8.3 Implications for social integration

In addition to the way patients perceived their symptoms and the consequences of HIV for themselves, there was also evidence of how patients perceived themselves as part of the wider healthcare community and society in general. In Chapter 6, evidence was presented on perceived stigma and discrimination and how this affected the attachment to HIV services, patient-provider relationships and positive partnership working. These values of HIV care also captured the cautious attitude that some patient participants had about their interactions with people outside the HIV setting.

Although stigma has already been presented in this findings section, evidence will now be presented on how stigma is integral to how people with HIV in this study perceived themselves as a person with HIV within the context of wider society. While feeling accepted has been shown to be a key value for patients within the healthcare environment, this was also a significant factor for the social aspect of their lives.

It's like now we're trying for children and I say to my partner I don't know whether I'll stay living in [name of place] because of people because of what people think they know which is actually true. But they think they know. Because I don't want my children to be affected growing up so it's like do I stay or do I go?

Sally, Age 27

If you say I've got cancer everybody sympathises. HIV is more like a dirty disease where everybody puts a black cross on it

Martha, Age 40

Like when I came for an operation I wanted to mention to people that I'm going to church with. But no my wife said don't tell anybody, don't tell anyone because they will all be there at the hospital and they will find out

Malcolm, Age 55

The benefits of the drugs are that we can be like everyone else and no one knows the downside is on the inside. We know we're not like cancer where if you tell people you have cancer an automatic response from most people which is to feel sorry for you and to offer you support. HIV still causes conflict in many individuals in the way in which they should respond. There are more people I suspect now than don't that are positive in terms of the way they respond. But still there is a sense that someone might not respond positively, that your employer might not respond well, that other healthcare workers might not respond well. other people in other areas where you might need support might not respond well

Morgan, Age 45

This concept of HIV being on the *inside* affected how patients integrated in their communities, their jobs, how they approached new relationships and how they perceived themselves as person with HIV. The secrecy and anxiety about how society would respond to them as a person with HIV impacted on normal social functioning and excluded people with HIV from fully participating in mainstream society.

This finding is consistent with the concept of HIV stigma as a social process that was developed by Parker and Aggleton (2003). These authors developed a conceptual framework on HIV/AIDS related stigma based on power and the exclusion of people with HIV from mainstream society. This social exclusion has also been highlighted in other studies on HIV stigma. One study carried out in 2009 on 876 people living with HIV in the UK showed that 11% of respondents were physically harassed due to their HIV diagnosis and 21% were verbally abused or harassed (The People Living with HIV Stigma Index 2009). This user-led interview research using a standardised questionnaire also showed that 17% of people with HIV were denied healthcare due to their HIV diagnosis (Ibid.). This may relate to pervading public attitudes towards HIV where one in ten people do

not have sympathy for people with HIV and this increases to three in ten when a person was infected sexually (National AIDS Trust 2011). Thirty-eight percent of this latter sample of nearly 2,000 people wanted to be informed if one of their colleagues was HIV positive. Research carried out by healthcare workers on illness representations in asthma used HIV as a downward social comparison for benchmarking affective representation of asthma (Peterson and Ritz 2010). This indicates that both the public view of HIV and healthcare workers views on HIV have negative connotations in comparison with other conditions.

Gill Green (2009) argues that public attitudes towards HIV are improving. She believes that advances in HIV treatment have reduced the visible signs of HIV infection and that people with HIV are now able to hide their HIV status. This was not evident in this research on HIV healthcare where the hidden nature of HIV infection seemed to contribute to the secrecy of living with HIV and to further underline the perceived social exclusion. More importantly, this perceived social identity was integral to the way that people with HIV viewed themselves and how they constructed their overall representation of HIV as a condition. The extent of social integration was fundamental to how patient participants viewed the role of HIV services in their care. For example, those who had a more positive social identity were less reliant on face to face interactions in the HIV clinics, as shown in Figure 8.1.

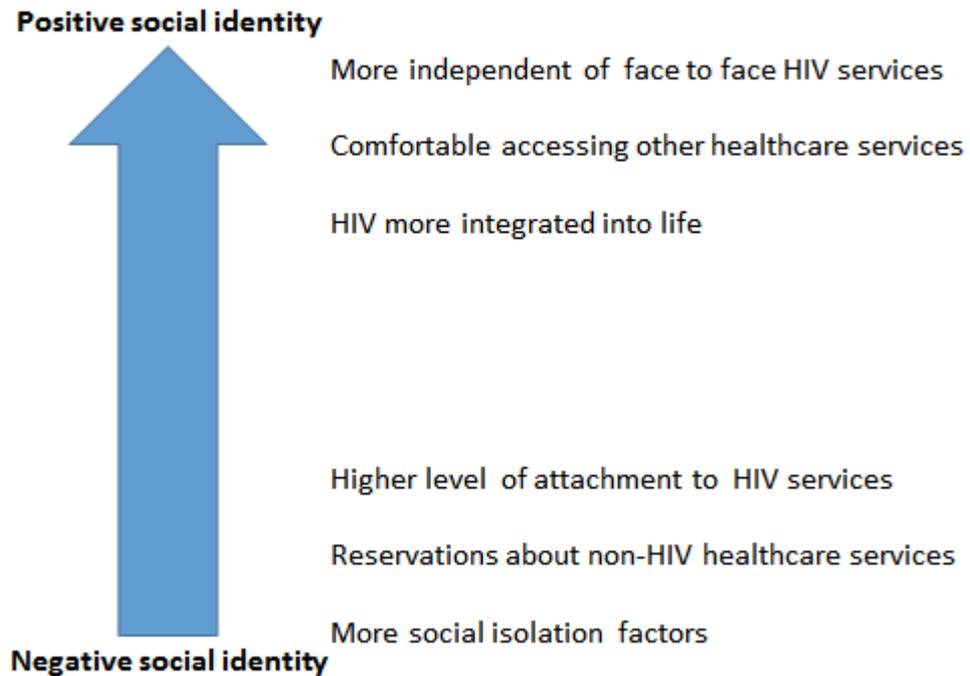


Figure 8.1: Relationship between social identity and use of HIV services

This highlights the emotional component involved in the way that people with HIV view themselves and their condition. In seminal work on illness representation, emotional factors were contributory to how patients viewed their illness and subsequently developed individual coping strategies (Leventhal, Nerenz and Steele 1984). So, alongside the cognitive or conceptual interpretation of symptoms and consequences of HIV on the self, there was a strong emotional component in relation to the social consequences of living with HIV.

The evidence from patient and staff participants in this thesis on HIV healthcare indicates that people with HIV also represent their condition based on the perceived **consequences of HIV** on their **social integration** and normal social functioning. The concept of **stigma as a social process** was observed throughout the data and was integral to how patient participants viewed

themselves as a person with HIV. Although there was a spectrum of views on the consequences of HIV on social functioning, these did relate to the way that HIV services were viewed or utilised and this is likely to be an important consideration in the planning of future services.

8.4 Summary factors and spectrum of patient illness representation

The above three sections of this chapter have presented the factors that comprise the illness experience of patient participants in this study on HIV healthcare. Concepts derived from the data indicate that people with HIV represent their condition based on both cognitive and emotional pathways that are rooted in symptom and illness experience, perceived consequences of HIV on the self and on their social functioning. These composite factors have been illustrated in Figure 8.2.

Factors in HIV Patient Illness Representation

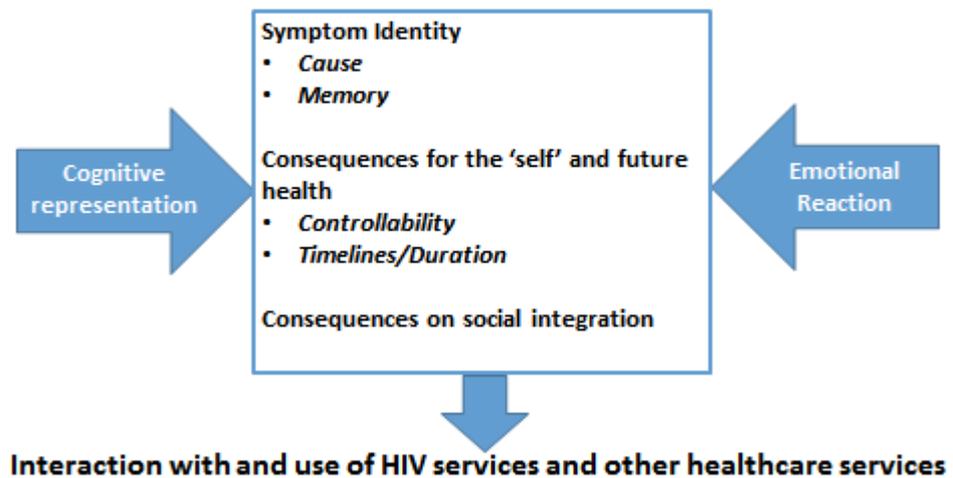


Figure 8.2: Pathways of patient illness representation in HIV

However, there was an observed spectrum of illness representations in the data. The conceptual interpretations of symptoms, uncertainty and social functioning experienced at cognitive and emotional levels appeared to differ across the patient participant group. Although almost all patients spoke of the concept of uncertainty and the need for reassurance, many described themselves in some form or other as medically stable. Figure 8.3 shows the distribution of perceived stability across the patient participant sample.

Patient perception of health status	Number of patients
Identified as being stable at present	8
Identified as being stable at present but transcripts included evidence of active health problems at time of interview	3
Identified as having multiple health issues	2
Total	13

Figure 8.3: Patient perception of health status

The patients' description of health status was therefore incongruent with the way they perceived HIV as a pervasive condition and was not a useful measure in assessing their views on the role of HIV services. For example, 10 of the 13 patients were attending appointments every 3-4 months that was in keeping with routine monitoring guidelines for stable patients at the time of data collection (See Figure 4.5 on Page 172). However, two patients were being monitored more frequently due to active health issues, one of whom described his condition as stable. Furthermore, one patient who was being routinely monitored perceived that they had multiple health issues. Finally, one who was an infrequent attender perceived their health status as stable. This highlights the difficulty with using broad definitions of health status that may not accurately reflect how patients experience their HIV or how they think or feel about their condition.

The way that patients reported their current health status influenced to some extent their views on engaging with new services in the future.

At my stage of the game to be honest there's probably not a great need to come and sit physically with a consultant and take up their time

Sebastian, Age 38

If you were saying to me would I be happy to see a nurse rather than a Dr on one of those visits or on an occasional visit, again if the situation was stable I see no reason providing that nurse could answer the questions that were necessary for me to ask

Simon, Age 56

However, this perception of stability did not influence how patients viewed the role of HIV services in their overall healthcare management. Conversely, there was an observed connection between the illness representation factors and the way HIV services were utilised. This was linked to the extent to which symptom/illness experience, perceived consequences of HIV on the 'self' and social integration dominated the illness identity of patients. This was conceptualised within three distinct groups.

8.4.1 Patients advocating less face-to-face contact with HIV services

Several patients in the sample perceived minimal health problems, less uncertainty and minimal impact of HIV on the rest of their health and social lives. This group were more likely to consider different models of care that included less face to face contact with HIV services. For example one patient who had been diagnosed for 19 years and was currently enrolled in a telephone clinic service in the HIV clinic felt he had reached a point where he was confident in navigating all forms of health service.

It is the same for me even if I was to come [to the clinic] or not to come. It would be the same, as long as I get to know how I am performing

Max, Age 56

This confidence seemed to relate to feeling comfortable with his HIV diagnosis and no longer needing to seek reassurance or advice.

Each time I came in I came with some questions and they spent quite some time [with me] until the last few years when I realised they had answered all my questions

Max, Age 56

Another patient who was keen to engage with new models of care explained this in terms of wanting to minimise his contact with HIV services and because he felt he had less need than other patients.

At one end of the spectrum you've got people like me who are trying to minimise as much as possible and I suspect at the other end you've got people who desperately want their appointments to be an opportunity to explode with all the things that have happened to them because they don't have the support or the self-confidence elsewhere

Morgan, Age 45

These two patients conceptualised a stable condition and reported minimal ill health experiences. Likewise the narratives of these patients did not imply that HIV was a dominating factor in their lives and they did not perceive overtly negative experiences of non-HIV healthcare. These three factors appeared to influence their emotional response to HIV and subsequently how they viewed their need for future contact with HIV services. There was no apparent link with length of diagnosis, age, gender or risk group.

8.4.2 Patients who viewed the current HIV service model as central to maintaining their health

In contrast to the two patients above, a second group of patients felt strongly that HIV services were central to maintaining their health. This second group

appeared confident in navigating health services but were more inclined to talk of current or previous health issues and how HIV impacted on the rest of their lives. These participants had a preference for using HIV services as opposed to GP services. In spite of apparent patient confidence in dealing with health problems, there were strong feelings in this group that HIV services were pivotal in their overall health and well-being.

I think if they took [the HIV clinic] away from me I'd crash. Then I'd definitely go the other way. I personally think you feel secure knowing that you have got somewhere or someone there that you can phone 24/7

Sally, Age 27

I think the [HIV clinic] is best placed to deal with my problems, because they know the underlying condition. They are aware of HIV and everything involved with HIV so they don't treat something just as an illness they treat it as a threat

Michael, Age 70

I think that separating [HIV care] gives me the best possible care for what is still a new illness [that is] only 15 years old and which is hugely complex. And who knows what the future may hold in terms of additional complexity. Hopefully there won't be any, but who knows?

Michele, Age 52

I think I would worry if I didn't come to the hospital at least on a sort of semi-regular basis that I'd put my own health at risk

Stewart, Age 39

The narratives of this second group included many references to the social stigma and the secrecy of living with HIV that have been raised earlier in this chapter. This factor, alongside a range of current and previous illness experiences, seemed to influence the patient conceptualisation of HIV within a specialist paradigm. There appeared to be a connection between the emotional experience of being a person with HIV and the occurrence of ill health that

resulted in HIV services being viewed as integral to the health and well-being of patients.

8.4.3 Patients who viewed the current HIV services model as an essential support structure

A third group of patients perceived HIV services as a key support structure and although they shared a similar illness experience to the second group, they tended to be more isolated with their HIV diagnosis and often used the HIV clinic for emotional support.

I don't have the family to fall back on. I have nobody who's close to me or didn't have until recently although my friendship with this particular person - he's not going to be close enough to discuss this sort of thing. I find I do need someone to talk to about and the fact that I can come down here at any given point with very little notice and discuss with the Dr any problem that I may feel I have

Simon, Age 56

Some of this group also experienced negative encounters with other services and were less likely to utilise other services as a result of this. For example, two patients talked about their strategies to avoid using general practice based on their previous experiences.

It makes me feel like what is the use. I'd rather wait until my appointment here [HIV clinic] because then I get better treatment

Malcolm, Age 55

I see when my next appointment is with [the HIV Clinic doctor] and if it's near to [my next appointment]. Or if it's far in time then I'll see the GP. But if it's like the last trip I have to be really bad

Martha, Age 40

There was a high emotional component to how this group conceptualised their HIV condition and this appeared to influence how they represented their condition and subsequently viewed the role of HIV services in their care. While the symptom/illness experience did not appear to differ in terms of severity or frequency from the second group, this group were more socially marginalised than the above two groups. The social isolation within this group appeared to be embedded in how they viewed themselves as a person with HIV and this was reflected in the way they utilised HIV healthcare services for support as well as for clinical monitoring. Therefore, for this group HIV was conceptualised from a more emotional perspective that minimised the use of services outside the HIV clinic.

Although data was not specifically collected on employment or relationship status, the narratives did not indicate any difference in illness conception or emotional interplay based on these factors. Likewise, length of diagnosis, age or severity of illness did not appear to be a factor in how HIV services were utilised.

There were, therefore, three distinct groups identified from the data in relation to the illness representation factors and how these underpinned patient views on the role of HIV healthcare services in their care. Those patients with more dominant illness identity and social isolation were more attached to the current HIV service model irrespective of biomedical stability. This spectrum of illness representations among the patient participants has been illustrated in Figure 8.4 below.

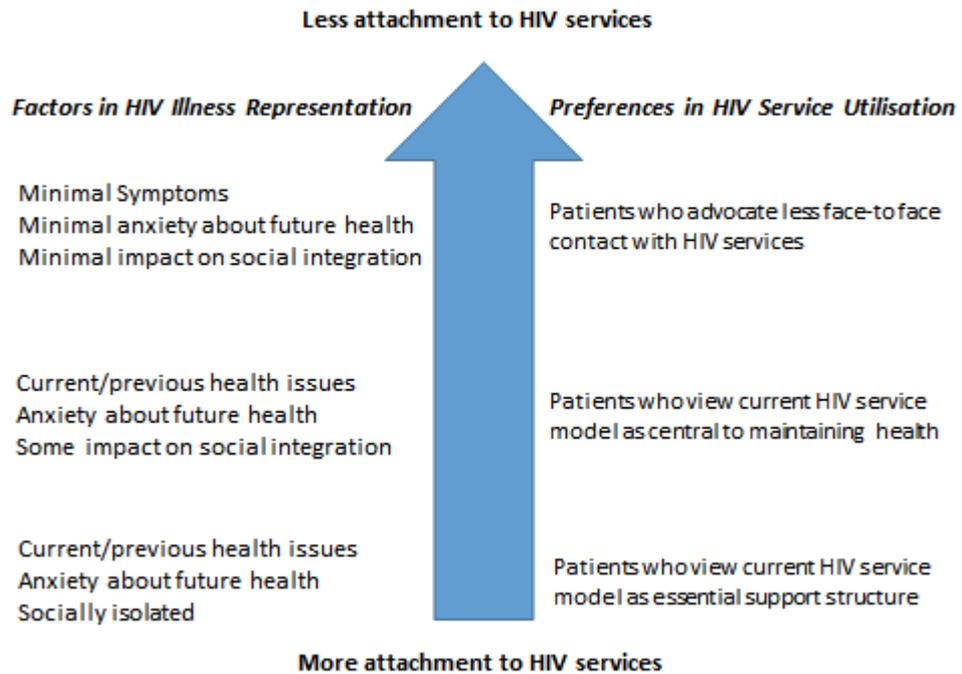


Figure 8.4: Spectrum of illness representations and service utilisation

This chapter has examined the factors involved in how HIV patients represent their HIV cognitively and emotionally and how this influenced their views on the role of HIV services in their care. Symptom/illness experience, consequences of HIV for the self and consequences of HIV on social integration have emerged as the key components in the representation of HIV from a patient perspective. These elements of illness construction were central to the way HIV services were viewed and to an extent the way services were utilised. There was a spectrum of views that incorporated **health and low emotional attachment** to HIV services on the one hand and **ill-health with high emotional attachment** on the other.

The next chapter of this section will present the substantive theory that has been developed from data findings.

Chapter 9: A theory of healthy-illness representation of HIV in the UK

The service model needs to take into account the spectrum of needs people have and that's not just about medical complexity

Melissa, Psychologist

9.0 Introduction to the chapter

The preceding four chapters have presented the evidence for what is involved in delivering and receiving HIV healthcare and the perceived interactions between how patients view their HIV and the processes in their care. This chapter will further develop the connections between the dimensions and properties and present a substantive theory of healthy-illness representation of HIV. The chapter will conclude by illustrating how the substantive theory has addressed the gaps in knowledge identified in Chapter 1.

9.1 Illness representations as the central perspective

Throughout the data analysis cycle, illness representation emerged as the central perspective of this research into HIV healthcare provision with respect to how services were organised by healthcare workers and utilised by patients. This has been discussed throughout the dimensions and properties presented in

Chapters 5, 6, 7 and 8. Although the concept of illness representations was initially developed through theoretical sampling and interrogation of the patient participant data (Glaser 1978; Strauss and Corbin 1990; McCann and Clark 2003b; Charmaz 2006), it became evident within all the data concepts and the assembled dimensions as the theory progressed. Further exploration of theories of illness representation in other disease areas highlighted the role of illness representation in determining how patients perceive their health condition, and their subsequent health behaviours (Leventhal, Nerenz and Steele 1984; Kemp, Morley and Anderson 1999; Moss-Morris, Weinman and Petrie et al. 2002).

The application of the explanatory matrix (Chapter 3) was pivotal in placing illness representations as the central organising perspective and in highlighting the explanatory power of this dominant perspective (Robrecht 1995; Kools, McCarthy and Durham et al. 1996). Figure 9.1 demonstrates the positioning of illness representation as the central organising perspective alongside the dimensions of benchmarking, adapting and engaging in care using the explanatory matrix.

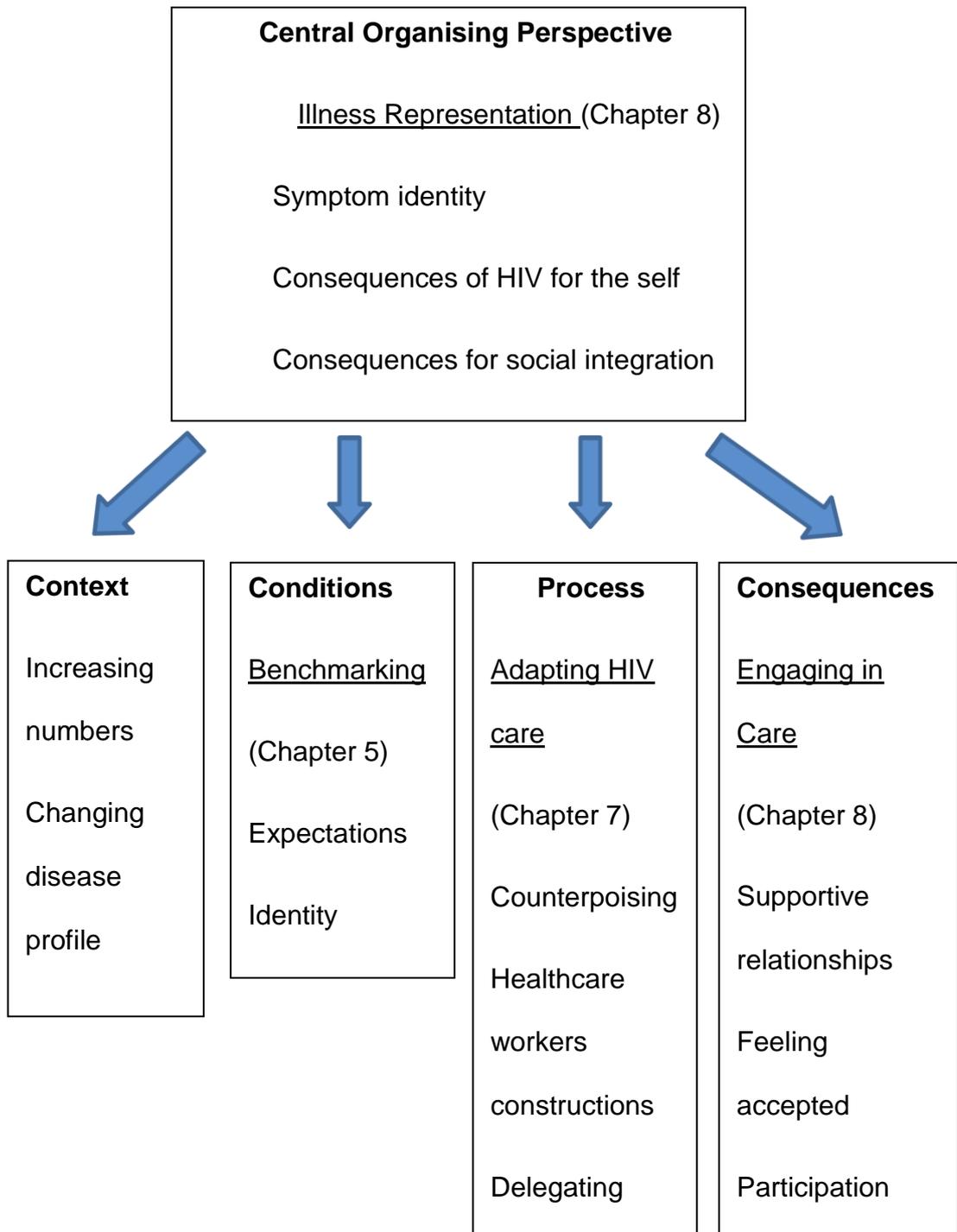


Figure 9.1: Illness representation as the central organising perspective

As the central perspective, the illness representations of patients both arise from and inform the way that patients benchmarked other healthcare encounters

based upon what they had learned to expect from HIV care. The way that HIV services were organised was informed by the healthcare worker constructions of HIV, and changes in the processes of service delivery in turn influenced the way that patients viewed their HIV as a condition. Likewise the values in HIV care had developed as a consequence of the way people viewed themselves as a person with HIV and the importance they placed on the interactions with their HIV healthcare providers.

The use of the explanatory matrix illustrated illness representation as the dominant perspective that situated the other dimensions as conditions, processes and consequences and formed the basis of the substantive theory on HIV healthcare.³⁶

9.2 A theory of healthy-illness representation of HIV in the UK

The central perspective of illness representations was further developed to build a substantive theory that related to the phenomenon of HIV healthcare and that would function as a foundation for the planning of future HIV services.

Throughout the data a spectrum of experiences, views and approaches towards HIV healthcare was observed. For patients, this was based on how they perceived their HIV in relation to symptoms, consequences on the self and consequences on social isolation. These factors seemed to occur along a

³⁶ See Figure S3.1 in the introduction to Section 3 for a summary of the dimensions and properties discussed in Chapters 5, 6, 7 and 8.

healthy-illness continuum. Those patients who experienced minimal illness experience, minimal impact of HIV on the self and minimal impact on social integration largely constructed their HIV as 'healthy'. Conversely, those with high symptom experience, anxieties about future health and who were socially isolated constructed their HIV as 'illness'. The three groups described in Section 8.4 represented their HIV along this spectrum of health and illness. Figure 9.2 shows how the concept of healthy-illness representation is related to the factors of illness representation and the preferences for service delivery that were previously illustrated in Figure 8.4.

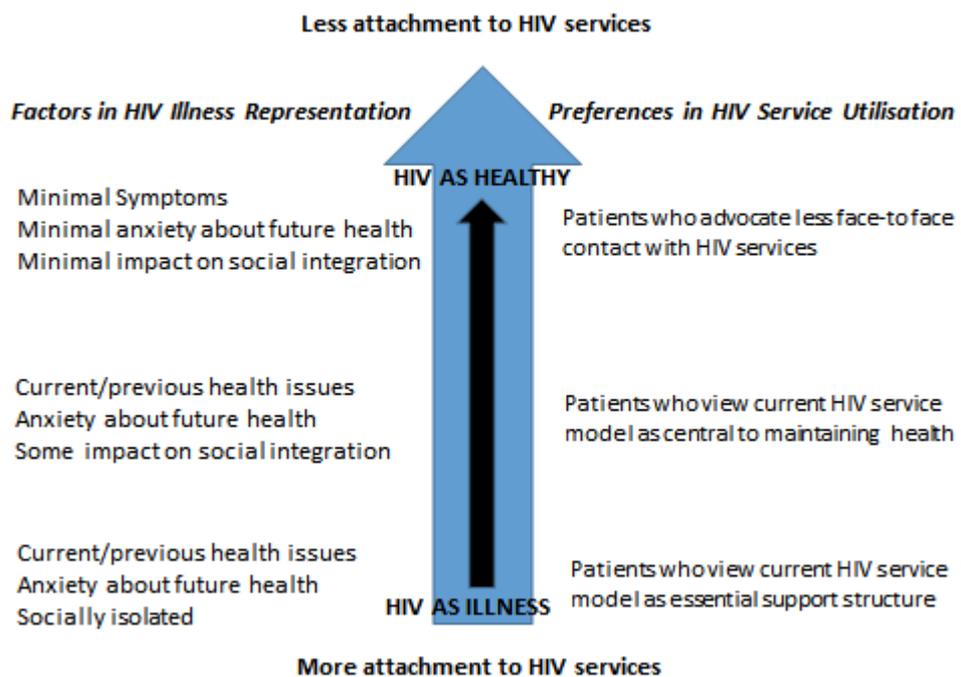


Figure 9.2: The healthy-illness spectrum of patients

In this context, health was viewed within a holistic definition that incorporated the physical, psychological and social needs of patients (see footnote 29 Section 5.2). So, while patients may consider themselves to be biologically and bio-

medically stable, their perceptions of health were constructed on symptoms/illness experience, degrees of social functioning and degrees of certainty about their future health. In essence, their healthy-illness spectrum incorporated their experience of living in society as a person with HIV.

Concepts from the data indicate that healthcare professionals hold different representations of HIV as a stable condition from those of patient participants. These have been presented as three models of stable patient representation as previously illustrated in Figure 7.2. These models have also been conceptualised along a healthy-illness continuum that places 'the stable patient as 'well'' at the healthy end of the spectrum and 'the stable patient as holistically complex' at the illness end of the spectrum as shown in Figure 9.3.

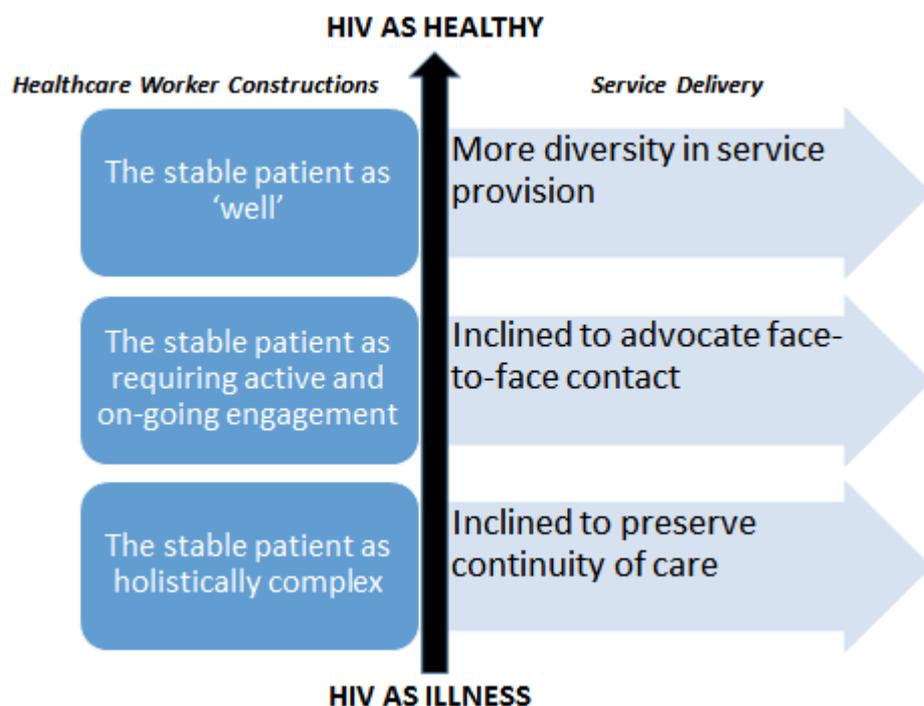


Figure 9.3: The healthy-illness spectrum of healthcare workers in HIV

Healthcare workers who perceived stable patients 'as requiring active and on-going engagement in care' were perceived as being in the middle of the healthy-illness spectrum. As shown, these healthcare worker constructions of HIV as a stable condition were linked to the way that services were planned and how roles were delegated to non-medical staff. Therefore, the way that healthcare workers constructed HIV as a stable condition informed their service planning and in turn influenced the way HIV was perceived as a condition by patients. This was evident in the way that patients considered changes in the frequency of their appointments and believed that this reflected their current medical stability in a positive way. There was, therefore, a perceived cyclical relationship between the way that services were organised and how patients viewed their stable condition. This appeared to centre around the trust and confidence that patients had in their HIV healthcare workers to know their individual case.

Although there was some observed congruence between the patient models of illness representation and those of healthcare workers in HIV, these were not evaluated at an individual level. Indeed, the majority of patient participants were very satisfied with their care, but most of these were currently in face-to-face appointments and highly valued their interactions with their healthcare workers in HIV services. This indicates that, within the research sample, their individual needs were being met through their current service delivery model. It is possible that those who came forward for the study had a vested interest in protecting their current model of care delivery. This theory of healthy-illness representation, however, is intended to inform future service planning and to illuminate the salient interactions and underpinning beliefs about HIV healthcare.

In spite of these apparent similarities between patient and staff models of illness representation, they were largely underpinned by different priorities. Essentially, what was important to patients was the presence or absence of symptoms and the perceived consequences of HIV on their future health and social functioning and it was these factors that drove the way they constructed their HIV. These representations contributed to how patients perceived the role of HIV services in their on-going healthcare and their attitude to different models of service delivery.

For staff, job role and casemix played a significant part in constructing HIV as a condition and in how they organised HIV care. For example, there was evidence that healthcare workers were transforming stability by changing services for stable patients and extending the parameters of HIV by introducing joint working with other specialities. This disparity in the way that HIV was represented as a chronic stable condition is likely to be significant in planning future services. While there is increasing demand on HIV clinics to manage growing caseloads within current financial constraints, many patients who are bio-medically stable are being monitored less frequently in keeping with recent national monitoring guidelines (British HIV Association 2011). Likewise, the national HIV Care Pathway that has been developed to inform the HIV pricing tariff (Department of Health 2011c) has categorised 80% of people with HIV as bio-medically stable (see also Section 1.3.1 for more detail on the HIV Care Pathway). This indicates a national discourse on HIV as a stable condition that places it on the 'healthy' end of the healthy-illness spectrum.

This 'HIV as healthy' narrative is not reflective of how patients in the study viewed their condition and their perceptions of 'self' as a person with HIV and the felt or enacted stigma that permeated their dialogues. This has been shown to influence how they view the role of HIV services and the way that perceptions of 'self' are integral to how they view their overall health status. There is the potential to marginalise some patients who are deemed bio-medically stable and who construct their HIV on very different factors from the dominant discourse of stable HIV infection. This was particularly evident in the narratives of patient participants who highly valued being able to talk about all aspects of their health in the HIV clinics. This ranged from asking about burial regulations for people with HIV to discussing the depressions that many associated with HIV infection. The need to feel accepted as a person with HIV included being able to talk freely about the experience of living with HIV and the opportunity to feel 'normal'. If HIV is exclusively conceptualised around the 'healthy' stable patient, HIV services may lose the ability to respond appropriately to those patients who construct their condition towards the illness end of the spectrum.

Overall however, there were perceived positive and negative consequences of the dominant stable patient narrative that was based on surrogate disease markers as opposed to the individual experiences of people living with HIV. At the 'healthy' part of the spectrum that conceived the stable patient as 'well', this afforded opportunity for less frequent appointments and greater independence from HIV healthcare services. Nevertheless, at the 'illness' end of the spectrum, this dominant narrative has the potential to overlook the way that people with HIV

represent their HIV on both conceptual and emotional levels. This has been illustrated in Figure 9.4 below.

Positive factors	Negative factors
Changes in service delivery models for stable patients may assist patients to conceptualise their condition as more stable	Depletion in the values associated with keeping people engaged in HIV care
Opportunity to promote independence from healthcare services	Disease labelling that does not include the illness representations of HIV patients along a healthy-illness spectrum
Move away from the HIV exceptionalist model to a more integrated model	Potential for one size fits all approach to HIV disease management

Figure 9.4: Positive and negative factors associated with the ‘healthy’ representation of HIV as a stable condition

In the data, there was little apparent conflict between the illness representations of healthcare worker participants and patient participants. Potential conflict was likely to be mitigated by the shared values of the participant groups, although this may not necessarily translate across all HIV services. This illustrates the connection between the values of HIV healthcare that emerged from the data and those that were conceptualised as central to maintaining engagement in HIV care. The properties of supportive relationships, feeling accepted and participating in care were the components of care that reflected longer-term engagement and were believed to contribute to the quality of care outcomes that

are seen at a national level (see Section 1.2.3 for quality of care measures in HIV). This indicates that, in order to maintain these high levels of engagement in care, future HIV services need to respond to a range of patient illness representations as opposed to labelling stable 'healthy' disease based on national categories and bio-medical markers. In other disease areas, recognition and understanding of illness representations of patients by healthcare workers has been shown to improve disease outcomes (Theunissen, de Ridder and Bensing et al. 2003; de Ridder, Theunissen and van Dulmen 2007; Sultan, Attali and Gilberg 2011). This supports an individual approach to assessing the illness representations of HIV patients in order to match the model of care with the way patients view their condition. Where sound patient-provider relationships and partnership working exist, the different constructions of HIV as a chronic condition may not present problems in clinical practice.

However, within the healthcare worker group, there were some tensions around the role of different staff groups in managing HIV as a stable chronic condition. Although the spectrum of healthy-illness representations was conceptualised across all disciplines in HIV, the narratives of nurses and psychosocial workers were generally but not exclusively more focussed on emotional or holistic needs. This was likely to be reflective of their roles and what they viewed as the issues for patients they saw in clinical practice. The roles of nurses in caring for stable patients were largely determined or instigated by medical leads and their representation of HIV on a healthy-illness spectrum. As shown in Chapter 7 and illustrated in Figure 7.4, those medical staff who advocated the de-medicalization of HIV were more likely to support and work collaboratively with nurses in caring

for stable patients. However, the healthy-illness spectrum created a confused picture of HIV as a chronic condition that ranged from perceptions of vulnerability to essentially healthy. This differed from other chronic disease areas where the roles of nurses were more clearly defined in undertaking specific tasks that had not previously been the sole domain of medical staff. This is likely to be reflective of the established nature of other chronic disease areas in comparison to HIV.

The way that patients interacted with HIV services and other healthcare services also appeared to reinforce their illness identity. For example, where patients had negative experiences of other services, this emphasised the need for specialist care and contributed to the way they viewed themselves as a person with HIV. The extent to which patients benchmarked other healthcare experiences against the care they had learned to expect from HIV services was also instrumental in constructing their HIV along a healthy-illness spectrum. Although the factors in benchmarking HIV care were based on quality and approach to care, patients who perceived substandard care in other healthcare settings based this on their perceived need to be treated holistically and with expertise. This extent to which patients perceived their needs as 'special' was grounded in how they constructed their HIV and how they viewed the responses from non-HIV healthcare workers. These factors in benchmarking also informed the values of HIV healthcare that reflected the core aspects of living with HIV in a society where they were often marginalised.

There was a spectrum of views from healthcare workers on the place for HIV disease exceptionalism in the current healthcare climate. The approaches to exceptionalism were connected to how healthcare workers viewed HIV as a stable condition and to the constructed models of HIV representation. For some, exceptionalism was believed to be still relevant for those patients who were perceived as vulnerable. For others, exceptionalism was viewed as an outdated approach to HIV care which reinforced the construction of HIV at the 'illness' end of the healthy-illness spectrum. This illustrates the link between the way that HIV services have been provided and where patients and healthcare workers were positioned on the healthy-illness spectrum.

This theory of the healthy-illness representation of HIV incorporates a range of cognitive and emotional constructions of HIV that differ between patients and between healthcare workers in HIV. It accounts for the way that HIV services had traditionally been provided and the effect on the way that both staff and patients viewed HIV as a chronic condition. The presence of a spectrum of illness representations among staff and patients has the potential to impact on the core values that keep people engaged with HIV care. Figure 9.5 is an illustration of the theory of healthy-illness representation and the connections between the dimensions and properties (also shown as S3.1 at the beginning of the findings section).

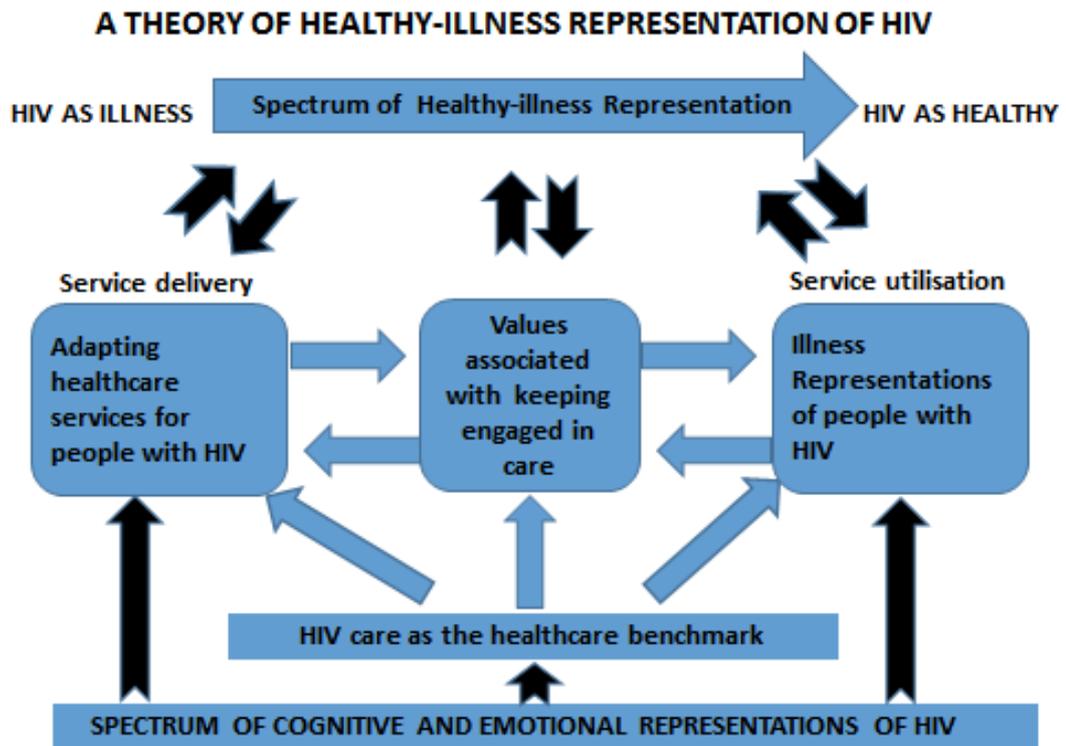


Figure 9.5: Illustration of the theory of healthy-illness representation of HIV

9.3 Summary points on the theory of healthy-illness representation

There were a number of gaps in knowledge identified in HIV healthcare provision in the introductory chapter of this thesis. This section will summarise the extent to which this theory of healthy-illness representation has addressed these gaps in knowledge and how this will assist in informing future HIV healthcare planning. Each subsection will commence with a summary of the gap in knowledge in italics.

9.3.1 Increasing numbers of people with HIV in treatment and care

There was limited primary research into different ways of working and the role of healthcare workers in HIV, particularly nurses, was relatively unexplored in the UK context.

There was evidence in the data that healthcare workers were actively changing the way that services were provided for stable patients in order to release appointment capacity for patients with more complex needs. This was based on the way that healthcare workers constructed HIV as a condition and influenced the way that stable patients perceived their HIV. The spectrum of healthy-illness representations seen in healthcare workers in HIV incorporated the 'healthy' patient who was perceived as 'well' and the more vulnerable socially complex patient who was perceived as being at the 'illness' end of the spectrum. The role of nurses in caring for stable patients was largely based on how medical staff constructed HIV and this affected whether nurses were viewed as substitutes in the care of people with HIV. This theory has highlighted the different underpinning beliefs of HIV as a stable condition that resulted in varied approaches to service delivery models.

9.3.2 Diverse groups of people infected with HIV

There was little empirical evidence on the models of care that are required to meet the future healthcare needs of the diverse groups of people infected with HIV.

The design of the research intended to include a sample that was largely reflective of the national demographics of people with HIV in the UK as shown in Chapter 4. The findings did not indicate that there were differences in illness perceptions between different risk groups, gender, age or length of diagnosis, although this was not specifically measured in this research. The way that patients viewed the future role of HIV services was linked to how they constructed their HIV along a healthy-illness spectrum.

9.3.3 Changing profile of HIV infection

Further understanding of how healthcare workers adapt their practice to respond to the changing needs of people with HIV is required to inform options for future service delivery. In addition, further insight into how HIV patients and services integrate with other healthcare areas is needed to plan cohesive care models.

There was evidence in the data that HIV services were changing in response to the changing profile of HIV. This manifested in offering a range of services for stable patients such as virtual clinics and less frequent face-to-face appointments. At the same time the parameters of the HIV speciality were being extended by working collaboratively with other disease areas. These service changes were informed by the way healthcare workers constructed HIV as a condition and contributed to shaping the way that patients represented their HIV. The spectrum of healthy-illness representations of staff meant that there was a range of approaches to service changes. This substantive theory indicated that the healthy-illness representations of staff were instrumental in either sustaining

or moderating the illness identity of patients. In addition, the way that HIV services have traditionally been provided led to patient expectations of other healthcare encounters that were often not met.

9.3.4 Stable and complex patient categories

HIV patients are now categorised into stable and complex groups. However, it is not known how patients perceive their health status and how this may contribute to optimum service delivery.

The evidence from the data indicates that, although patients may perceive their overall condition as stable, there are a number of other factors that contribute to how they construct their HIV. This theory of healthy-illness representation in HIV proposes a spectrum of illness perceptions among stable patients that drives service expectations and service utilisation. The 'routine' nature of HIV follow-up for patients who are viewed as bio-medically stable does not always reflect how people with HIV represent their condition.

9.3.5 HIV as a long-term condition

At present HIV services are delivered and funded differently from those for other chronic disease areas in the UK. Further understanding of the concept of HIV as a long-term condition will assist in informing the way that services and care are organised.

This theory of healthy-illness representation in HIV highlights the disparity between the way that people with HIV represent their condition and the range of healthcare workers' perceptions of HIV as a chronic condition. This indicated a confused definition of HIV as a chronic condition that resulted in different management approaches towards stable patients. While there were some similarities to other chronic disease conditions in terms of uncertainty and anxiety about reduced contact with specialised services, there were several factors that distinguished HIV from other disease areas. Firstly, there was a strong biographical relationship with the way HIV services had evolved for staff and patients that influenced how they viewed HIV along a healthy-illness spectrum. Secondly, there was a strong element of perceived or enacted stigma in the narratives of patients to the extent that it shaped their identity as a person with HIV. Stigma has been shown to be higher in people with HIV than in many other disease areas. Thirdly, the interactions between patients and their healthcare workers in HIV moved beyond traditional patient-provider relationships and were largely based on the need to feel accepted as a person with HIV. Lastly, the utilisation of multidisciplinary staff roles in HIV services was different from that in other chronic disease areas where there were more consistent definitions of roles across the care pathway. The healthy-illness spectrum of HIV that was conceptualised from the evidence suggests a constantly evolving health condition that has not yet reached the maturity of other long-term conditions.

9.3.6 High prevalence of symptoms and stigma experience

It is not known how these factors relate to the way services are viewed or utilised by HIV patients and how this may affect future planning.

This research has shown that the presence or absence of symptoms and illness experience form part of the way that people with HIV construct their condition. The extent to which these symptoms and illness are perceived to be a problem is linked to the way that patients view future services. Perceived stigma and discrimination were found to be integral to the illness identity of patients. Again the extent to which HIV affected the social integration of patients determined how they viewed the role of HIV services as their main care provider.

9.3.7 Quality of care

There are excellent clinical outcomes and high levels of retention in care within the current model of specialist secondary care provision. However, further exploration of the interactions involved in HIV healthcare is required to understand the factors that may contribute to achieving these outcomes and the implications of this for future care models.

This research has provided further insights into the factors that are integral to maintaining patient engagement in care among a largely stable patient sample in the UK setting. The interactions between patients and their healthcare workers in HIV were instrumental in fulfilling the patient's expressed need to feel accepted

as a person with HIV and in reinforcing a more positive identity for themselves. On the whole this was in contrast to how they were treated in other healthcare settings and by society in general although there was a range of experiences and reactions to this. The perceived interactions between patients and HIV healthcare services largely served to alleviate negative experiences elsewhere that suggest that the reported outcomes and high quality of care in HIV may be a product of the way that services are currently provided. This has significant implications for the future planning of services as low levels of engagement and retention in care have been associated with increased transmission of HIV. Therefore, these quality of care outcomes were viewed as a measure of the balance between the healthy-illness representations of patients and their healthcare workers.

9.3.8 Patient involvement in care

Many people with HIV have traditionally been involved in decisions about their care. It is not clear how this patient-centred model will translate across non-HIV services as utilisation of these services increases.

The evidence indicated that participation in care was a core value for people with HIV but was predominantly associated with established patient-provider relationships and confidence in the knowledge of healthcare providers. As many patients reported negative perceptions of their condition from non-HIV healthcare workers, attempts to work in partnership outside the HIV setting reinforced the 'illness' end of the healthy-illness spectrum.

9.4 Chapter summary

In exploring the interaction between how patients perceive their HIV, and the processes involved in their healthcare, this thesis has developed a substantive theory of healthy-illness representations of HIV. This theory has highlighted an inconsistency in how HIV is viewed as a chronic stable condition from macro, meso and micro perspectives. This is likely to be important in considering the planning of future HIV services and in maintaining high levels of patient engagement in care in the longer-term.

The final section of this thesis will present further discussion on the substantive theory and considerations for future HIV services.

Section 4: Discussion and Implications

The final section of this thesis will discuss the substantive theory in relation to existing theories and present the proposed implications for clinical practice and service delivery. The section will include the limitations of this research and contribution to knowledge that has been made as a result of the research findings.

Chapter 10: Discussion on the theory of healthy-illness representation of HIV

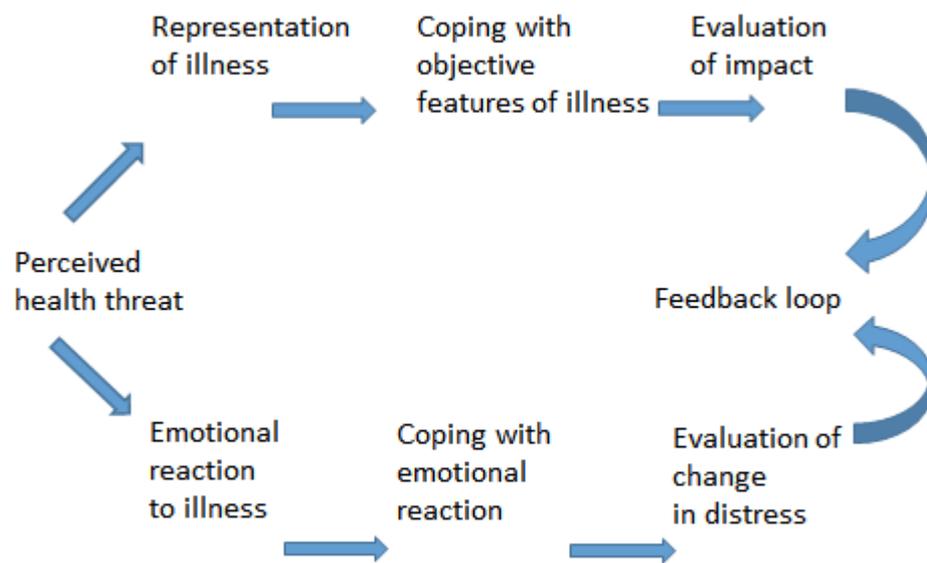
10.0 Introduction to the chapter

This chapter will further discuss the substantive theory of healthy-illness representation in HIV and compare and contrast with existing theories in order to situate the proposed theory within the wider academic domain. The chapter will begin with an introduction to the seminal work on illness representations and proceed to discuss how this theory has been adapted to inform the planning of HIV healthcare services. The key principles of the theory of healthy-illness representation and how they interact with other established sociological theories will then be discussed. Lastly, the potential for further development into formal theory will be explored.

10.1 Adapting the common-sense model of illness representation

Illness representation has been well described in the literature mostly in relation to how patients respond to symptoms and develop adaptive strategies to illness based on cognitive and emotional pathways. The Common Sense Model of Self-

Regulation was first described by Leventhal, Meyer and Nerenz in 1980 after undertaking semi-structured interviews with patients to understand how they perceived various health conditions (Leventhal, Nerenz and Steele 1984; Kemp, Morley and Anderson 1999; Moss-Morris, Weinman and Petrie et al. 2002). The Common Sense Model of Self-Regulation (CSM-SR) is constructed in three stages. This first stage involves the conceptualisation of a health threat along cognitive and emotional pathways and is known as illness representation (Leventhal, Nerenz and Steele 1984; Theunissen, De Ridder and Bensing et al. 2003; Hagger and Orbell 2003; Rozema, Vollink and Lechner 2009). Cognitive pathways are further differentiated into concrete and abstract perceptions of health threats that incorporate five dimensions; *identity*; *timelines/duration*; *controllability*; *cause*; and *consequence* (Leventhal, Nerenz and Steele 1984; Moss-Morris, Weinman and Petrie et al. 2002; Hagger and Orbell 2003). The second stage in the CSM-SR involves the formation of action plans to address the health threat and the third and final stage relates to appraisal of those action plans (Leventhal, Nerenz and Steele 1984; Decruyenaere, Evers-Kiebooms and Welkenhuysen et al. 2000; Reynolds, Sanzero Eller and Nicholas 2009; Breland, Fox and Horowitz et al. 2012). There is a cyclical relationship between the three stages of the model and this theory has been utilised in many disease areas to understand health behaviours and subsequent disease coping strategies (Kemp, Morley and Anderson 1999; Hagger and Orbell 2003; Rozema, Vollink and Lechner 2009). These three stages are processed along both cognitive and emotional pathways simultaneously. Figure 10.1 shows an illustration of the original common-sense model of illness representation described by Leventhal, Nerenz and Steele in 1984.



Adapted from Leventhal, Nerenz and Steele 1984

Figure 10.1: Illustration of the common-sense model of illness representation

This established theory of cognitive illness representation has been widely utilised in the health literature and illness perception questionnaires have been developed in a number of disease areas to identify or evaluate patient coping strategies (Moss-Morris, Weinman and Petrie et al. 2002; Hagger and Orbell 2003; Spirig, Moody and Battegay et al. 2005; Breland, Fox and Horowitz et al. 2012; Phillips, Leventhal and Leventhal 2012).

While the theory of this thesis has been built on the concept of illness representation, it proposes an adaptation of the common-sense model. Illness representation of HIV has not been specifically viewed from a symptom or physical health threat perspective. Instead the first stage of the Common Sense

Model has been utilised as a theoretical structure to conceptualise the relationship between HIV patient perceptions of their healthcare needs and the way they view and utilise healthcare services. Therefore this adapted model focusses more on the abstract (as opposed to concrete) and the emotional representation of HIV as a stable condition. The dimensions of *identity*, *cause*, *timelines/duration*, *consequences* and *controllability* have been applied to the way that patients viewed the role of HIV healthcare and the emotional components involved in this. In addition to patient perceptions, the representation of HIV by healthcare workers has been included and has been viewed as integral to the way that patients construct their HIV as a stable condition. The spectrum of representations observed within the data across both patient and healthcare workers was utilised to develop the adapted model of healthy-illness representation of HIV.

The second stage of the CSM-SR focuses on the coping responses to perceived illness representation. This theory on healthy-illness representations includes the service delivery and service utilisation behaviours of staff and patients and partly addresses coping strategies in this way. However, these behaviours have not been specifically tested or measured at this stage in theory development. The coping strategies that are integral to the CSM-SR have therefore provided some structure with which to view the behaviours associated with the spectrum of illness representation found in the research data.

The concept of illness representation is not new in the field of HIV but has focussed mostly on patient experiences. The role of illness representation has previously been measured in HIV, mostly using questionnaires, in relation to: comparing health beliefs in HIV and Hepatitis C (Krauskopf, McGinn and Federman et al. 2011); self-care management and outcomes (Reynolds, Sonzero Eller and Nicholas et al. 2007); and symptom control and management (Spirig, Moody and Battegay et al. 2005; Vincenzi, Moody and Spirig 2009). The concept of using the illness representations of healthcare workers and patients to inform future service delivery appears relatively unexplored. Therefore, this adapted model may have the potential to contribute to academic theory about the interactions between HIV patients and healthcare services and how these may affect the future organisation and delivery of HIV healthcare.

10.2 Symptoms as part of illness representation

Illness identity is a key concept in illness representation and is related to the label that patients give to a particular symptom or health threat in traditional models of illness cognition. In this theory of healthy-illness representation in HIV, illness identity was perceived as a key factor in how patients viewed their service needs. This was manifested in the data as individual symptoms or illness experience.

The majority of patient participants in this study identified themselves as currently stable with HIV. However, this perception of disease stage in itself did not appear to influence the perceived role of HIV services for patients. The

presence of symptoms, either currently or previously was associated with illness *identity* and with more reliance on specialist HIV services. Conversely, those patients who described minimal symptom experience were more confident about reducing face to face contact with HIV services. This is consistent with illness representation theories where patient recall of previous illness informs their illness *identity* and their individual responses to new or recurrent symptoms (Leventhal, Nerenz and Steele 1984; Lowe, Porter and Snooks 2011). Therefore, those who had symptom or illness experience to draw from had a stronger *identity* associated with their experience of living with HIV.

In other disease areas, illness identity is believed to be stronger where there is a higher profile of symptoms. For example, increased seizure frequency has been shown to shape the illness representation of people with epilepsy (Kemp, Morley and Anderson 1999). In breast cancer, patients who perceived that they had serious symptoms reported more physical and mental health problems than those with lower symptom profiles (Rozema, Vollink and Lechner 2009). Lowe, Porter and Snooks (2011) associated severity of symptoms with increased access to unscheduled care services in a questionnaire-based study using the Brief Illness Perception Questionnaire. This study of 588 people used cluster analysis to analyse service utilisation and concluded that intensity of symptoms and to some extent more chronic illness perceptions led to greater access to healthcare services.

There are many reports in the literature of high symptom prevalence among patients with HIV (Spirig, Moody and Battegay et al. 2005; Harding, Molloy and Easterbrook et al. 2006; Harding and Molloy 2008; Mosack, Weinhardt and Kelly et al. 2009; Vincenzi, Moody and Spirig 2009; Fierz, Nicca and Spirig 2012). Harding, Lampe and Norwood et al. (2009) showed that symptom prevalence in HIV was at times comparable with end stage malignant disease. The same study linked high psychological symptom prevalence to poorer outcomes for adherence and unprotected sexual intercourse (Ibid.). While these studies were aimed at informing service delivery models or designing tools to measure symptoms in HIV, there were no direct associations with service utilisation. Although the research for this thesis did not include specific measures of illness perception, some patients always attributed the *cause* of their symptoms to their HIV. This perceived *cause* was likely to inform their illness *identity* and to account for why many patients in the study were more drawn to the model of HIV specialist services.

Therefore, in keeping with research on illness representation and illness identity, patients with HIV shaped their illness *identity* based on symptom experience and perceived *cause* of illness episodes. This informed their service utilisation behaviours and further testing of the theory of healthy-illness representations may establish how this could be factored into future service planning. Symptoms however were not just viewed on a conceptual level and there was a strong emotional component in the way that patient participants viewed their condition. The following sections will compare the perceived consequences of having HIV on individual and social levels with other academic theories.

10.3 Consequences on future health

In addition to how patients perceived their symptoms and medical stability, their illness identity also consisted of their perceptions of the 'label' of having HIV. This label was conceptualised on two levels: the consequences of having HIV on their future health and the consequences of having HIV on other aspects of their lives.

Disease labelling has been linked to both the 'self' and identity and is believed to be shaped by social interaction (Baumgartner 2007; Kralik, Koch and Eastwood 2003). Baumgartner (2007) believed that in HIV illness identity the concept of 'self' was linked to internal factors and identity to external factors. Thus, this theory of healthy-illness representations in HIV has viewed the *consequences on self* and future health as internal processes and the *consequences on social identity* as a partially external process. This is reflective of a symbolic interactionist belief that individuals develop meaning from the 'self' and from interaction with the society they inhabit (Blumer 1969; Chenitz and Swanson 1986; Benzies and Allen 2001; Klunklin and Greenwood 2006).

In relation to the internal factors of 'self', almost all patients spoke of uncertainty about their future health and the expectation that their health would not always remain stable. The exception to this was the youngest participant who did not consider her future health status. This uncertainty was linked to the perceived *duration* of treatment response and *controllability* of HIV as a long-term condition. *Duration* and *controllability* are concepts used in traditional models of

illness representation to categorise symptom severity (Leventhal, Nerenz and Steele 1984; Moss-Morris, Weinman and Petrie et al. 2002; Hagger and Orbell 2003). In the context of HIV healthcare provision, these concepts were related to how patients viewed their HIV as a condition and how this interacted with the way they utilised services.

In the earlier work on the Common Sense Model of Illness Cognition, Nerenz and Leventhal (1983) proposed a link between illness representation and the 'self' and they conceptualised three groups of people in relation to this:

1. Illness permeates every aspect of living
2. People who 'encapsulate' the illness that only affects certain aspects of their lives
3. Illness free but at risk of recurrence or relapse

While this model is specifically related to episodes of ill health, these are consistent with the concepts of 'self' as a component of HIV disease representation found in this study on HIV healthcare. Although most patients in the HIV study perceived themselves as stable, the uncertainty around *duration* and long-term *controllability* seen in the data was suggestive that they also perceived themselves as being at risk of recurrence or relapse sometime in the future. This is reflective of the *Remission Society* that Arthur Frank conceptualised from people who had successful treatment and were "effectively well but could never be considered cured" (Frank 1995, 9). Frank draws on

Sontag's concepts of the kingdom of the sick and the kingdom of the well and concludes that people with chronic conditions belong to neither of these kingdoms but may move between them throughout the course of their illness (Frank 1995). Uncertainty about future health has been well described by academics in other chronic disease areas (Bury 1982; Charmaz 1994; Bailey, Barroso and Muir et al. 2010) and is believed to be integral to coping and adaptive behaviours. This has also been found in a number of recent studies on HIV. Bravo, Edwards and Rollnick et al. (2010) undertook a qualitative study on the psychosocial needs of people with HIV from a support worker perspective. Their findings from a thematic analysis revealed that people with HIV had difficulty in contemplating a future and this was linked to decisions to start treatment. In a grounded theory study on adapting to HIV Perrett and Biley (2012) identified that 'negotiating uncertainty' was the core concept that underpinned transitional and adaptive strategies in people with HIV.

A meta-analysis of illness representation studies identified that there was a positive relationship between perceived *controllability/cure* of illness with psychological well-being and normal social functioning (Hagger and Orbell 2003). On the other hand, illness *identity*, *timelines* of illness and potential *consequence* of illness were negatively associated with poorer psychological well-being and reduced social functioning (Ibid.). Lowe, Porter and Snooks (2011) also made a link between *identity*, *controllability* and *consequence* in their more recent study on the illness perceptions of unscheduled care in different healthcare settings.

The perceived consequences on future health that were found in this thesis are therefore supported by other studies on illness representation and in people with HIV. The unknown *duration* and long-term *controllability* of HIV on the internal 'self' were believed to form part of the illness representations of people with HIV, even when they viewed their current disease status as stable. This ambiguity in health status with the potential for future ill health reinforced the concept of a spectrum of healthy-illness representation in HIV. These perceived consequences on the self therefore influenced the way that people with HIV engaged with specialist and generic health services and how they responded to perceived changes in health status.

10.4 Consequences of HIV on social integration

As part of the emotional pathway of representing HIV as a condition, patients in this study on HIV healthcare had a range of perceptions of the social consequences of having HIV. This was integral to how they viewed themselves as a person with HIV and their place in society. This section will now discuss the consequences of HIV on the social identity of people with HIV in relation to established theories.

Yanos, Roe and Lysaker (2010) describe illness identity as the individual interpretation of illness that is based on the sociological notion of identity. Illness identity has also been linked to social interaction in several studies in HIV (Baumgartner 2007; Tsarenko and Polonsky 2011). This places the illness representation of people with HIV within a wider social context. Therefore, in

relation to the perceived consequences on social integration, the 'illness' portion of healthy-illness representation was viewed, not as a physical manifestation, but as a psychological component and an absence of holistic good health. For many patients in this study, their HIV was perceived in relation to how it affected the rest of their lives. This manifested in perceived stigma within and towards families, employment and future relationships.

Kralik, Koch and Eastwood (2003, 13) describe identity "as a dynamic process that evolves from an on-going interaction between the individual and (her) social environment". In their qualitative interview study on self, identity and transition in women with multiple sclerosis, they concluded that the way participants viewed themselves was closely linked with how other people responded to them (Ibid.). In a study on epilepsy, using a range of illness representation measures, Kemp, Morley and Anderson (1999) included perceived and enacted stigma to measure perceived consequences of epilepsy diagnosis. Yanos, Roe and Lysaker (2010) linked illness identity with hope and self-esteem in their study on recovery from severe mental health illness. In HIV, a number of studies have suggested that stigma negatively affects illness identity and subsequent integration into mainstream society (Baumgartner 2007; Baumgartner and David 2009; Tsarenko and Polonsky 2011; Fielden, Chapman and Cadell 2011). In a narrative analysis of 18 people with HIV over four years, Baumgartner (2007) showed how people with HIV based their identity on how they were viewed by society. Fielden, Chapman and Cadell (2011) undertook a qualitative enquiry with professionals working with adolescents with HIV. Their thematic analysis indicated that stigma permeated the lives of young people with HIV and resulted in secrecy and

silence (Ibid.). These studies are consistent with the findings from this research on HIV healthcare where there were high levels of perceived stigma that were integral to how participants viewed themselves and their place in society.

There is, however, some contested evidence that stigma is still a relevant concept in HIV. Gill Green (2009) maintains that technological advances in HIV mean that the stigma (or mark) of HIV infection has become hidden and that this has significantly reduced the stigma experience of people with HIV. This belief is based on two studies that were carried out by the author. The first was an interview study with 66 HIV positive people from 1990-1994 and the second a comprehensive literature review on the psychosocial aspects of HIV treatment in 2004. Green (2009) argues that the dramatic response to HIV/AIDS in the 1980s where contagion, deviance and impairment were dominant public narratives, has moved on and that the advent of treatment means “it is clear that HIV-positive people with access to HAART³⁷ have greater opportunities for social and economic participation” (Green 2009, 64). While she acknowledges that public attitudes towards HIV and disclosure remain challenges for people with HIV, she advocates that the ‘public identity’ of people with HIV is now concealed as the visible signs of AIDS have been replaced with the hidden appearance of treated HIV infection. This, in her view, reduces the opportunities for stigmatisation to occur and for people with HIV to be “passing as normal” (Ibid.,70).

³⁷ Highly Active Antiretroviral Therapy or combination therapy. See also glossary.

This theory of Gill Green's is based on the assumption that stigma is rooted in visible impairment and as this is considerably less frequent in people with HIV in the post HAART era she argues that stigma is no longer a useful theoretical concept in HIV. Undoubtedly, the success of treatment in HIV has been a significant achievement. There are indeed less opportunities for stigma to occur as it is hard to identify a person with HIV by merely looking at them. However, this debate is more centred on how stigma is viewed as a theoretical concept. Parker and Aggleton (2003) view stigma as a social process and propose that the origins or history of stigma are an important part of understanding how stigma is produced. They suggest that stigma is enacted to promote social exclusion and that it involves an interaction between "culture, power and difference" (Parker and Aggleton 2003, 17). Granted, in the UK that "difference" may be less visible than in other epidemics as the majority of people known to be HIV positive are treated and can appear visibly 'well'. However, the essence of stigmatisation as a social process is the way in which it generates internalisation of negative identities in those who are stigmatised (Parker and Aggleton 2003; Fielden, Chapman and Cadell 2011). This social theory incorporates the work of Goffman on 'spoiled identity' and of Foucault on power. The process of stigmatising those with 'spoiled identity' leads to concealment of the object of stigma and avoidance of further negative reactions thereby compounding social isolation (Dodds, Keogh and Chime et al. 2004; Fielden, Chapman and Cadell 2011). This process of stigmatisation has also been found to exist within communities of high HIV prevalence, such as in men who have sex with men (Smit, Brady and Carter et al. 2012). This extensive literature review found that HIV negative gay men felt that their communities were threatened by HIV

positive gay men who they held responsible for becoming infected with HIV (Ibid.).

Thus, if stigma is viewed as a social process that serves to reinforce the dominant accepted social norms, the very nature of HIV being hidden, as proposed by Green, further marginalises people with HIV. The healthy presentation of HIV may reduce opportunities for stigma to occur but the very fact that concealment is seen as protective indicates a negative social perception. The concept of secrecy was evident in the research data with some still referring to HIV as a “dirty secret” and evidence has been presented on how this concealment affected community integration for participants in the research. The healthy face of HIV does not necessarily reduce stigma and/or discrimination; it just removes it from the public dialogue. People with HIV do indeed have “greater opportunities for social and economic participation” due to advances in HIV treatment (Green 2009, 64), but this appears to come at a cost and more importantly appears to be integral to their illness identity and how they view themselves as part of wider society. The higher rate of perceived stigma compared to enacted stigma in study participants suggests that an internalisation process is occurring and this is well recognised in HIV stigma and in other disease areas such as mental health and diabetes (Shiu, Kwan and Wong 2002; Baumgartner 2007; Baumgartner and David 2009; Yanos, Roe and Lysaker 2010; Tsarenko and Polonsky 2011; Fielden, Chapman and Cadell 2011).

Gill Green's argument, that stigma as a theoretical position is no longer useful for HIV in the UK today, is perhaps a few years premature. The narratives of participants in this thesis strongly suggest that stigma remains an undercurrent in the identities of many people with HIV and that this influences their perception of patient-provider relationships and engagement in treatment and care.

This social identity as part of the healthy-illness representation of people with HIV may also explain the attachment to HIV services that some patients expressed. The concept of attachment styles in HIV has been explored elsewhere and has been associated with different levels of social support (Hinnen, Schreuder and Jong et al. 2012). This questionnaire study from The Netherlands concluded that people with HIV who were secure in their attachment style had less need for social intervention support (Ibid.). This suggests that the attachment and need to feel accepted by participants in this thesis research was largely fulfilled through HIV services, but perhaps to the detriment of their social integration. Many felt secure and safe in HIV services but less so in other settings. In social interaction theory, individuals are involved in mutual reinforcement where behaviour is rewarded or punished (Scott 2000). While any behaviour has the potential to reinforce the behaviour of another, approval is considered by some to be the most fundamental human aim (Scott 2000). This approval appeared to be inherent in the relationships between HIV healthcare providers and people with HIV and was evidenced in the dialogues of all participants. While, on the one hand, this was a positive interaction that led to patients feeling accepted, it may have further reinforced the negative identity of patients within mainstream society and non-HIV healthcare settings. The more

an identity is reinforced, the more it becomes embedded within individual explanatory models (Baumgartner 2007). The positive identity that patients in the study developed through their interactions with HIV services became embedded in how they viewed themselves. The negative experiences within other healthcare services and society further reinforced the need for specialist HIV healthcare.

Thus, the perceived consequences of HIV on social integration that were seen in the data were largely underpinned by perceived stigma and were partially mitigated by the relationships that patients had with HIV services. This strongly influenced the way that patients viewed the role of HIV services and their expectations of their future healthcare provision.

The illness representations of patients have been viewed as a combination of both cognitive and emotional representations of HIV because of the inter-relationship between physical presentation and psychological components. This approach is consistent with previous studies on illness representation where cognitive and emotional pathways have been viewed and measured as parallel processes (Leventhal, Nerenz and Steele 1984; Hagger and Orbell 2003; Rozema, Vollink and Lechner 2009). The presence of a spectrum of healthy-illness representation within the patient group may be helpful in identifying the strategies required to empower patients to integrate with other healthcare services and society in general. For example, those patients who remained strongly attached to HIV services may benefit from interventions that build their

confidence in accessing non-HIV services. Likewise, further programmes in tackling and addressing HIV-related stigma may assist in mediating the strong bond with HIV services and promote further integration with the wider healthcare climate and society as a whole.

However, the perceptions of healthcare workers were also a factor in how HIV was represented along a healthy-illness spectrum and the next section will discuss this in relation to relevant literature in the field.

10.5 Healthcare workers representation of HIV

This study on HIV healthcare provision has shown a strong relationship between the ways that healthcare workers construct HIV as a long-term condition and how services were planned and delivered. This also manifested along a spectrum of illness representation that ranged from perceptions of vulnerability to the essentially well person with HIV. Although there was some congruence between how healthcare workers viewed HIV and how patients perceived their needs, the underpinning beliefs on HIV as a chronic condition were largely based on different priorities. This section will explore this further in relation to existing academic theories on the relationship between healthcare workers and illness representation.

The Common Sense Model of Illness Representation has been used successfully in understanding the health beliefs of patients and in directing

healthcare workers to address the patients' representation of their illness to improve self-care and health outcomes. Some studies have used the cognitive markers of identity cause, consequence, controllability and duration to compare patient perceptions with biomedical models of illness in a similar vein to this study on HIV healthcare (Krauskopf, McGinn and Federman et al. 2011). Other studies using the Common Sense Model with healthcare workers have focussed on measuring the impact of addressing illness representations on patient behaviours and patient self-regulation. For example, Phillips, Leventhal and Leventhal (2012) measured healthcare worker approaches to promoting adherence to medication and concluded that the assessment of patient illness representation in clinical practice was more effective in facilitating adherence than the use of good interpersonal skills. This has also been shown in studies on the patient health beliefs associated with HIV treatment decisions (Horne, Cooper Gellaitry et al. 2007). Higher levels of patient satisfaction with care has been shown in studies where healthcare workers actively assess and address the individual illness representation of patients (Sultan, Attali and Gilberg 2011; Phillips, Leventhal and Leventhal 2012).

The practice of addressing illness representations in clinical practice has been shown to influence patient self-care strategies and health outcomes in other studies (Theunissen, de Ridder and Bensing et al. 2003; de Ridder, Theunissen and van Dulmen 2007; Sultan, Attali and Gilberg et al. 2011). Although there was no evidence that the illness representations were consciously being addressed in this thesis research, there were some shared representations along a healthy-illness spectrum. This may account for the high levels of satisfaction with HIV

care and indicates that there was sufficient variety in the way that services were provided to meet the spectrum of needs identified in the data. This again suggests that the current model of HIV care provision is effective in meeting the individual illness representations of people with HIV.

There are, however, criticisms of using the Common Sense Model of Self-Regulation for understanding healthcare worker behaviours. Eccles, Grimshaw and MacLennan et al. (2012) undertook a study on the relevance of five theoretical models in measuring clinical behaviour in healthcare professionals. The illness representation questions related to specific clinical activities and the emotional response of doctors to those clinical presentations (Eccles, Grimshaw and MacLennan et al. 2012). The authors concluded that the Common Sense Model was the least effective theoretical model for evaluating clinical behaviour and advised the use of other models such as Social Cognition Theory and Theory of Planned Behaviour.

However, the Common Sense Model of Self-Regulation was not designed to measure clinical behaviour that may be governed by additional factors. It is, instead, designed to measure illness perception and subsequent coping strategies that are distinctive from the behaviour of trained clinicians. It may be that the way that services are planned and delivered by healthcare workers is more reflective of the illness representations of healthcare workers than clinical practice is.

The seminal work by Leventhal and his colleagues referred to the role of healthcare organisations in contributing to the way illness is represented by patients (Leventhal, Neretz and Steele 1984). Green (2009) suggests that way healthcare services responded to people with HIV at the beginning of the epidemic may have contributed to how they viewed their healthcare needs. This is likely to be of particular relevance when new HIV funding mechanisms come into place in 2013-2014 (see Section 1.3.1). At a macro level, the dominant discourse of HIV care is based on the concept of the stable HIV patient that has been constructed on surrogate disease markers and the absence of active health issues (Department of Health 2012b). The consequence of this is that 80% of people with HIV are estimated to be stable within this definition and financial tariffs have been formulated based on this premise (Ibid.). This macro representation is not reflective of how participants in this HIV healthcare study viewed their condition and could have a detrimental effect on their care if funding is based solely on the perceived medical needs of patients.

This disparity in disease representation between healthcare bodies and patients has been played out in other disease areas in various ways. For example, the needs of cancer survivors were not met through “a one size fits all approach to follow-up” (Department of Health, Macmillan Cancer Support and NHS Improvement 2010, 7). This resulted in the recent National Cancer Survivorship Initiative developing an individualised care planning approach that includes the whole illness experience of cancer survivors (Ibid). In contrast, the classification of diabetes as a long-term condition and subsequent devolvement to primary care (Department of Health 2005a), has not been successful in meeting the

baseline health or psychosocial needs of people with diabetes (Diabetes UK 2012). What this illustrates is a stark difference in the way that health conditions are constructed at a macro level and it suggests that there may be a link with the way that health planners conceptualise specific disease areas.

10.6 Ascribed or achieved status of the stable HIV patient

The success of HIV treatment is something to be celebrated and the fact that discussions about long-term service provision are now taking place is testament to the availability and success of treatment for HIV. The dialogue has firmly changed from terminal care to long-term disease management. This thesis indicates that people with HIV do not perceive their condition in terms of physical stability but in relation to their overall experience of living with HIV. Their perception of 'routine' care is entangled with how they perceive themselves as a person with HIV and their integration with society as a whole. This disparity in how HIV is represented at macro and micro levels may influence how people with HIV develop their identities. Social identity theory suggests that the behaviour of people is directed by the groups that they belong to (Herriot 2007) but this will depend on whether membership of those groups is 'ascribed' or 'achieved' (Aggleton 1990). The construction of illness identity is often influenced by prevailing stereotypes (Aggleton 1990) and it is possible that the 'ascribed' stable status of some people with HIV does not necessarily reflect how they perceive themselves or how they perceive they are viewed by others. Patient perceptions can create very different illness constructions from the macro

dialogue and as Frank states “more is involved in their experiences than the medical story can tell” (Frank, 1995, 6).

The master status of HIV as a long-term condition is still being defined at this stage in the HIV epidemic in the UK. Long-term change implies choosing from a range of identities (Cassidy and Trew 2001), so perhaps in terms of future service planning, the focus needs to be on supporting patients to reach an ‘achieved’ status of holistic stability as opposed to an ‘ascribed’ status based largely on biomedical disease markers.

10.7 Further development of the theory

This theory of healthy-illness representation of HIV is a substantive theory on the way that patients and healthcare workers perceive HIV as a stable condition and how this affects the way that healthcare services are utilised and delivered. While further testing of this theory is required in practice, it may serve to inform service planning to some extent. However, in order to contribute to formal sociological theory, abstraction from the field of HIV and healthcare is required. The sociological issues that have emerged from this research include how behaviours are underpinned by values and beliefs and shared perspectives on an entity in transition. There is some resonance with theories of practice, a formal theory on social change and the relationship between micro and macro interests in transition (Shove, Pantzar and Watson 2012). This will require further exploration, data interrogation and testing in the field to establish theoretical fit with the findings of this thesis.

10.8 Chapter summary

This chapter has discussed the theory of healthy-illness representation of HIV in relation to established sociological theories. The key components of the substantive theory have been compared with conventional models of illness representation across a number of disease areas. The chapter has demonstrated how the concept of healthy-illness representation in HIV is supported by previous research and academic theories on the cognitive and emotional representation of illness from both patient and healthcare worker perspectives.

The following chapter will conclude this thesis and will include the specific contribution to knowledge and identify considerations for future service planning.

Chapter 11: Contributions, considerations and conclusions

11.0 Introduction to the chapter

This final chapter will explore the contribution to knowledge that has been made by undertaking this research and developing a theory on healthy-illness representation of HIV in the UK. The implications for future HIV healthcare delivery will then be explored. The chapter will conclude with the limitations of the study and reflections on undertaking the research.

11.1 Contribution to knowledge

In order to address the gaps in knowledge that were identified in section 1.4, there was a need to discover what underpinned the phenomena of HIV healthcare. The aim of this thesis was to generate a theory that explains what was involved in receiving and delivering HIV healthcare to inform future models of care delivery. The research examined the interaction between the perceived needs of adults with HIV and the processes involved in their care were explored using a grounded theory methodology and dimensional analysis strategy.

11.1.2 Contribution to established theories of illness representation

The substantive theory has illuminated a spectrum of illness representation that specifically related to HIV and that indicated a connection with the way services

were planned by healthcare workers and utilised by patients. This theory adds to the body of existing knowledge on illness representation in the following ways. It:

- Identifies that medically stable people with HIV experience their condition on cognitive and emotional levels that affect their concept of being healthy despite their chronic illness label. This affects how they represent themselves and how they feel the illness is represented to the wider society
- Illuminates a spectrum of illness representation along a health-illness continuum. Where the patient is situated on this spectrum affects how HIV patients view the role of healthcare services and which services they choose to use
- Introduces the concept that healthcare worker, like patients, view HIV along a healthy-illness spectrum. How the disease is represented affects the way in which services are planned and how various health care worker roles can be adapted, developed and deployed
- Demonstrates how Leventhal's Common Sense Model of Illness Cognition may be adapted to understand how patients view their healthcare services in meeting their perceived needs

This substantive theory of the healthy-illness representation of HIV has the potential to increase our understanding of how patients perceive their condition and how this may drive their expectations of healthcare services. The disease representations of healthcare workers have highlighted how staff perceptions can underpin the way that clinical practice is adapted to meet changing needs. While this theory remains substantive and specifically relates to the field of HIV healthcare, the adaptation of existing models of illness representation has

enabled a comparison with a number of other chronic health conditions. This has assisted in situating HIV alongside other chronic disease areas within the wider healthcare context.

11.1.3 Contribution to knowledge in the field of HIV healthcare

In addition to its contribution to illness representation theories, this thesis has uncovered several factors that relate to the phenomenon of HIV healthcare in the UK. These factors are; perceptions of HIV as a stable condition; engagement in care and stigma. These theoretical elements may help to inform the future planning of HIV healthcare within the context of a changing healthcare climate.

HIV as a stable condition

HIV as a stable condition was perceived differently at micro, meso and macro levels of healthcare provision along a healthy-illness spectrum. The dominant discourse of HIV as a largely stable infection was based on biomedical disease markers and was not reflective of the way that patients perceived themselves as a person with HIV. Patients represented their condition based on symptom identity and experience and on the physical and social consequences of living with HIV. This strongly influenced their views on the role of HIV services in their healthcare and their reliance on specialist HIV healthcare staff. This contribution to knowledge has the potential to assist in planning a range of services to meet the spectrum of needs for medically stable HIV patients. The psychosocial component within this spectrum of need supports a multidisciplinary approach to

care provision that includes medical, nursing and other health and social care roles.

Engagement in care

The findings in this thesis have highlighted the values inherent in HIV healthcare that strongly influenced the engagement and retention of largely stable patients in HIV healthcare services. Supportive relationships, feeling accepted and participating in care were key factors that shaped patients' perceptions of their physical and psychosocial needs and how they would engage with the service to address their illness concerns. These factors could assist in relating HIV quality of care measures to the way that designated HIV services are organised. Further, these findings are indicative of the need for a specialist approach to HIV disease management.

While these factors seem to have evolved from the early models of HIV care delivery and there was a spectrum of reliance on them, they remained essential components of care for patients. This contribution to knowledge could inform the future configuration of HIV services with respect to maintaining high levels of engagement in HIV treatment and care in the interests of the wider public health agenda.

Stigma

Although stigma is a well-recognised concept in HIV, this thesis adds further insights into the role of stigma in informing patients' perceptions of their healthcare needs and the role of HIV services. In spite of the technological advances in HIV treatment and the less visible mark of HIV/AIDS, the end of HIV stigma was not evident in the narratives of patients or healthcare workers. Felt and enacted stigma were common and presented challenges in disclosing and developing new relationships with other healthcare workers outside the HIV setting. Stigma was viewed as an emotional component in patient illness representation that drove their preferences in accessing healthcare services. This contribution to knowledge highlights the need to consider social and internalised stigma and how this might be addressed in the way healthcare services are planned and delivered for people with HIV.

The work of this thesis and the substantive theory of the healthy-illness representation of HIV have contributed to the knowledge base on theories of illness representation and in relation to HIV as a chronic stable condition. The next section will consider the implications of these findings for the planning and organisation of HIV services.

11.2 Implications for HIV healthcare delivery

This theory of the healthy-illness representations of HIV has been presented as an evolving theory concerning the delivery and utilisation of HIV healthcare

services. This section will give an overview of the potential implications for future planning that have been highlighted through the development of this theory.

11.2.1 Specialist model of care

Firstly, the needs of people with HIV do not necessarily reflect the needs of patients with other chronic conditions and caution will need to be exercised in adapting existing long-term condition models. Throughout this thesis, HIV has been shown to differ from other chronic disease areas in a number of ways and service planning will need to focus on the specific needs of people with HIV as opposed to replicating generic chronic disease templates. The association between patient expectations and values and the HIV quality of care outcomes (Health Protection Agency 2012) have highlighted the importance of keeping HIV within a specialist model of care at the present time. Likewise, the expressed need for patients to feel accepted by healthcare workers and the negative experiences of care outside the HIV setting suggest that further training on HIV care is required in generic healthcare environments. The provision of joint clinics by HIV services and other specialist areas as well as liaison roles with general practice may assist in promoting increased integration and education at this stage in the evolution of HIV healthcare.

11.2.2 Sustainability of current model

The sustainability of the current model of HIV specialist care is likely to depend on the ability of services to diversify and to identify the best use of resources to meet the needs of patients who are essentially medically stable. The high

psychosocial component in the way that HIV patients represent their HIV is strongly suggestive of a multi-disciplinary model of care that includes utilising the skills of nurses in supporting and empowering patients to build confidence in managing some aspects of their condition. This is in keeping with the early chronic disease models that have evolved in other areas (Gee 2004; Woodward, Wallymahmed and Wilding et al. 2006; Gosden, Winocourt and Walton et al. 2009) and could assist in supporting the continuation of an HIV specialist model in a more cost effective way. The direct commissioning of HIV nursing services, whether at advanced practice level or otherwise, would supplement the dominant approach of medical commissioning and nurture a more multi-disciplinary and psychosocial approach to care provision at a macro level.

The fragmentation of funding streams for HIV presents some challenges in meeting the holistic needs of patients across service providers. Consideration could be given to the inception of national HIV commissioning strategy that incorporates commissioning across pathways of HIV care to preserve the current standard of quality of care outcomes.

11.2.3 Assessing patient illness representations

This theory of the healthy-illness representation of HIV has highlighted the potential disparity between the way that patients view their condition and the way that services are funded and delivered. In order to respond to the spectrum of needs for stable patients, it may be beneficial to assess the individual illness representations of HIV patients and provide a range of services to meet these

needs. The development of illness representation assessment criteria for HIV patients could assist in matching service delivery options with the perceived needs of patients. The latter could also assist in identifying a plan of care to support and empower individual patients to move from the illness end of the spectrum towards a more healthy disease representation.

11.2.4 Stigma reduction

Stigma and discrimination seemed to play a significant role in the way that people with HIV viewed themselves and the value they place on the role of HIV services. As the parameters of HIV infection widen to include co-morbidities and co-infections, further integration of HIV healthcare within the wider health environment will be required to meet the needs of patients. A national strategy to address HIV stigma among healthcare workers and in society would greatly assist in creating a more conducive environment for people with HIV to achieve their full health and social potential. A summary of the theoretical components of HIV healthy-illness representation and the potential implications for future service delivery is given in Figure 11.1 that is continued over the page.

Theoretical components of healthy-illness representation	Considerations for future service delivery
The legacy of HIV healthcare has created patient expectations of a high standard of care and contributes to the cognitive and emotional representation of their well-being despite their HIV status / diagnosis	Education of non-HIV healthcare workers Joint working with other healthcare settings

Figure 11.1: Summary of considerations for future care (part 1)

Theoretical components of healthy-illness representation	Considerations for future service delivery
Spectrum of healthy-illness representation among adults who were medically stable with HIV	<p>Assessment of individual patient illness representations to identify need</p> <p>Provision of a range of service models for stable patients</p> <p>Supporting patients to develop self-care strategies to create confidence in managing some aspects of their condition</p>
Psychosocial components are inherent in the way that people with HIV view themselves along a healthy-illness spectrum	<p>Utilise a range of staff groups that reflect the psychosocial aspects of care</p> <p>Increased utilisation of nursing roles in the routine care of stable patients</p>
Supportive relationships, feeling accepted and participating in care are core values for people with HIV and linked with maintaining engagement in care	<p>Maintain HIV services within a specialist service setting</p> <p>Support patients to develop skills in building relationships with other healthcare providers</p>
Felt or enacted stigma is integral to the way that people with HIV view themselves and their healthcare needs	Education and training among healthcare workers and sections of society to address stigma and to help patients overcome stigmatic self- image
Healthcare workers in HIV perceive HIV as a stable condition along a healthy-illness spectrum and plan services in relation to this	Workforce planning at a national level that reflects the spectrum of need identified by patients with HIV

Figure 11.1: Summary of considerations for future care (part 2)

11.3 Limitations of the research

This substantive theory on illness representation in medically stable patients with HIV requires further comparison (testing) in different patients groups. This includes further theoretical sampling of patients such as those who are more recently diagnosed with HIV and more patients who have engaged with virtual results services.

The selection of three sites across diverse geographical locations and service structures was helpful in identifying cases for comparison. However, for practical reasons, the site visits had to be planned in advance over fixed time periods and this may have influenced an optimal approach to theoretical sampling. Participants were therefore selected from those who were available for theoretical sampling and able to attend an interview when the researcher was present in the field.

A significant majority of patient participants were very satisfied with their care and perhaps had a vested interest in maintaining the current standard. Although there was concurrent open recruitment on each site, those who came forward for the study may not be representative of the illness perceptions of the wider population with HIV. Further testing with a larger group of patients will assist in developing the theoretical concepts across a wider sample. It may also be beneficial to explore patients who have disengaged with virtual clinics and to test the strength of the healthy illness theory with this group. The exclusion of patients who were dying and acutely unwell may have influenced the parameters

of the proposed healthy-illness spectrum. Further investigation of the illness perceptions of this group in relation to service utilisation may contribute to defining the spectrum of HIV illness representation across whole patient pathway.

The range of healthcare worker roles was directed by theoretical sampling and therefore did not include all staff groups who work in HIV. Although some non-HIV specialists were included, they were all keen to work with HIV services and may not reflect the views of healthcare workers who are less inclined to become involved in the care of HIV patients.

Finally, the development of this theory did not include measures of specific aspects of illness representation such as symptom occurrence scales or social integration. Further research is required to identify the spread of patients across the proposed illness representation models.

11.4 Reflections on the research

My intention in undertaking this research was to understand 'what is involved' in the field of HIV healthcare from the perspectives of people with HIV and healthcare workers. I set out to explore how patients viewed the role of HIV services, how HIV was perceived as a long-term condition and the interactions, processes and changes involved in HIV healthcare. Choosing a grounded theory methodology enabled me to drill down into the main concerns of patients and

healthcare workers and deconstruct the components of HIV healthcare. This process challenged my perceptions and underlying assumptions in relation to HIV healthcare in a number of ways.

Firstly, when I asked patient participants about their healthcare, they told me about their lives with HIV. Some patients spoke of how they had acquired HIV and most spoke of their HIV diagnosis, irrespective of how long ago this occurred. They talked about relationships, having babies and going to the dentist. I learnt that, however I framed the questions about the interactions and processes in their care, their narratives were always about their holistic experience of living with HIV and there was no explicit separation of their healthcare needs from this. I did not expect to find this to such an extent across the patient participant group and this focussed my thinking on the way that healthcare services can compartmentalise illness in isolation from the wider determinants of health. This expression of health as a holistic entity is likely to present challenges in providing joined-up services that are responsive to the range of issues experienced by people with HIV and that are conceptually integrated with health and well-being. The recognition and verification of this with participants was instrumental in informing the theoretical sampling strategy for healthcare workers and in exploring how their operational philosophies were connected with the fundamental perceptions of people with HIV in this study.

Secondly, as a clinical nurse, I was aware of the stigma that people with HIV can and have experienced although this was only raised on occasion during clinic

appointments and less so in the past few years. As a result, I was quite shocked at the blatant discrimination that was reported by some patient participants and even more so when I learned how recently these events had occurred. I was also surprised to discover the degree to which perceived stigma was an inherent factor in the lives of people with HIV 30 years after the first case reports of AIDS. This really highlighted the strength of a research approach in bringing these issues to the surface. The stories and accounts I heard from patients were very different to those I heard in routine clinic appointments where, in my experience, they would discuss concerns of this nature only if they were dominant issues. The concept of stigma and social isolation as an underpinning factor in the way that people with HIV view themselves and the role of HIV services was not something I had expected to emerge in a group of patients who were largely medically stable and relatively self-reliant. This factor needs significant consideration with regard to the way services are planned in the longer term.

When I embarked on this research, I did so as a nurse clinician who had been actively involved in delivering and developing nursing practice for people with HIV. I made an underlying assumption that nurses were part of the solution to the issues facing HIV services but this was difficult to articulate and to quantify within the domain of evidence based care. The process of using grounded theory and dimensional analysis enabled me to step back from this perspective and explore the phenomenon of HIV healthcare from a more neutral position. This required a considerable philosophical paradigm shift from searching for a single truth towards a more constructivist position that integrated multiple interpretations of reality from the data. The use of multiple perspectives in the

sampling greatly assisted with this and cycles of abduction and deduction helped with creating sociological distance from my original assumptions. I undertook this research on a full-time basis and was not in clinical practice for the duration of the project. Although this removed me from a familiar clinical environment, it enabled total immersion in the data and the perceptions of the participants. This process, alongside the use of constant comparative analysis, a reflexive diary and an explanatory matrix subsequently diluted my assumptions and facilitated a macro representation that moved beyond my perspective as a nurse in the field of HIV.

This shift in my underlying assumptions created challenges when reviewing my research objectives and resulted in reframing my approach to the research from a more multidisciplinary perspective which included nurses. Although my research goals clearly remained the same, the way I viewed them changed as the underlying concerns of participants were revealed through data analysis, theoretical sampling and theoretical integration.

Throughout data collection and analysis, I also utilised a chronic disease lens to view the data. This highlighted the differences in HIV as a long-term condition and helped to situate HIV within a chronic disease paradigm. This lens was particularly valuable in exploring the components of care and highlighting better use of resources and skills in HIV healthcare.

At the later stages of writing up my theory of healthy-illness representations in HIV, I returned to my role as a nurse consultant and was again challenged in relating the theory to the realities of clinical practice. This experience further highlighted the spectrum of approaches to delivering services for stable patients and the different ways in which healthcare workers conceptualised HIV as a stable condition. In addition, this return to practice further developed my thinking around the range of services required to meet the diversity of need across this group of patients.

While my intention was always to include patient participants as part of the study, they became central to the development of theory. It was further data interrogation and verification of the perspectives of patients that provided the key to seeing healthy-illness representation as a development of the central organising perspective. Although I had expected that the perceived needs of patients would inform the overall theory, they in fact functioned as a pivotal conceptual lever which unlocked the connections between the data categories. In this sense, it feels absolutely appropriate that any theory on HIV healthcare should be constructed around the experiences of people with HIV.

During the course of the research, I had many discussions with colleagues around what constituted a healthcare need and how this differed from wants or desires. This is an important consideration in a financially challenged healthcare environment. Thus, need was viewed in terms of the capacity to benefit within a holistic definition of health and not merely the absence of disease. There was an

observed capacity to benefit in relation to patient interaction with other healthcare services and with perceived social integration. There was also a capacity to benefit from sustaining the HIV quality of care measures that have been identified nationally and in relation to wider public health interests. This theory of how healthy-illness representations may be utilised to inform future healthcare for people with HIV is not intended to represent utopia or idealism in healthcare provision. It is, instead, anticipated that this theory will assist in identifying the strategies required to promote and support patient self-sufficiency and in developing a sustainable healthcare environment that reflects the spectrum of needs of people with HIV.

11.5 Conclusion

This thesis has presented what is known about HIV healthcare delivery in the UK and identified gaps in knowledge that relate to the future planning of healthcare services as HIV evolves into a more chronic health condition. The emergent grounded theory placed illness representations as the central influence on how both patients and healthcare workers construct HIV as a condition and subsequently on how HIV services were viewed, utilised and delivered. For future models to succeed in meeting the needs of people with HIV, a balance between preserving the values of HIV healthcare and delivering a range of stable patient services will be required to maintain long-term engagement and retention in care.

This thesis concludes with an extract from a video transcript of a speech by Annmarie Byrne given to the Health Select Committee on HIV/AIDS on 8th October 2011. This quote captures the essence of living with HIV and the difference between this and other health conditions.

“Doctors keep on saying; people keep on saying these days this [HIV] is a manageable condition much like diabetes. But I have yet to meet a doctor who says to a person with diabetes ‘don’t worry it’s no worse than having HIV’! And until that actually happens I don’t think that things have changed very much. And also people with diabetes don’t find that people don’t want to kiss them or have sex with them or share the cups that they use and so on. So it is a very very different condition and while it is manageable it is definitely a social a huge social condition. You wouldn’t have a problem telling somebody you were diabetic you would definitely think twice about telling somebody that you are HIV positive. And why should that be? I mean if I was standing here today saying I had breast cancer, I would expect so much love and support from everybody. And the fact that I’m HIV, it’s a virus, it’s not a moral judgement but that’s the way it’s seen”

Annmarie Byrne, Body and Soul, a charity for children and young people with HIV.

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Appendices

Appendix 1	Site invitation letter	2 pages
Appendix 2	Participant information leaflet for patients	2 pages
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Appendix 5	Study site questionnaire	2 pages
Appendix 6	Recruitment e-mail for healthcare workers	1 page
Appendix 7	Nursing role survey	1 page



To: HIV Clinical /Research Lead.

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Date: 16th November 2010

Dear

Title of Study: Models of HIV Care in the UK

Thank you for your interest in the Models of HIV Care study.

This research is for a PhD project that I am undertaking as a full time 3-year secondment from the HIV Team in Brighton. The study aims to explore models of HIV healthcare to respond to the evolving needs of people with HIV infection. I enclose a study outline and a short C.V. for your information.

If you agree to participate in this research your team will be asked to identify and initially approach patients who fulfil the eligibility and purposive sampling criteria during the recruitment periods when I will be on site. I will undertake the recruitment of potential participants and obtain written consent. In addition, I will require your assistance in identifying potential healthcare worker participants who I will then contact by letter/e-mail. I will also need access to an interview room for data collection, preferably within in your clinic or a networked location.

As an ethics application is currently in progress, it is anticipated that recruitment and data collection will start in the study sites in spring 2011 and will last for intermittent periods of 1-2 weeks over a maximum period of 18 months. Precise dates will be negotiated following ethics and R&D approval if you would like to be involved in this project. Participating sites will have the opportunity to contribute to development of future models of HIV healthcare delivery and will have access to the study results prior to publication.

I would be grateful if you could contact me by letter or e-mail if you choose to participate in this research and I will send a short study questionnaire for your completion.

Please don't hesitate to contact me if you have any questions or if you wish to discuss this proposal further.

Eileen Nixon

PhD/MPhil Student/ HIV Nurse Consultant

CC: Nursing Leads



Title of Study: Models of HIV Care in the UK

Chief Investigator: Eileen Nixon, PhD/M Phil Student at University of Brighton currently seconded from the HIV team at Brighton and Sussex University Hospitals.

Background:

The majority of HIV healthcare is delivered through specialised HIV Clinics based in secondary care settings. In light of increased life expectancy of people with HIV and the growing spectrum of HIV disease, there is a need to consider different ways of working to address the long-term care needs of people with HIV. There is limited primary research in the UK on multidisciplinary models of HIV healthcare to inform future service delivery.

Aims of research:

To explore current models of HIV healthcare delivery and to develop a model for future HIV healthcare provision across health sectors that reflects the evolving needs of people with HIV.

Primary research questions

1. How do HIV patients view their current and future care needs?
2. How do healthcare workers in HIV adapt the way they provide care to meet the changing needs of HIV patients?

Secondary research question

What is the role for HIV nurses in response to the ongoing needs of people with HIV?

Methodology

A qualitative grounded theory methodology will be used to build a theoretical model of HIV healthcare delivery using emerging data from semi structured interviews with both patients and healthcare providers across primary, secondary and third sector sites. Participants will be recruited from 3 HIV service sites across England. Patients >18 years of age across all HIV disease stages will be eligible and purposive sampling will be undertaken across age, risk and disease groups. Patients diagnosed in the last 6 months or who have been admitted to hospital in the last month or with a life expectancy of < 3 months will be excluded from the study. Initially 10 patients will be recruited from each site. Additional purposive sampling will target key roles/services such as clinics for routine stable patients, community posts, nurse specialists, pharmacy and medical staff to a maximum of 10 staff posts per site. Participants will be invited to attend one or two interviews of 60 minutes duration.

Transcribed data will be analysed using a constant comparative method. All study data will be coded and anonymised.

Timescales

Ethical approval is currently in progress and data collection is expected to commence in spring 2011 over a period of 15 - 18 months across the 3 sites.

Benefit of undertaking this research:

It is hoped that this study will inform the future setting and organisation of healthcare for people living with HIV in the UK.

Appendix 2: Healthy-Illness Representations of HIV in the UK

Patient Participant Information Sheet: Part 1

© University of Brighton



INTRODUCTION

Thank you for your interest in this research on HIV healthcare provision. This study is being carried out as part of a PhD training programme for clinical nurses and is sponsored by the University of Brighton. Before you decide if you would like to be involved, please read Part 1 and Part 2 of this information leaflet.

WHAT IS THE RESEARCH ABOUT?

People with HIV have many different healthcare needs. Some require routine follow-up only while others have more complex needs and see a lot of different healthcare professionals in the hospital and community.

The purpose of the research is to find out if there is a better way to organise HIV healthcare in the future. This study will explore the role of patients in managing their HIV health and will examine the way that doctors, nurses and other healthcare workers provide healthcare in the clinic and the community.

It is hoped that this research will help to inform the way that HIV healthcare is provided in the future.

WHY HAVE I BEEN CHOSEN?

You have been approached to take part in this research as you are over 18 years of age and have been diagnosed with HIV for more than 6 months. In order to include the characteristics of HIV patients across the UK, patient participants who decide to take part in the research will be chosen to attend 1 or 2 interviews according to age, gender, sexuality and ethnic background who have a broad range of HIV healthcare needs. In this instance the researcher will ask you to consent to 1 or 2 interviews. Those not selected for interview may choose to contact the researcher informally about any views they have on HIV healthcare provision and this information will be used to contribute to the background of the study and no direct quotes will be used.

Please go to top right column

DO I HAVE TO TAKE PART IN THE RESEARCH?

Taking part in the research is completely voluntary and if you choose not to take part, this will not affect any current or future care you receive. If you decide to participate, you are also free to withdraw at any time without having to give a reason.

WHAT WILL THE RESEARCH INVOLVE?

If you decide to take part in the research, you will be asked to attend your clinic for 1 – 2 interviews, lasting one hour each. You will be paid back any reasonable travel costs to attend the interview.

The researcher will ask you how your HIV healthcare meets your needs and how you think HIV healthcare services could be planned in the future. You will also be asked to consider the role of different healthcare workers involved in your care. The interviews will be recorded and direct anonymous quotes will be used for reporting any results. Any information about you is confidential and will be stored on secure computers.

WHAT ARE THE POSSIBLE DISADVANTAGES OF TAKING PART IN THE RESEARCH?

You may find that talking about your HIV healthcare raises worries or concerns about previous, current or future healthcare services. You will be given a telephone contact number after the interview if you wish to discuss any concerns further.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART IN THE RESEARCH?

There is no direct benefit to you to participating in this research. However, by participating in this study, you will have the opportunity to contribute to the debate on the delivery of HIV healthcare in the future..

If you are considering being involved in this study, please read the additional information in Part 2 before you make any decision

WHAT IF I WANT TO WITHDRAW FROM THE STUDY?

You are free to withdraw from the study at any time without giving a reason. If you choose to withdraw from the study no direct quotes will be used from your interview(s).

WHAT IF THERE IS A PROBLEM?

If you have any concerns or complaints about any stage of the research you can discuss this with the researcher or with her supervisors (details below). In addition you can speak to your local contact for the study: Name:*****Contact details*****. Alternatively, the independent contact at the University of Brighton for any concerns about this research is Professor Valerie Hall: V.Hall@brighton.ac.uk.

WILL MY PERSONAL DETAILS AND INFORMATION FROM MY INTERVIEWS BE KEPT CONFIDENTIAL?

Direct quotes from your interview will be anonymised and coded to protect your confidentiality and identification of individual patient participants. For example, broad categories will be used to describe age; time since diagnosis and location of HIV service. Any information about you or your interview(s) will be stored separately in password protected documents initially on a password protected laptop computer. This information will be transferred to a secure computer at the University of Brighton. Any hard copies will be kept in a locked metal cabinet at the University of Brighton.

The only people who will have access to your personal details and your taped interviews will be the study team and all personal data will be permanently deleted at the end of the study period. The study team have a duty to keep all information about you confidential unless you disclose information to the researcher that indicates possible harm to yourself or to others. In the event that this occurs, the researcher will contact your clinic doctor or nurse following discussion with you.

WHO IS ORGANISING THE RESEARCH?

The researcher is Eileen Nixon who is currently a PhD student from the University of Brighton. Eileen has been working in HIV healthcare for the past 10 years as a senior nurse practitioner. The study team consists of Eileen Nixon, Professor Julie Scholes at the University of Brighton (J.Scholes@brighton.ac.uk) and Dr Martin Fisher at Brighton and Sussex University Hospitals (Martin.Fisher@bsuh.nhs.uk). The research is primarily funded through an educational scholarship programme for clinical nurses.

WHO HAS REVIEWED THIS RESEARCH?

This study has been developed in conjunction with an HIV Patient Advisory Group and has been reviewed by two independent researchers at the University of Brighton. The study has received ethical approval from the University of Brighton and from Brighton East NHS Research Ethics Committee as well as research management approval in your hospital.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of this research will be used to develop a model of HV healthcare provision and direct anonymised quotes will be published in health literature and presented to HIV Conferences and National Health Service organisations. If you choose to participate in the study, you will receive feedback on the results of the research.

IF YOU ARE INTERESTED IN TAKING PART IN THIS RESEARCH, PLEASE CONTACT EILEEN ON 07766 732609 OR E.Nixon@brighton.ac.uk.



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CONSENT FORM

HIV MODELS OF CARE STUDY – VERSION 2.2: 14/01/2011

Name of participant:

Site Number:..... Name of Researcher.....

Please initial box

- 1. I confirm that I have read and understood the participation information sheet dated 14/01/2011 for the above study and that I have had the opportunity to ask questions and have received satisfactory answers to these.
- 2. I understand that my interview with the researcher will be recorded and that direct quotes will be used from my interview in an anonymous format.
- 3. I understand that my participation in the study is voluntary and that I am free to withdraw, without giving a reason, at any time during the study period.
- 4. I understand that if I wish to withdraw from the study that no direct quotes from my interview will be used for publication.
- 5. I understand that information about me will be kept confidential and anonymous unless I disclose information that indicates possible harm to myself or to others.
- 6. I understand that the research data collected during the study may be looked at by individuals from the study team, the sponsor, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to my data for monitoring purposes if required.

Name of ParticipantSignature.....Date...../...../2011

Name of person taking consent.....Signature.....Date...../...../2011

INTRODUCTION

Thank you for your interest in this research on HIV healthcare provision. This study is being carried out as part of a PhD training programme for clinical nurses and is sponsored by the University of Brighton. Before you decide if you would like to be involved, please read Part 1 and Part 2 of this information leaflet.

WHAT IS THE RESEARCH ABOUT?

While many people with HIV require routine monitoring, an increasing proportion are presenting with complex chronic conditions that require access to a number of healthcare professionals in outpatient clinics and in the community.

The purpose of the research is to find out if there is a better way to organise HIV healthcare in the future. This study will explore the role of patients in managing their HIV health and will examine the way that doctors, nurses and other healthcare workers provide healthcare in the clinic and the community.

It is hoped that this research will help to inform the way that HIV healthcare is provided in the future.

WHY HAVE I BEEN CHOSEN?

You have been chosen to take part in this research, as you are working with HIV patients and have been in your current workplace for longer than 6 months. In addition, you have been selected to represent a specific healthcare worker role or discipline or related to a specific service for people with HIV infection. Your participation in this research will be kept confidential and a coding strategy will be established to protect your identity. .

Please go to top right column

DO I HAVE TO TAKE PART IN THE RESEARCH?

Taking part in the research is completely voluntary and if you choose not to take part, this will remain confidential. If you decide to take part in this research, you are also free to withdraw at any time without giving a reason.

WHAT WILL THE RESEARCH INVOLVE?

If you decide to take part in the research, you will be asked to attend one or two semi-structured interviews of one hour in length in an agreed work-based location. Any travel expenses incurred to attend the interview will be reimbursed.

You will be asked to discuss your views on the current and future healthcare needs of people with HIV and to consider the roles of different healthcare workers involved in providing HIV healthcare.

The interviews will be recorded and direct anonymous quotes will be used for reporting any results. Any information about you is confidential and will be stored on secure computers.

WHAT ARE THE POSSIBLE DISADVANTAGES OF TAKING PART IN THE RESEARCH?

Taking part in this research may raise questions for you about your role in HIV healthcare. You will be given a telephone contact number after the interview if you wish to discuss any concerns that may arise during the interview.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART IN THE RESEARCH?

There is no direct benefit to you to participating in this research. However, by participating in this study, you will have the opportunity to contribute to the debate on the delivery of HIV healthcare in the future..

If you are considering being involved in this study, please read the additional information in Part 2 before you make any decision

WHAT IF I WANT TO WITHDRAW FROM THE STUDY?

You are free to withdraw from the study at any time without giving a reason. If you choose to withdraw from the study no direct quotes will be used from your interview(s).

WHAT IF THERE IS A PROBLEM?

If you have any concerns or complaints about any stage of the research you can discuss this with the researcher or with her supervisors (details below). In addition you can speak to your local contact for the study: Name:*****Contact details*****. Alternatively, the independent contact at the University of Brighton for any concerns about this research is Professor Valerie Hall: V.Hall@brighton.ac.uk.

HOW WILL MY CONFIDENTIALITY BE PROTECTED?

Direct quotes from your interview will be anonymised and coded to protect your confidentiality. For example, staff participants will be referred to by discipline and not job title and broad categories will be used to describe job roles. In addition, the study sites will be kept anonymous to minimise identification of unique or site specific roles. The content of your interview will remain confidential unless you disclose information to the researcher that indicates possible harm to yourself or to others. In this instance, the researcher will follow your Trust policy and procedures.

Any information about you or your interview(s) will be stored separately in password protected documents initially on a password protected laptop computer. This information will be transferred onto a secure computer at the University of Brighton and any hard copies will be kept in a locked metal cabinet at the University of Brighton. The only people who will have access to your personal details and your taped interviews will be the study team and all personal data will be permanently deleted at the end of the study period.

WHO IS ORGANISING THE RESEARCH?

The researcher is Eileen Nixon who is currently a PhD student from the University of Brighton. Eileen has been working in HIV healthcare for the past 10 years as a senior nurse practitioner. The study team consists of Eileen Nixon, Professor Julie Scholes at the University of Brighton (J.Scholes@brighton.ac.uk) and Dr Martin Fisher at Brighton and Sussex University Hospitals (Martin.Fisher@bsuh.nhs.uk). The research is primarily funded through an educational scholarship programme for clinical nurses.

WHO HAS REVIEWED THIS RESEARCH?

This study has been developed in conjunction with an HIV Patient Advisory Group and has been reviewed by two independent researchers at the University of Brighton. The study has received ethical approval from the University of Brighton and from Brighton East NHS Research Ethics Committee as well as research and development approval in your hospital.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of this research will be used to develop a model of HIV healthcare provision and direct anonymised quotes will be published in health literature and presented to HIV Conferences and National Health Service organisations. If you choose to participate in the study, you will have the opportunity to see the results before any presentation or publication.

IF YOU ARE INTERESTED IN TAKING PART IN THIS RESEARCH, PLEASE CONTACT EILEEN ON 07766 732609 OR E.Nixon@brighton.ac.uk.

Appendix 5: Healthy-Illness Representations of HIV in the UK

Study Site Service Questionnaire



REC Ref: 10/H1107/76

R&D Ref:

January 2011

Study Site Questionnaire

Title of Study: Models of HIV Care in the UK

Thank you for agreeing to participate in this PhD research on HIV healthcare provision. I would be grateful if you could provide me with the following information regarding your particular site.

CASELOAD DEMOGRAPHICS

1. How many HIV patients do you have in your clinic caseload?

2. What is the approximate demographic breakdown of your HIV caseload?

MSM

Heterosexual

IVDU

Other

White UK

Black and ethnic minority groups

16-20 year olds

Patients over 50 years

Newly diagnosed patients per year

Non-English speaking

HIV SERVICE SPECIFICATION

3. Number of HIV clinics per week?

4. Do you have a designated clinic for routine stable patients?

Yes

No

If yes, how is this provided? Tick all that apply

Telephone

E-mail

Nurse-led

Doctor-led

5. What type of pathways do you have in place for patients with co-morbidities and co-infections?

None	<input type="text"/>	Informal arrangements across network	<input type="text"/>
Identified key worker	<input type="text"/>	Multidisciplinary meetings	<input type="text"/>
Joint clinics	<input type="text"/>	Formal pathways across network	<input type="text"/>
Other (please specify)	<input type="text"/>		

6. What type of service do you have for patients who present with non-routine problems between scheduled appointments? Tick all that apply

No specific service	<input type="text"/>	Refer to GP	<input type="text"/>	HIV Triage	<input type="text"/>
HIV walk-in or emergency clinics	<input type="text"/>	Other	<input type="text"/>		

7. Please state the number of HIV specialist roles you have access to in your service.

Medical Consultant	<input type="text"/>	Specialist Registrars	<input type="text"/>	Clinical Nurse Specialist	<input type="text"/>	Advanced Nurse Practitioner	<input type="text"/>				
Pharmacy	<input type="text"/>	Social Worker	<input type="text"/>	Physiotherapy	<input type="text"/>	Dietician	<input type="text"/>	Psychology	<input type="text"/>	Mental Health	<input type="text"/>
Community Matron	<input type="text"/>	Community Nurse Specialist	<input type="text"/>	Other	<input type="text"/>						

COMMUNITY PATHWAYS

8. What type of links do you have with GP's in your area?

Shared care with GP's for the majority of patents	<input type="text"/>	Specific package with GP's for individual patients	<input type="text"/>
No formal links	<input type="text"/>	Other/Comments	<input type="text"/>

9. What HIV voluntary sector services do you have access to in your area?

DATA COLLECTION PRACTICALITIES

10. What days/sessions do you not have any HIV clinics?

11. Do you have any evening or weekend clinics?

If yes, please specify:

12. What access do you have to a booked room for conducting interviews on site?

13. Please provide the name of the **MAIN** PCT/PCT's that your HIV patients reside in.

Thank you for completing this form. Please return to Eileen Nixon, Chief Investigator by e-mail to e.nixon@brighton.ac.uk or retain for the study set up visit.

Appendix 6: Healthy-Illness Representations of HIV in the UK – Recruitment e-mail for healthcare workers.

E-mail Subject title:

INVITATION TO PARTICIPATE IN RESEARCH INTO HIV MODELS OF CARE DELIVERY

Dear.....

I am undertaking a PhD research project on Models of HIV Care with the aim of developing a theoretical model for HIV healthcare delivery over the medium to long term.

I would like to invite you to participate in one or possibly two research interviews lasting one hour. The interview will explore your views and experiences as a healthcare professional providing HIV care and discuss your opinions on future HIV healthcare provision.

In the event that you are interested in participating, I enclose a participant information leaflet that contains further details of the study and contact details for me should you wish to find out more or should you wish to volunteer to be involved in the research.

If you choose to participate, data from your interview will be coded and anonymised and study sites will remain confidential to minimise identification of unique or site specific staff roles.

I must stress that you are not under any obligation to participate in this research and your choice not to participate will remain confidential.

Please don't hesitate to contact me by phone or e-mail if you have any further questions about this research.

With regards,

Eileen Nixon

HIV Nurse Consultant / Clinical Academic Fellowship Programme
Centre for Nursing and Midwifery Research
University of Brighton
E.Nixon@brighton.ac.uk. Tel: 07766 732609

Appendix 7: Healthy-Illness representations of HIV in the UK:

Outline of findings from the survey of nursing roles

Service Location and participant description	Number of patients	Nurse-led Stable patient clinics	Complex care	Prescriber
Edinburgh X2 clinical nurse specialists (CNS)	550	Some	Yes IVDU	no
North Yorkshire Primary Care Trust X2 clinical nurse specialists (CNS)	205	CNS Outreach clinics for stable patients	Yes Co-morbidities and co-infections	no
Leeds X1 clinical nurse specialist (CNS)	800	CNS daily clinics	Some in stable clinics	yes
Brighton X1 Clinical Nurse specialist x1 Practice Nurse	1800 104	Weekly stable clinics Annual reviews for stable patients	Yes mixed	No yes
London East London – Nurse Consultant West London – Lead Nurse	2000 6000	Regular stable clinics Telephone clinic/virtual clinics Regular stable clinics	Yes mixed Yes mixed	Yes No
Birmingham	900	CNS telephone clinics	Yes/Case management	no
Liverpool X1 Nurse Consultant	1200	Nurse Consultant	Pregnancy	yes

This survey was carried out in preparation for an invited lecture on models of HIV nursing in June 2011. The findings were utilised as additional information to support the thesis. Participants gave permission for the results to be shared in a public forum.