BY VIRTUE OF CIRCUMSTANCE:

HIV/AIDS IN MOBILE AND RURAL POPULATIONS IN WESTERN AUSTRALIA, AN ETHNOGRAPHIC STUDY

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This thesis is presented for the degree of Doctor of Philosophy of Murdoch University

Supervisor: David Nolan
DECLARATION

The research presented in this thesis is my own work unless otherwise stated and contains as its main content work which has not previously been submitted for a degree at any tertiary education institution.

Susan Elizabeth HERRMANN

Signature

Date
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And in the end, loving thanks to my family for their unflagging support.

This work is dedicated to my beloved parents

Hugh Davey

17th October 1927 – 30th June 2011

& Jean Davey

24th April 1932 – 29th April 2012

*Voici mon secret. Il est très simple: on ne voit bien qu’avec le cœur. L’essentiel est invisible pour les yeux*

*Here is my secret. A very simple secret. It is only with the heart that one can see rightly. What is essential is invisible to the eye*

From Le Petit Prince (1943), a novel by Antoine de Saint Exupéry (1900-1944)
ABSTRACT

HIV/AIDS is an incurable, infectious condition that, without access and adherence to lifelong treatment with specific antiretroviral drugs (ARVs), leads to declining immune-competence and death, usually within ten years of acquiring the infection. Australians have benefited from universal access to ARVs under patent through the national health care access scheme, Medicare. Since 2005 there has been a steady rise in notifications, dispersed across Western Australia (WA), indicating HIV infection in women, and men who have sex with women, against the previous trend of risk and transmission in men who have unprotected sex with other men. Many people diagnosed hold temporary visas and come to WA with their families to work or study and are ineligible for Medicare. This compromises their access to effective antiretroviral treatment by virtue of their visa status.

Between 2007 and 2008, one hundred and seventeen people living with HIV in WA participated in an international, mixed methods study of health-related quality of life. This thesis describes and references those findings to examine, through an ethnographic perspective, and within the context of current epidemiology: (1) the experience of managing HIV in a rural or remote environment; (2) the effect of visa status in mediating the experience of HIV; and (3) aspects of access and adherence to ARVs that influence the outcome of treatment. In 2010 and 2011 data were gathered from interviews with thirty participants (nine women) with HIV-infection: twenty-two had been granted temporary work or student visas, fourteen were current business or student visa holders, and nineteen lived or worked in rural areas. Group data from two rural-based cohorts is referenced and twenty-one key informants were interviewed to augment context, and contribute thick description.
Limited access to ARVs posed by non-citizen status and/or distance from dispensing pharmacies was overcome largely by motivation to accept treatment and support from key health professionals (HPs), which resulted in high levels of adherence and engagement with care. However, there were differences in approaches to HIV supportive care between indigenous and non-indigenous cohorts with more intense involvement of HPs in the former group. The data showed a pattern of stigma characterised by persistent fear of disclosing HIV serostatus and infecting others. This was nuanced by the particular circumstances of individuals, for example, non-citizen status, and living and/or working in regional areas. In particular HIV-positive serostatus affected, and frequently limited, social relationships, employment and the likelihood of successful migration.

These data indicate, firstly, that the immunopathological consequences of HIV infection can and should be avoided by policies that facilitate unfettered access to treatment and medical care; and secondly that the psychosocial aspects of HIV disease that limit the lives and livelihoods of people with HIV infection require intervention.

**Key Words:** HIV/AIDS, Access, ART, Medication Adherence, Health-Related Quality of Life, Stigma, Visa Status, Rural, Employment, FIFO, Immigration, Ethnography
ACADEMIC OUTPUT DURING CANDIDATURE

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Herrmann S., Williams L., McKinnon E., Nolan D. Substance use in the WA HIV cohort: 2002-2008. 21th Annual Conference Australasian Society for HIV Medicine, held 9-12 September 2009, Brisbane, Queensland, Australia, Poster Presentation
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>AFAO</td>
<td>Australian Federation of AIDS Organisations</td>
</tr>
<tr>
<td>ART</td>
<td>Anti Retroviral Therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>BBV</td>
<td>Blood Borne Virus</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>Doha</td>
<td>WTO Declaration on TRIPS and Public Health</td>
</tr>
<tr>
<td>DIDO</td>
<td>Drive in Drive Out</td>
</tr>
<tr>
<td>FDC</td>
<td>Fixed-dose Combination</td>
</tr>
<tr>
<td>FIFO</td>
<td>Fly in Fly Out</td>
</tr>
<tr>
<td>Generic Drug</td>
<td>A bioequivalent of a propriety (brand name) drug</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GIPA</td>
<td>Greater Involvement of People with HIV/AIDS</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>MHS</td>
<td>Mental Health Summary</td>
</tr>
<tr>
<td>NAPWA</td>
<td>National Association for People Living with HIV/AIDS</td>
</tr>
<tr>
<td>NRTI</td>
<td>Nucleoside/tide Reverse Transcriptase Inhibitor</td>
</tr>
<tr>
<td>NNRTI</td>
<td>Non-Nucleoside Reverse Transcriptase Inhibitor</td>
</tr>
<tr>
<td>PBS</td>
<td>Pharmaceutical Benefits Scheme</td>
</tr>
<tr>
<td>PHU</td>
<td>Population Health Unit</td>
</tr>
<tr>
<td>PHP</td>
<td>Public Health Physician</td>
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<tr>
<td>PHS</td>
<td>Physical Health Summary</td>
</tr>
<tr>
<td>PLWH</td>
<td>People Living With HIV</td>
</tr>
<tr>
<td>PI</td>
<td>Protease Inhibitor</td>
</tr>
<tr>
<td>RPH</td>
<td>Royal Perth Hospital</td>
</tr>
<tr>
<td>RRN</td>
<td>Rural and Remote Clinical Nurse Specialist</td>
</tr>
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<td>S100</td>
<td>Section 100</td>
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<tr>
<td>TRIP Agreement</td>
<td>Trade Related Intellectual Property Agreement</td>
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<tr>
<td>WAAC</td>
<td>Western Australian AIDS Council</td>
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<td>WACHS</td>
<td>Western Australian Country Health Service</td>
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<tr>
<td>WAHCS</td>
<td>Western Australian HIV Cohort Study</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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THE CONTRIBUTION OF OTHERS TO THIS WORK

I acknowledge the contribution of others to this thesis. The Quality of Life Study presented in Chapter Three grew from my organisation’s contribution to an international project (PRO-QOL HIV) which developed a psychometric instrument to assess the health-related quality of life impacts of HIV. The study was designed and coordinated by Dr Martin Duracinsky and funded by Sidaction. In accordance with the research contract, the Western Australian data remained under the governance of the Australian investigators to be published independently of the larger project. The manuscript, which I wrote during my candidature, is presented as a single chapter in the thesis in the form of a manuscript as it complements and informs the two subsequent sections concerning HIV infection in regional Western Australia and the growing epidemic in non-citizens. Therefore, I acknowledge the considerable contribution of others to that original work.

My contribution to the work was as follows: I led the two-stage Australian arm of the study; wrote and managed the ethics submission; conducted the majority of the interviews; and the face to face questionnaire administration in stages one and two of the study; and analysed the qualitative data. I assisted with the presentation of the preliminary findings of the international study at international conferences, and prepared and presented the Western Australian data at two national ASHM conferences and local branch meetings. I liaised closely with co-author Noel Hyland (Clinical Psychologist, Sexual Health and Communicable Diseases at Royal Perth Hospital), who conducted four of the fifteen interviews and we reviewed the data together, and independently. Statisticians Christophe Lalanne (Assistance Publique–Hopitaux de Paris, Saint-Louis Hospital, Department of Clinical Research, PRO unit,
Paris, France), and Bethy McKinnon in the Institute of Immunology and Infectious Diseases (IIID), worked on the data at some stage. However, Bethy conducted the most recent and thorough data analysis for the Western Australian manuscript; and we explored the quantitative data iteratively, and in consultation with Martin Duracinsky, Christophe Lalanne and Noel Hyland. Bethy also wrote the results section and prepared some of the tables. As the primary author of the manuscript, I wrote the majority of the paper and am responsible for the interpretation of the analyses. I chose to present the qualitative and quantitative results in stages one and two of the study, as a single manuscript in order to provide a clear, rich and thick description of the work. The PROQOL-HIV study provides the reference data for the subsequent studies presented in this thesis.

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I received an Australian Post Graduate Award and a $10,000 research grant from the Nurses Memorial Trust of Western Australia for which I am very grateful.
INTRODUCTION

Successful resolution of diseases in humans caused by infectious pathogens is predicated largely on compliance with medical care and, more specifically, access and adherence to anti-infective pharmaceutical drugs. Whilst infection with the human immunodeficiency virus (HIV) is incurable, treatment with antiretroviral drugs (ARVs) can suppress levels of the virus in the blood to levels undetectable by current laboratory assays; prevent progression to AIDS (acquired immune deficiency syndrome); and transmission to the unprotected contacts of an infected person (Cohen et al., 2011; Cohen & Gay, 2010). However, access to potent and effective medicines can be limited by issues of cost and supply (Crane et al., 2007; Bangsberg, 2008a) and many bio-psychosocial factors can threaten successful medication-taking behaviour, for example, side effects, depression and tenuous engagement with health care services (Gardner et al., 2011; Heath, Singer, O’Shaughnessy, Montaner & Hogg, 2002; Starace et al., 2002).

The premise of this thesis is that the path to restoration of health and well-being in HIV is predicated on the unique social, cultural and geographical context in which the person experiences the disease. This research describes the impact of HIV and treatment in non-citizens and people living and/or working in rural and remote areas in Western Australia (WA), identified as ‘priority’ populations in the 6th National HIV Strategy (2010). The results are referenced and interpreted against the findings of a WA-based study of health-related quality of life (HRQL) conducted within the WA HIV Cohort Study (WAHCS) over a two-year period in 2007-2008. Ethnography was chosen as an approach to this investigation, it being especially concerned with cultural
context, detailed description, and questions that demand detailed explanation (Beebe, 2001).

The primary aims of this thesis are to describe (1) the impact of HIV on the health of these groups; (2) the experience of managing HIV in a rural or remote environment; (3) the effect of visa status in mediating the experience of HIV; and (4) particular issues regarding access to ARVs and barriers to medication adherence.

**Origins and Context of the Study**

The study grew from clinical and behavioural research conducted over a number of years in the WAHCS (Mallal, 1998) at Royal Perth Hospital, the premier state tertiary institution for HIV care. However, it was also fired by a presentation from Professor David Wilson, later published in the journal, *Lancet* (D. Wilson & Halperin, 2008), which highlighted the importance of understanding the particular characteristics of local epidemics in order to formulate effective responses. Although the premise of the argument was based on approaches to HIV prevention, the message could be applied, equally, to ensuring appropriate clinical and community services are in place to support affected individuals in such an epidemic. This presentation seemed particularly relevant in light of the changing epidemiological pattern of HIV in Western Australia over the preceding five years (Combs & Giele, 2009). Since I had recognised that geographical and social contexts were important in the approach to an earlier survey of HIV medication adherence, and critical if we were to implement interventions, it was logical to look to the changing demographics of the cohort and explore gaps in our research program. This program had grown from the findings of the aforementioned survey which had given a broad perspective on factors influencing medication adherence in the WA context, to examining aspects of HIV infection and treatment
that may impact on health-related quality of life and have direct and indirect associations with medication adherence (Carrieri et al., 2003; William Holmes et al., 2007; Mannheimer et al., 2005; Xianhong et al., 2011).

**Uptake and Adherence to Treatment**

Within the time frame of this study (2009 to 2012), HIV/AIDS remains a fatal infectious disease unless treated with potent antiretroviral drugs (ARVs) and people adhere to the lifelong requirements of the therapy. Access to ARVs is limited by their cost and supply, and medication adherence behaviour, a dynamic state, is influenced by a number of bio-psychosocial factors that are critical to achieve the clinical benefits of treatment (Abel & Painter, 2003; Altice et al., 2001; Ammassari et al., 2002; Carrieri et al., 2001; Chesney et al., 2000; Friedland, 2006; A. Gonzalez et al., 2011; Heath et al., 2002; Herrmann et al., 2008; Hill et al., 2003; Ickovics & Meade, 2002b; Li et al., 2011; Murphy et al., 2000; Murri et al., 2000; O'Brien et al., 2003; Ortego et al., 2010; Xianhong et al., 2011).

A precondition of successful adherence is acceptance of the treatment as being necessary and beneficial. Predictors of acceptance include trust in the clinician and engagement with health care (Altice et al., 2001; Friedland, 2006). Once acceptance has taken place and treatment has commenced, it is widely recognised that personal, environmental and drug-related characteristics (Table 1) mediate behaviour by either promoting or detracting from medication adherence. (Ickovics & Meade, 2002a, 2002b; Ickovics & Meisler, 1997) The personal, such as motivation, information, resilience and behavioural skills; environmental, such as social support and access; and finally the intrinsic properties of the medication such as tolerability and dosing schedule are influential. However, the impact of an HIV diagnosis and the lifelong...
experience of living with the disease can mediate factors associated with adherence in a way that moderates the pathogenic benefits of ARVs and this appears to be consistent across multiple international settings (Mills et al., 2006).

**Current Epidemiology: Regional Spread**

Since the middle of the last decade there has been a steady rise in notifications indicating HIV infection in women, and men who have sex with women, against the previous trend of risk and transmission in men who have unprotected sex with other men (Combs & Giele, 2009). This trend is particularly apparent in WA where 57.5% of notifications in 2010 alone were reported as from heterosexual transmission in comparison with 42.2% for the period 2001-2005. In 2010 WA had its highest rate of HIV notification since the epidemic began in the early 1980’s (National Centre in HIV Epidemiology and Clinical Research, 2011). Half of the women diagnosed were from sub-Saharan Africa and a third were Asian-born (Kwan, Mak, & Minas, 2010). Increases in infections have been attributed to: migration of people from HIV-prevalent regions; frequency of transmission and casual sexual encounters; and decreased condom usage (D. Wilson & Halperin, 2008). Of relevance to health services, people with the infection—men and increasing numbers of women, citizens and non-citizens—are no longer concentrated in urban areas and are dispersed across regional WA (Figure 1), reflecting the general trend in population dispersal across the state over the last 10 years (Australian Bureau of Statistics, 2011).

People living in rural areas rely on: services from community Population Health Units, which have a responsibility to provide preventative medical care and contain outbreaks of communicable diseases; and the city-based rural outreach programs
which deliver clinical and supportive HIV management to patients and provide expertise to the regional health professionals including GPs and the Prison Service.

Figure 1: Increasing number of PLWH in regional areas between 1998 and 2009 (Numbers in 2009 refer to HIV positive patients and HIV-negative babies born in the Pilbara as well as one HIV positive baby)

(Data courtesy David Nolan and Allison Cain)

The 6th National HIV Strategy (2010) identified vulnerable or ‘underserved’ populations with HIV infection in Western Australia as groups needing a research and funding focus. Despite the important and relevant qualitative research studies exploring Aboriginal experiences of HIV in WA; and barriers and incentives to HIV treatment uptake, including the influences of culture (Bonar et al., 2004; Newman et al., 2007a; Newman et al., 2007b; Thompson et al., 2009), little is known about the experience of non-Aboriginal people living with HIV infection in rural areas. Although the ‘adherence studies’ (Herrmann et al., 2008b) and the WA arm of the PROQOL-HIV study (Duracinsky et al., 2012a, 2012b) captured a representative proportion of all people living with HIV across the state, including those from rural and remote areas who travel to the clinic in Perth, it did not seek to study groups defined by geography,
ethnicity or residency status. It also didn’t address health care access. Arguably the rise of population mobility including within the country, i.e. internal migration, and the health issues that arise from such mobility, is an area that could be informed by focused qualitative research. In particular, and in light of these gaps in knowledge and the changing epidemiology of HIV in our region, it appears important to understand the features of the current local epidemic taking into consideration transmission dynamics (D. Wilson & Halperin, 2008), as well as the interaction of local and macro factors that might impact on access to services and life-saving antiretroviral medication.

**HIV and Migration Status in Australia**

The experience of HIV in individuals identifying themselves as belonging to culturally and linguistically diverse (CALD) communities in Australia, has been described by Henrike Körner in New South Wales in a number of publications (Körner, 2005, 2007a, 2007b, 2007c). Her research described how themes of HIV diagnosis, access to care and support, and forming social relationships were ‘interwoven’ with migration status. Körner also strove to explicate the reasons that people from CALD communities delay seeking help for symptoms of HIV, and how cultural background mediated the impact of an HIV diagnosis. In 2009, Asante and colleagues produced a monograph of their periodic ‘Survey of HIV knowledge, perceptions and use of health services among people from culturally and linguistically diverse (CALD) backgrounds’. Shortly after, Chris Lemoh and colleagues (Lemoh, Baho, Grierson, Hellard, Street & Biggs, 2010) provided a clinical report on a group of African-Australians as part of a study conducted in consultation with members of the African Australian Community, the importance of which he highlights in an earlier publication (Lemoh, Biggs & Hellard,
His research recommended that Victoria’s African communities address the possibility of exposure to HIV in Australia; and the need to better engage with public health services to understand and overcome obstacles to timely diagnosis of HIV. More recently, in Western Australia, the diverse cultural and socioeconomic backgrounds and HIV/AIDS knowledge and attitudes among West African immigrant women in Western Australia were surveyed by Drummond, Mizan and Wright (2008). They reported a wide cultural and socioeconomic diversity among the refugee population which might impact on beliefs and understandings of health issues. The findings of their study of 52 West African women and 100 West Australian women who acted as a control group, inferred that messages about HIV should be tailored to target particular demographic groups in WA, and take into consideration educational level, health belief systems and cultural norms for any given group.

Although skilled workers and educated students from HIV-prevalent areas in Africa and Asia who come to WA to work or study may share belief systems and cultural norms with others of similar ethnicity, they also have characteristics that link them with others who may not share their ethnic identities, for example guest worker or student status as opposed to asylum-seeker, or indeed the fact that they reside in a remote country town rather than in a city. The distinction in visa status is significant because of differing ‘qualification’ for services; for example, asylum-seekers have access to government funded and charitable organisations by virtue of their assigned status. International students may have access to student centred services and supports through their affiliations with universities and colleges but guest workers are largely unsupported, must advocate on their own behalf and seek out services using their own personal and financial resources. In WA guest workers with non-citizen status are often employed in jobs in the mining and construction industries in a fly in fly out
(FIFO) or drive in drive out (DIDO) capacity and so become internal migrants along with their resident Australian fellows. Another sector which is relying more heavily on guest labour in Australia is health.

**HIV Diagnosis, Treatment and Care**

Since HIV testing is not a prerequisite for a Temporary Business (Long Stay) - Standard Business Sponsorship (Subclass 457) visa unless work in the health sector is sought, people may not know of their infectious status until diagnosis is made on application for permanent residency or a continuation of a 457 or Student Visa. Peripatetic lifestyle, residency status and geographic remoteness can impact on access to health care by limiting opportunity for continuity and follow-up which are critical for successful health outcomes particularly in HIV disease (Gardner et al., 2011; Giordano et al., 2007; Mugavero et al., 2009; Park et al., 2007). Another important and obvious issue for those on temporary visas is lack of Medicare cover. In instances where an application for permanent residency is made, a temporary Medicare card is granted although in some instances interim access is granted. Temporary visa holders are required to have private medical cover and to date this does not cover the cost of antiretroviral treatment. Temporary visa holders ineligible for Medicare-subsidised patented antiretroviral drugs must either pay full price or import from a limited range of generic, bioequivalent versions manufactured mainly in India. What, if any, difficulties arise from this and how does this impact on their overall health? Does limited access to services, enjoyed by citizens and Permanent Residents, result in harm for temporary visa holders? If so, Pollard and Savulescu (2004) argue that this practice is unethical. The role that Medicare access and non-standard medication distribution
networks play in ensuring an uninterrupted supply of antiretroviral drugs to citizens and non-citizens in Western Australia needs investigation.

**Contribution to the Field of HIV Social Research**

Critical to qualitative research in this area is context (*Table 1*), in that unique and dynamic socio-cultural factors can have an influence on how people engage with medical care as well as access and adhere to prescribed medication (Carrieri et al., 2001; Ickovics & Meade, 2002a, 2002b; Ickovics & Meisler, 1997; Mills et al., 2006; Mugavero et al., 2009a; Mugavero et al., 2009b; Mugavero et al., 2009c; Murphy et al., 2000; Nachega & Mills, 2007; O'Brien et al., 2003; Ortego et al., 2010). I acknowledge that our previous surveys and audits (Herrmann, et al., 2008a, 2008b, 2009, 2012) of factors influencing adherence, including the role of side effects, dosing schedule and substance use, had limitations. In particular, a survey instrument is an inadequate tool to glean understanding of the motivations, beliefs, values, and processes underlying patterns of behaviour. In order to gather rich information about how a phenomenon is experienced, including such issues as how HIV reverberates within the families of those affected, and what motivates individuals to engage with care, qualitative research offers pertinent methodology. The quality of life study presented in this thesis addresses some of these methodological shortcomings since it employed both quantitative and qualitative research methods. It is ethnography, however, which offers an appropriate theoretical platform for studying groups of people in a given setting in order to reach an understanding of influential factors at play.

People and populations now move further and more rapidly than ever before between and within countries. An International Labour Conference Report (2009) estimated that there are over 90 million people working outside their countries of origin. Greater
population exchanges have implications for the spread of infectious disease, and international travel opportunities support the ebb and flow between migrant origin and destination locations (Gushulak & MacPherson, 2006). Of relevance to HIV is that prevalence rates may be higher in immigrant populations and even higher in ‘internal’ migrants moving from one region to another (Soskolne & Shtarkshall, 2002).

The number of qualitative studies in the field of HIV in Western Australia is limited. Other than the insightful studies by Newman and colleagues, referenced in this introduction, I am unaware of any qualitative study of factors affecting access to HIV treatment, medication adherence and clinical outcomes in Western Australia in ‘temporary visa holders’ or people living and working in rural and remote environments. These are vulnerable and potentially ‘underserved’ populations.

There is intense focus on the health of people living and working in rural Australia and this is reflected by State and Federal Government initiatives, such as the National Rural and Remote Health Infrastructure Program, and Royalties for Regions. Current media interest in the particular mental health challenges posed by rural living; and more recently the growth in remote mining industry employment opportunities and the biopsychosocial impacts of FIFO and DIDO work practices (Joyce, Tomlin, Somerford, & Weeramanthri, 2012) is intense. Although I have been made aware that the WA Health Department via WA Country Health Service (WACHS) has recently reviewed HIV services in the regions, this work has not been published and there is little or no research about the experience of living with HIV from the perspectives of recipients of those services.
<table>
<thead>
<tr>
<th>CHARACTERISTICS</th>
<th>YEAR 2002 Demographic profile</th>
<th>YEAR 2010 Demographic profile</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERSON</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosocial/support</td>
<td>Homosexual transmission</td>
<td>Heterosexual transmission</td>
</tr>
<tr>
<td>Health beliefs/ intent to</td>
<td>Mostly men</td>
<td>More women, implications for gender related issues eg fertility desires</td>
</tr>
<tr>
<td>adhere</td>
<td>Mostly Australian citizens-Medicare eligible, English first language</td>
<td>Increased number of visa holders - Medicare ineligible, English not first language</td>
</tr>
<tr>
<td>Use of substances</td>
<td>Socio-cultural norms shared by health care providers</td>
<td>Socio-cultural norms may not be shared by health care providers</td>
</tr>
<tr>
<td>Social stability</td>
<td>Pattern of substance use common</td>
<td>Pattern of substance use in recent referrals unknown</td>
</tr>
<tr>
<td>Social support</td>
<td>Host genetics – largely Caucasian</td>
<td>Host genetics - increased African and Asian</td>
</tr>
<tr>
<td>Host/viral genetics</td>
<td>Viral genetics – Clade B</td>
<td>Viral genetics – Clade C</td>
</tr>
<tr>
<td>DRUG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access</td>
<td>Potent, common adverse side effects</td>
<td>Potent, tolerable</td>
</tr>
<tr>
<td>Side effects</td>
<td>Twice daily (BD) and three times daily (TDS) dosing common</td>
<td>Once daily (OD) dosing common</td>
</tr>
<tr>
<td>Potency</td>
<td>Co-formulation uncommon</td>
<td>Co-formulation common</td>
</tr>
<tr>
<td>Complexity of regimen</td>
<td>Pill burden high</td>
<td>Reduced pill burden</td>
</tr>
<tr>
<td>Duration</td>
<td>AIDS prophylaxis common</td>
<td>AIDS prophylaxis less common in treated patients (reduces pill burden)</td>
</tr>
<tr>
<td>ENVIRONMENT</td>
<td>ART &amp; HIV prophylaxis available free from the hospital/no copayment</td>
<td>Not for Medicare ineligible patients</td>
</tr>
<tr>
<td>Work and/or child</td>
<td>PBS listed drugs available to Medicare eligible patients</td>
<td>Choice of drug limited by availability of generic bioequivalent and cost.</td>
</tr>
<tr>
<td>rearing responsibilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demographic</td>
<td>Approximately 50% in paid employment outside the home</td>
<td>Largely in paid employment</td>
</tr>
<tr>
<td>Patient provider</td>
<td>Small number living with children</td>
<td>An increase in number of people living with children</td>
</tr>
<tr>
<td>relationships</td>
<td>Travel for holidays</td>
<td>Travel to visit country of origin</td>
</tr>
<tr>
<td>Access to services</td>
<td>Majority living in metropolitan area</td>
<td>Increase in people living, working in regional areas of WA</td>
</tr>
<tr>
<td></td>
<td>Workplace in metropolitan area in wide range of occupations</td>
<td>Residential work, outside country of origin, male dominated workplace.</td>
</tr>
<tr>
<td></td>
<td>HIV prevention &amp; supportive community services geared towards gay men and Sex Workers</td>
<td>City based services for migrants from high prevalence countries around education &amp; prevention of HIV are emerging, underpinned by advice and input from CALD Communities.</td>
</tr>
</tbody>
</table>

References: (Combs & Giele, 2009; Herrmann et al., 2008a, 2008b; Ickovics & Meisler, 1997)
The demography of mobile populations is becoming more diverse and Figure 2 provides a representation of this actuality. To date, knowledge of health outcomes is often limited to that attached to specific groups, for example, refugee populations, and responses have been framed by that which is legally mandated within jurisdictions. However, in two papers Gushulak and MacPherson (2004, 2006) assert that it may be more useful to take into consideration the particular nature of the ‘migration’ process in order to formulate adequate health responses. HIV provides an
example of a disease which has a ‘prevalence gap’ in Australia compared with other regions in the world. And, in the case of long-staying mobile populations from regions with disparate risk environments from that of the destination country, this gap can complicate public health responses. Indeed, aspects of health systems that may need to adjust to meet the challenges will need to be driven by policies and programs that consider not only linguistic, cultural and gendered aspects of service delivery, but also address the basic human rights of non-citizens such as international skilled workers and students, to access health care wherever they may find themselves. Research into the health of mobile individuals is limited and, to date has been largely confined to the situation of either migrants, asylum seekers or illegal workers, within the context of the social determinants of health (Ahonen, Benavides & Benach, 2007). But over the last few years, in the context of HIV, research on the growing population of guest workers, international students and internal migrants, is emerging (Connell & Negin, 2010; Elinav et al., 2012). This thesis will, in part, focus on people with HIV whose visa status in Australia might affect their health and quality of life.

The potential for social research to uncover a rich source of data that can inform the field in HIV and be generalised to other health conditions has been recognised, internationally, by large funding organisations such as the National Institutes of Health (NIH) (2009). This research proposes to address a number of the current international priorities of the NIH in HIV adherence research to advance understanding of adherence to ART in underserved groups, for example, people with HIV residing in this country as temporary visitors or non-citizens, with regard to factors that lead to linkage with and retention in clinical care. It also considers structural factors that affect engagement with care and the intersections of adherence and HIV prevention.
The 6th National HIV Strategy for 2010-2013 (2010) also identified the following priorities: Social, behavioural and epidemiological research in prevention, diagnosis, treatment, care and support of people with HIV. This thesis fits the criteria of those research priorities and has the potential to inform the provision of targeted services.

**Research Purpose**

The purpose of this research is to describe (1) the experience of managing HIV in a rural or remote environment (2) the impact of HIV in people on temporary visas; and (3) the outcome of ARV treatment for those individuals. The work will be positioned in the context of a study of health-related quality of life carried out in the WAHCS in 2007-2008 and in the environment of current service delivery. **Figure 3** is a schematic of the populations of interest to this research. The overlap between citizens and non-citizens represents the ‘grey area’ of access since some visas offer some citizens’ rights, albeit temporarily; and Permanent Residents, while lacking full citizens’ rights have access to Medicare and other associated benefits.

**Organisation of the Thesis**

The thesis is divided into six chapters. The first chapter comprises a literature review which is concerned with current knowledge pertaining to HIV disease and treatment. The role of medication-taking behaviour in achieving good clinical outcomes, the research evidence that has arisen around issues impacting on health-related quality of life in HIV, a summary of research literature pertaining to HIV in rural populations and non-citizens, and national laws that are relevant for people living with HIV, specifically access to antiretroviral drugs, visa requirements and migration restrictions, is presented. The aim of the literature review is to position the study in the current context as it applies to: the state of HIV clinical care in Western Australia; the
individual’s experience of HIV disease and treatment from the perspective of a person living and or working in rural or remote areas and those who hold temporary visas; and the policies that prescribe access to ARVs, and Australian residency. The second chapter, concerning the methods used in this research, explores the methodological considerations, specifically the principles of ethnography and the rationale for taking an ethnographical perspective to the issues outlined. The aims, objectives and the specific methods used are detailed as are the setting and context of the study. Pertinent ethical issues are discussed, including observations made during the course of the study in interactions with participants and key informants. Chapters Three, Four and Five contain the research findings and discussion relevant to those results. In Chapter Six the findings from the three results chapters are synthesized and the patterns that emerged from the data gathered are discussed, and conclusions drawn against caveats imposed by the limitations of the work. Finally, the contribution to current knowledge and the implications of the study findings for policy, practice and future research are presented.

Figure 3: Schematic of population of interest, showing overlapping, contingent groups and the ‘grey area’ between citizens and non-citizens
CHAPTER ONE

LITERATURE REVIEW
CHAPTER ONE  LITERATURE REVIEW

Overview

The chapter will present literature that provides background relevant to the thesis, the overall aim of which is to explore the experience of people living with HIV who are potentially challenged by factors that might influence HIV health outcomes, with a particular focus on the impact of HIV disease on people’s lives, and access and adherence to treatment. People on temporary visas and those living or working in regional areas of Western Australia are seen to fit this category. Factors pertaining to health-related quality of life in HIV have been studied in our WA setting and this data will be used to position the findings in context.

In order to understand the weighty health and social implications of a diagnosis of HIV it is necessary to appreciate the biology of the organism, the medical treatment for the condition, the availability of that treatment and the context in which people live their lives with HIV. This approach is consistent with ethnographic theory. Therefore this chapter will present material relevant to:

- The biology and treatment of HIV disease
- Current epidemiology
- Medication adherence theory
- Health-related quality of life in HIV
- The current status of HIV treatment access nationally and internationally
- Aspects of visa status and population mobility
- Aspects of geography that affect access to medical care and treatment in WA
I will highlight where this research is positioned within current knowledge of these topics. Reference to research conducted in the WAHCS over the last ten years that is pertinent to this thesis will be made.

**Search strategy**

Databases were searched for peer reviewed manuscripts on the topics of HIV disease, treatment access, medication adherence, migration, guest workers and rural living – in the context of HIV. The Scopus database was used extensively since it is the largest publication database with 100% Medline coverage and has a number of features that enable the user to make connections between research fields and identify key information in less well known journals. The reference lists of retrieved articles were scrutinised, and these provided leads to other relevant documents. The Murdoch University librarian accessed articles on demand if they were not available on-line. Likewise with texts of interest accessed from other universities but not necessarily cited in this work. The Royal Perth Hospital librarian sent a monthly report of an Ovid/Medline search for articles in English on medication adherence and antiretroviral drugs. This was filtered and directly imported into Endnote. Colleagues were consulted, and serendipitous contacts made at conferences suggested material that might prove useful, including a confidential report by the Australian Federation of AIDS organisations (AFAO) released in 2009, but not publicly distributed (I was given access to this in 2011); and a submission by NAPWA (2009) to the Joint Standing Committee on Migration Inquiry into Immigration Treatment of Disability. Graham Brown, the then President of AFAO sent me his unpublished West Australian-based research paper on “The Male Overseas Acquired HIV Social Research Study”. In addition to this document, two unpublished theses were shared with me by their authors and these
were: “Seeking asylum and living with HIV: an ethnographic study” by Lois Orton; and Jane Bruning’s Master’s thesis on “Stigma and women living with HIV”. Ellen ‘t hoen’s thesis on “The global politics of pharmaceutical monopoly power” was discovered, publicly available, online. Selected conference proceedings were perused, particularly those from the Australasian HIV/AIDS National Conferences from 2007-2011, in order to uncover contemporary, national research reports concerning migrants, visa holders and people living or working in rural areas, in the context of HIV.

HIV and AIDS in Context

Infection with the human immunodeficiency virus (HIV) is the precondition for developing acquired immunodeficiency syndrome or AIDS. AIDS occurs as a consequence of damage to the immune system, specifically death mediated by the virus, of an important subgroup of lymphocytes called CD4 T-cells. Profound immunodeficiency ensues resulting in vulnerability to infection which is termed opportunistic and includes cancer-causing (oncogenic) viruses resulting in conditions such as Kaposi’s sarcoma and Hodgkin’s Lymphoma. One or more clinical problems may occur in someone with AIDS —therefore it is referred to as a syndrome — and certain clinical problems are called AIDS defining because they occur at a particular stage of immune deficiency (Figure 4) (Crowe, Carlin, Stewart, Lucas & Hoy, 1991; P. Williams, Currier & Swindalls, 1999). A person infected with HIV and untreated with ARVs usually dies within 10 years. Unlike many other infectious diseases transmission of HIV occurs in a social and frequently highly charged emotional context and this has significant implications for how people perceive the disease and how it can be prevented (Bartlett, Gallant & Pham, 2009; Coates, Richter & Caceres, 2008).
The Origins of HIV

HIV is classified as a retrovirus because of the manner in which it reproduces. Experimental data indicating the connection between AIDS and retroviruses was published in France by Luc Montagnier’s team (Barré-Sinoussi et al., 1983) and then researchers led by Robert Gallo in the US, published epidemiological and virological data that a virus which we now call HIV caused AIDS (Gallo et al., 1983). However, the first case of HIV-1 was thought to have occurred in Africa around 1930 (Korber et al., 2000). Viral mapping or sequencing reveals that HIV probably arose from a number of zoonotic transmissions to humans from chimps endemic to central West Africa since these primates are susceptible to simian immunodeficiency virus (SIV) and were hunted for bush meat (Sharp & Hahn, 2010). A syndrome described as ‘slim disease’ characterised by a slow wasting illness and described by Serwadda and colleagues.
(1985) in Ugandans, was subsequently attributed to infection with the human immunodeficiency virus. This wasting came to represent the physical manifestation of HIV/AIDS stigma. Increased population mobility was largely responsible for the initial spread of HIV, when transport networks between African regions expanded in concert with increased economic development (Lagarde et al., 2003; Perrin et al., 2003; Salit et al., 2005; Tatem et al., 2006).

HIV is classified into two major types: HIV-1 and HIV-2. The latter, endemic to West Africa, is considered less infectious, associated with a lower viral load and slower CD4 T-cell count decline and slower progression to AIDS, however many people are coinfected with HIV-1 and the prevalence of HIV-2 is low. HIV-1 is divided into subtypes or clades with subtype C the most common in South and East Africa followed by subtype A and a mixed or recombinant form (CRF) 02-AG in West and West-Central Africa. Subtype B is dominant in North America, Western Europe and Australia; and in East Europe, Central Asia: A and B; East Asia: B, C, BC, CRF 01; and in the largest epidemic, South Asia, subtype B and AE have been described (Bartlett et al., 2009). The genetic diversity of HIV and the evolution of subtypes and recombinant forms has grown (Easterbrook et al., 2010). How this influences the pathogenicity of the disease and whether this is clinically relevant has become an important issue because of the significant migratory ebb and flow of people across international borders.

In WA there has been an increase in the diversity of HIV subtypes sequenced from people diagnosed with HIV infection demonstrating the ingress of Clade C virus into the local population. This represents a shift in prevalence away from Clade B as the dominant circulating strain, 92% in 2000 vs 61% in 2009 (Castley, Gizzarelli, Whidbourne, Nolan & John, 2010), and reflects the trend in European countries that
are also experiencing a rise in migration from HIV-prevalent areas where Clade C is the dominant strain (Easterbrook, et al., 2010).

**Life Cycle of the Virus**

Viruses cannot replicate independently and rely on their hosts’ intracellular processes to reproduce. Retroviruses such as HIV use an enzyme called reverse transcriptase to copy or transcript their RNA into a DNA copy thus enabling integration with human DNA in the CD4 T-cell nucleus (Figure 5). RNA viruses have a high mutation rate and naturally occurring strains replicating in the absence of any suppressive drug therapy are called ‘wild type’ virus. In addition, HIV has a high error rate during reverse transcription. These factors together mean that when wild type HIV replicates it has a high rate of mutation. It is estimated that every possible mutation at every position in the virus occurs once a day. Such genetic changes which result in altered viral proteins are called polymorphisms. Particular mutations which allow the virus to resist the action of an anti-HIV drug would thus become naturally selected if the virus is exposed to drugs but can still replicate, such as when the patient is partially adherent to antiretroviral drugs (Bangsberg, 2008b). Individuals can become infected with multiple strains of HIV and this is called ‘superinfection’ (Goulder & Walker, 2002), though is considered a rare phenomenon.

**Reproduction**

The circulating HIV particles (virions) are surrounded by an envelope which contains proteins that must bind to the CD4 T-cell receptors and co-receptors such as CCR5 and CXCR4 on the surface of the cell before the virus can enter it. On entry the virion releases its genetic material into the cytoplasm of the CD4 T-cell. The HIV genome consists of nine genes. *Gag* encodes the structural proteins of the virus. *Pol* gives rise
to the expression of three enzymes essential for HIV replication: (1) reverse transcriptase (RT) which acts to transcribe viral RNA to DNA; (2) integrase which enables HIV to insert its genetic material into the host cell’s genome; and (3) protease which cleaves the newly produced viral proteins and repackages them into mature virions which are released from the CD4 T-cell cytoplasm into the lymphatic system. These three enzymes are the individual targets of antiretroviral drugs which, given in combination disrupt HIV from multiple angles optimizing the potency of the therapy and decreasing the opportunity for viral escape and virological failure. Importantly, each person differs in their response to a drug and these differences can in large part be attributed to an individual’s genetic makeup or ‘host genetics’.

![Figure 5: Lifecycle of HIV. A virion invades a CD4 T cell and provides a target for antiretroviral drugs (Fauci, 2003)](image-url)

**Acute infection**

After infection the virus is largely concentrated in gut-associated lymphoid tissue (GALT) in the small bowel where the number of viral particles or copies amplifies to ‘peak viraemia’ (Brenchley et al., 2004). At this time there is significant depletion of CD4 T cells (again in the gut where the majority are found) and 60-80% may be
destroyed in the first 17 days of infection when clinical symptoms may be apparent during *acute retroviral syndrome*. During this phase an individual is acutely infectious and some studies suggest that between 40 and 45% of transmissions occur in this phase when individuals may be unaware that they carry the virus (Wawer et al., 2005). More recently the Centers for Disease Control has estimated that about 21% of HIV-infected individuals who are unaware of their HIV infection account for 54% of new diagnoses and that the number of transmitted infections could reduce by 30% by informing those unaware of their status. Preventing transmission during this highly infectious period of the disease clearly poses a major public health challenge (CampsSmith, Rhodes, Hall & Green, 2010; Centers for Disease Control, 2008).

A number of tests are performed after exposure to HIV. The most common test for HIV diagnosis is a serological antibody test called the enzyme linked immunosorbent assay or ELISA which measures antibody responses to the presence of HIV infection. Since antibodies may take up to six weeks post exposure to appear, newer generation testing kits also incorporate the direct detection of HIV viral proteins (typically p24) to provide a more comprehensive assessment of recently acquired HIV infection.

Between two and twelve weeks after infection an illness called *acute retroviral syndrome*, occurs in approximately 50-80% of infected people (Figure 6). Seroconversion is the transition in status from HIV antibody negative to HIV antibody positive. This illness can manifest from mild malaise and swollen lymph nodes, through to gastrointestinal effects, ulceration of mucosa and neurological abnormalities.

Although the high levels of virus in the body stimulate the production of CD4 T-cells these become targets for the virus and the immune system is quickly damaged. Cytotoxic T lymphocyte cells (CTLs) or CD8 T-cells act to kill cells infected with foreign
antigens and, in response to HIV antigen, become HIV-specific. They are also involved in ongoing immune activation by secreting pro-inflammatory cytokines that can have both beneficial and detrimental long term effects, and influence progression both to AIDS and non-AIDS illness. Important among these cytokines are the interferons alpha and gamma, TNF alpha and interleukin-2. This version of natural immunity governed by the T lymphocytes is known as cell-mediated (Kelly, 2003). More recent research has indicated that within the so called humoral or B cell responses to infection, neutralising antibodies and complement proteins may play a greater role mediating the interplay between the host immune system and the virus than was previously thought (Moir & Fauci, 2009). Unfortunately the virus evades any HIV antibodies produced by the human by rapidly mutating two of the viral proteins: gp120 and gp41 which would be the natural targets of the antibodies and this is one of the reasons that HIV is difficult to eradicate. Furthermore, since each generation of viruses is different from the former and the immune system only recognises viruses that resemble the previous generation the virus is able to evade detection – in effect it escapes (Fellay, 2009; C.B Moore et al., 2002).

**Chronic Infection**

At a round six months post infection and following the initial CD8 T-cell activation and CD4 T-cell decline, a transient equilibrium is reached and there is deceleration of CD4 T-cells depletion. Thereafter, in untreated individuals, CD4 T-cell count declines by approximately 60 CD4 T cells/mm$^3$ per year, although this loss is highly variable between individuals. However, attrition of CD4 cells and particularly the memory subset of these cells mean that the immune system has lost some ability to recognise, and fight, previously known antigens and this is what makes people, particularly
children, more susceptible to infections from a range of other microorganisms. A viral set point (Ho, 1996; Mellors et al., 1996) is reached when viral load plateaus to a steady state—this is also indicative of rate of progression to AIDS and comes about from the dynamic interaction between HIV and the host’s cell-mediated immune responses which are governed largely by genetic factors specifically the Human Leucocyte Antigens or HLA (Bartlett et al., 2009).

Transmission event (usually occurs in a social context)

<table>
<thead>
<tr>
<th>Event</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Viral transmission</td>
<td>2-3 weeks</td>
</tr>
<tr>
<td>Acute retroviral syndrome</td>
<td>2-3 weeks</td>
</tr>
<tr>
<td>Recovery + seroconversion</td>
<td>2-4 weeks</td>
</tr>
<tr>
<td>Asymptomatic chronic HIV</td>
<td>avg. 8 years</td>
</tr>
<tr>
<td>infection</td>
<td>avg. 1.3 years</td>
</tr>
<tr>
<td>Symptomatic HIV infection</td>
<td>avg. 1.3 years</td>
</tr>
<tr>
<td>AIDS</td>
<td>Death</td>
</tr>
</tbody>
</table>

**Figure 6:** The natural stages of HIV infection. Adapted from Bartlett et al. (2009)

**Host genetics**

HLA antigens are the major determinants of recognition and differentiation of self from foreign pathogens and are found in nearly all nucleated cells in the body and in high concentrations on lymphocytes. They form part of the Major Histocompatibility Complex or MHC, a region found on the short arm of chromosome 6. There are more than 220 highly variable HLA molecules and many of them encode proteins of the immune system. The genes are categorised into three basic groups Class I (HLA-A, HLA-B and HLA-C), Class II (HLA-DPA1, HLA-DPB1, HLA-DQA1, HLA-DQB1, HLA-DRA, and HLA-DRB1) and Class III. The proteins produced or expressed by the genes are exported from within human cells and are bound to protein fragments known as peptides which, in effect, mark the cell. These are displayed to CD8 T-cells and, if recognised as foreign, initiate a cascade of events leading to either destruction of the foreign cell or an inflammatory reaction with accompanying activation of cytokines, depending on which class of genes is activated. Alternatively, if the proteins are
recognised as ‘self’ then the system downregulates to prevent immune activation —
failure to do this results in autoimmune disorders. Presentation of peptides can occur
in response to the incursion of intracellular pathogens, spontaneous genesis of
malignant cells and also ingestion or exposure to man-made substances such as drugs
(Delves, Martin, Burton & Roitt, 2006).

The Class I pathway and its major genes: HLA-A, HLA-B and HLA-C play a primary role in
mediating pathogenic viruses like HIV, and their specialisation has evolved across
centuries, shaped by exposure to ancient epidemics such as the plague, tuberculosis
and malaria that have impacted upon natural selection. That this has occurred
translates to racial differences in polymorphism frequency of certain HLA alleles
between global regions, and this has implications for the progression of infection and
how different individuals respond to drug therapy and are susceptible to adverse side
effects. There have been numerous studies that describe these polymorphisms and
demonstrate that the MHC genes are the major factor modulating durable control of
HIV infection (Pereyra et al., 2010).

**Host viral interaction**

Three of the HIV-1 genes *tat*, *nef* and *vpu* encode for proteins of the same name and
all can affect host cell recognition of the virus. While *tat* is a viral protein mainly
involved in the transcription of HIV from the integrated viral genome, it also regulates
the amount of virus presented to the HLA genes and chemokine and cytokine
production, thus reducing immune responses against HIV. Similarly *nef* interferes with
antigen presentation to CTLs and the *vpu* protein acts to reduce the number of CD4 T-
cells available to assist in eradicating the virus (Bartlett et al., 2009).
This is important because, as previously mentioned, RNA viruses mutate in order to avoid immune recognition and escape from cytotoxic T-cells (largely CD8) which can kill HIV before it has replicated. The chance of escape and the context under which it occurs have been described elsewhere (C.B Moore et al., 2002), however two important conditions are that: first, mutation can occur under selective pressure from drug therapy; and second, that human genetic makeup by way of polymorphisms, can affect protein expression in cells. Striking examples of these are the chemokine ‘docking’ receptors which are necessary for the entry of HIV into the cells found on the CD4 T cell surface: CCR5 and CRCX4 are examples of these and they have been exploited in new drug treatments. Although polymorphisms are uncommon they may be nuanced in that other chemokines that can bind to these receptors can result in cell-mediated responses that influence the course of the infection (Dolan et al., 2007).

In summary, the science reveals that there is a complex relationship between the parasitic virus and the human host’s ability to withstand the damaging effects of the virus on the immune system which, without treatment, are likely to be overwhelming within an average of ten years.

**Treatment for HIV/AIDS**

It was not until 1986, five years after the first cases of AIDS were identified in the US that the short term, small, placebo controlled trial sponsored by Burroughs Wellcome Company demonstrated the antiretroviral effectiveness and potency of azidothymidine or AZT (zidovudine), a drug previously tested for the treatment of cancer, at reducing viraemia in people with HIV/AIDS (Fischl, Richman & Grieco, 1987; McLeod & Hammer, 1992). And it was some long years and many more deaths before protease inhibitors and combination antiretroviral therapy commonly referred to as highly active
antiretroviral therapy or HAART was introduced in the mid-1990’s (Flexner, 1998). Since then there has been a dramatic reduction in mortality and morbidity from HIV/AIDS (Hogg et al., 1997; Palella et al., 1998). The current view is that administering ART is preventive in the sense that it reduces the infectivity at an individual level and reduces rates of transmission (Cohen & Gay, 2010). Furthermore, early intervention with ART may prevent irrevocable immune damage and the systemic effects of ongoing immune activation stimulated by the presence of virus (Cohen et al., 2011).

To date, the primary aim of ART has been to lower viral load by preventing replication of the virus and thereby restore immune function (Fauci, 2003), and the pathway to achieve this outcome is complex (Figure 7) (Friedland, 2006). The indirect effects of reducing viral load, especially in acute infection, are also beneficial in that: the rate and number of mutations can be reduced and some HIV-specific T-helper cells preserved. But in general, the mutable characteristics of HIV, including the propensity of the virus to become resistant to drugs has presented a huge challenge to researchers and a burden for those with the infection. As previously mentioned, a regimen is usually constructed from a combination of several drugs from at least two classes that act variously on the life cycle of the virus (Figure 5). A person who has never been exposed to antiretroviral treatment is said to be drug naïve and therefore the initial therapy is termed a ‘first-line’ regimen (HIV Treatments Directory, 2008).
The selection of a first-line regimen and consequent determinants of efficacy are predicated upon a number of factors. In the developed world, sensitivity of the virus to antiretroviral agents is tested in any individual, \textit{ex vivo} to ensure that a drug treatment will be effective. Genetic testing may also be carried out to ensure that a person does not have a predisposition to drug hypersensitivity. However, access to testing and access to antiretroviral drugs is not universal and selection of suitable ARVs may be limited. Cost may be a factor even in settings where the drug is freely available if a co-payment is required. Acceptance of the treatment and potential adverse side effects: including a belief in its being effective; and the ability to adhere to a lifetime of ‘pill taking’ and attendant medical supervision are important aspects which both the physician and patient must consider at the commencement of therapy. Other aspects include the characteristics of the drug that are influenced by its inherent pharmacokinetic properties (including ease of storage) as well as the individual genetic and viral characteristics that influence absorption and metabolism. Pre-treatment HLA-typing and drug resistance testing is recommended to avoid prescribing either a potentially toxic or ineffective regimen (Hirsch et al., 2008). Pre-treatment discussion

\textbf{Figure 7}: Therapeutic schema of the determinants of drug efficacy adapted from Friedland et al. (2006)
between provider and patient is considered best practice (De Bruin et al., 2010; Harman, Amico & Johnson, 2005) in adherence management, and key to maintenance of optimal medication adherence.

**Antiretroviral Drugs**

The points at which drugs target particular stages of the life cycle of HIV can be visualised in Figure 5.

**Nucleoside reverse transcriptase inhibitors**

The first drug to be approved for the treatment of HIV in 1987 was zidovudine, commonly abbreviated and known as AZT (Fischl et al., 1987). Classified as a nucleoside analogue reverse transcriptase inhibitor (NRTI) or simply, nucleoside analogue, this drug and others of its class work to block the action of reverse transcriptase. However, before they can be used they must be converted to an active form of triphosphate by a process of phosphorylation. Nucleotide RT inhibitors are similar to nucleosides but only require one step in the process of phosphorylation to convert to triphosphate (HIV Treatments Directory, 2008).

**Non-nucleoside reverse transcriptase inhibitors**

The second class of antiretroviral drugs closely related to the NRTIs, are the non-nucleoside reverse transcriptase inhibitors, or NNRTIs, these act on RT but at a different site from the former and they are not incorporated into the viral DNA—they are therefore complementary (HIV Treatments Directory, 2008). The most commonly prescribed and licensed in WA are efavirenz (EFV), nevirapine (NVP) and a more recent addition—etravirine. The half life of these drugs is long and this has implications for the maintenance of therapeutic drug levels, as shall be described further. Skin rash and
liver toxicity are the major concerns with the administration of NNRTIs, particularly nevirapine, and approximately 15% of people starting may develop rash within the first couple of months of treatment, with a smaller proportion developing a multisystem drug hypersensitivity syndrome that can include a systemic illness with fever, hepatotoxicity, and peripheral blood eosinophilia. Predisposition to this hypersensitivity syndrome is thought to be genetic in origin involving HLA alleles (Yuan et al., 2011), with an additional affect of higher CD4 T-cell counts at the time of commencing nevirapine. The drug is generally unsuitable for people with HIV/hepatitis C coinfection or other co-existing liver disease, but is used safely in pregnant women to prevent mother to child transmission of the infection (Sturt, Dokubo & Sint, 2010). Efavirenz in contrast, is not safe to use in pregnant women but, similar to nevirapine, appears to be influenced by host genetic factors in that more severe side effects are experienced by people of African descent. This seems to be as a consequence of high blood levels related to the metabolism of the drug (Ribaudo et al., 2006). Major side effects appear to affect the central nervous system and at worst cause depression, disorientation and psychosis however, most commonly, EFV affects sleep and dreams. Efavirenz can be detected in the urine as tetrahydrocannabinol, or THC, and this has implications for patient management.

**Protease inhibitors**

This class was introduced in the mid 1990’s and the use of protease inhibitors (PI’s) in combination with NRTIS’s reduced mortality in those with access to this treatment. As the name suggests protease inhibitors block the action of the protease enzyme during the assembly of virions from the larger precursor (gag, pol) polyproteins (Figure 5). There are ten drugs from this class licensed for use in Australia and about six of these
are commonly used in WA. Common side effects are gastrointestinal, but drug-induced dyslipidaemia is common and monitoring of fasting blood lipids is routinely carried out. One important characteristic of HIV protease inhibitor therapy is that low-dose ritonavir is commonly used to boost the effect of other protease inhibitor drugs by inhibiting CYP3A4 metabolism. This increases the propensity for HIV protease inhibitor treatment to interact with other drugs including anti-tuberculosis agents, contraceptives and opiate substitution therapy such as methadone (HIV Treatments Directory, 2008).

Entry inhibitors

Entry inhibitors include CCR5 and CXCR4 antagonists, and fusion inhibitors. These drugs act variously to block HIV from binding to either one of the two receptors on the CD4 surface or the chemokine receptors CCR5 and CXCR4 (Figure 5). Again host genetics play a role in determining which chemokines are likely to be expressed and viral genetics determine the attraction or tropism of the virus to the hosts CD4 cell (Ahuja et al., 2008; Swenson et al., 2011).

Integrase inhibitors

The second important enzyme in the life cycle of the virus is integrase (Figure 5) which acts to insert viral DNA into the host chromosome in the nucleus of the CD4 T cell (HIV Treatments Directory, 2008). Raltegravir is an example of an integrase inhibitor drug now in use in WA for people for initial therapy as well as with treatment-experienced patients (personal communication David Nolan, August 2012).
Potency of antiretroviral therapy

The efficacy of the treatment relies on achieving optimal systemic and intracellular concentration of drug levels in the blood to suppress the virus. The ability of the body to absorb, distribute, metabolise and eliminate or clear the drug from the body is influenced by inherited genes. However, only a small number of gene variants have been discovered that are known to predict outcomes (Lubomirov et al., 2011). Of particular relevance currently is the HLA-B* 5701 allele, presence of this allele confers a highly predictive hypersensitivity to abacavir, a commonly prescribed NRTI (Mallal et al., 2002, 2008). Another common important polymorphism is G516T which is linked to rate of clearance of efavirenz, this change is located on the gene for cytochrome P-450 2 B6 which influences metabolism of the drug (Ribaudo et al., 2006) More commonly, drug interactions and, in particular inadequate medication adherence, lead to sub-therapeutic drug levels which can result in the emergence of drug resistance via a mechanism known as selective pressure (Richman, 1996).

Figure 8: How drug resistance arises (Richman D, 1998)

Drug resistance

Mutations in the genetic material of a virus in response to a drug usually result in the virus becoming less sensitive or insensitive to anti-viral drugs; in effect it becomes ‘resistant’ (Figure 8). Resistance to antiretroviral drugs may be de novo or acquired
following non-suppressive treatment, this is called secondary resistance. However, if it is transmitted between individuals it is termed primary resistance (Turner & Wainberg, 2006). Since HIV is highly mutable, at any one time a person can have several species of circulating virus or quasi species, and one or more may be drug resistant. A feature of drug resistance is cross resistance which means a virus resistant to one drug may be resistant to the entire group or class of drugs. Since tests designed to pick up drug resistance are only sensitive to detect mutations with a frequency above 10-20% of the total viral population, low level drug resistance may be undetectable. Drug resistant viruses are not necessarily more able or ‘fit’ than drug sensitive viruses however replication of the resistant virus can occur over time in a treated person leading to a dominance of drug resistant over drug sensitive virus and someone with a viral load previously undetectable using current testing methods may begin to show low levels of viraemia which will alert the practitioner to investigate the likely causes. In effect the binding capacity of the drug to the virus gradually diminishes until the drug is ineffective and viral rebound is said to occur. As the availability of ART increases, the proportion of new HIV infections that involve resistant strains also tends to increase, which has implications for public health interventions. However resistance can be avoided with the careful individualization of treatment to patients, as is the standard in developed countries (Hirsch et al., 2008; Little et al., 2002)

Sub-optimal antiretroviral drug levels can occur as a consequence of poor absorption of drugs which can in turn come about from a drug-drug interaction for competition with sites of metabolism in the liver or genetic differences that result in variability in drug metabolism. However, in any individual, by far the most common reason for sub-optimal drug levels arises from missing doses in a regimen that is otherwise followed persistently (Paterson et al., 2000).
Adherence to and Persistence with Antiretroviral Drugs

Adherence to medical care or treatment is a dynamic behaviour that can change over time. It can be defined as the extent to which a person’s behaviour, for example, taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider (Haynes, Wang & Da Mota Gomes, 1987; World Health Organisation, 2003). Medication adherence refers specifically to the ability to take medication as prescribed, which means taking the correct dose of the intended drug at the right time and following any special instructions as specified, for example: take with meals. In effect adherence refers to the outcome of the comparison of the prescribed dosing regimen and the patient’s dosing history, while they remain engaged with treatment (Vrijens, Vincze, Kristanto, Urquhart & Burnier, 2008). This is often expressed by patient self-report or by using data from an electronic medication event monitoring system (MEMS) as a percentage of doses taken over a prescribed period of time (Lu et al., 2008). Persistence with medication is defined as the “continuous treatment with a prescribed medication or intervention without interruption beyond the therapeutic range of the treatment” (Bae, Guyer, Grimm & Altice, 2011). Conceptually, persistence is related to adherence behaviour, but it further discriminates pill taking behaviour by describing the duration of time that a person remains on a course of treatment. Bernard Vrijens and colleagues (Vrijens & Urquhart, 2005) plotted the chronology of adherence and persistence in four patients taking an antihypertensive drug once daily. Their findings are shown in Figure 9.
A person is defined as persistent to a drug as long as the ‘permissible gap’ has not been breached and this may vary according to the constituent drugs in the regimen. The permissible gap is defined as the “duration between the initiation and discontinuation of a specified antiretroviral regimen as agreed upon by the patient and the health care provider” (Bae et al., 2011). Persistence differs from adherence in that adherence behaviour is subject to the attributes of the individual, drug or environment of the person executing the regimen (Ickovics & Meisler, 1997) whereas non-persistence can be attributed to both patient or regimen factors which may be outside the patient’s control (Bae et al., 2011). In essence the concepts of adherence and persistence are interrelated but the former pertains to the quality of executing of the regimen whereas the latter represents disengagement from treatment and the two behaviours may have varied clinical and economic consequences (Vrijens et al., 2008). Hill, Kendall and Fernandez (2003) while not differentiating these terms, described patterns of adherence to ARV regimens in HIV which usually contain a combination of at least three drugs as:
• Skipping one type of medication
• Taking medication several hours late
• Taking medication very rarely (once a week/month)
• Not sticking to eating or drinking restrictions
• Adhering to a purposely modified regimen
• Adhering to an unknowingly incorrect regimen
• Alternating between long periods of taking and not taking medications

The Concept of ‘Forgiveness’

Hill’s findings have particular relevance for people on once-daily, and including fixed-dose combination regimens, with regard to a pharmacological concept known as ‘forgiveness’. The ‘forgiveness’ of a drug is the difference between a medication's post-dose duration of beneficial action and the prescribed dosing interval. Most drugs used in the general population today, have plasma half lives of 12 hours or less (Osterberg, Urquhart & Blaschke, 2010). If dosing schedules are interrupted, concentrations of the drug in the blood will fall below the level considered therapeutic that would have been maintained by continuous dosing. Drugs that are described as ‘forgiving’ generally have a prolonged pharmacodynamic effect typically because the plasma half-life has been extended or because, as a characteristic of the drug, a receptor or enzyme is knocked out and regenerates slowly. As a concept, forgiveness is probably best understood in the way the oral contraceptive pill has been designed and marketed. Indeed, the contraceptive pill represents one of the first instances where written instructions have been prepared for consumers on what to do if they miss one or more pills. A group of drugs designed to treat a particular condition for example, depression or hypertension may have widely differing plasma half-lives so that forgiveness may be
very narrow, and missed doses can have an immediate clinical consequence. This phenomenon might also explain why different values of forgiveness result in some medications seeming more effective than others (Osterberg et al., 2010). In the management of HIV infection drug ‘forgiveness’ has important clinical implications (Bangsberg, 2006a; Bangsberg et al., 2003; Bangsberg, Moss & Deeks, 2004; Knobel et al., 2009; Parienti, 2002; Parienti et al., 2008; Pham, 2009).

**Why is Medication Adherence so Important?**

The World Health Organisation reports that adherence to long term treatments for chronic conditions averages about 50% in developed countries and less in least developed countries (World Health Organisation, 2003). In the United States between 33% and 69% of medication-related admissions in the US are as a consequence of poor medication adherence which is estimated to cost the country approximately $100 billion dollars per year (Osterberg & Blaschke, 2005). Poor adherence in clinical trials can result in an underestimation of treatment side effects and efficacy, although adherence is better in clinical trials and this is thought to be a consequence of bias in patient selection and the positive attention from health care providers that patients receive in the course of the trial. There are now organisations engaged by pharmaceutical companies to monitor medication adherence during drug trials. Monitoring adherence has now become something of an industry, for example, the advertisement:

‘The future of healthcare—there’s an app for that’


Arguably, resolution of many infectious diseases, like tuberculosis (TB) which is curable and malaria which is preventable, is predicated on adherence to antibiotic or antiviral
treatment. Sometimes this treatment may be short term but in the case of hepatitis C treatment can last up to 18 months. During the early years of HAART, near perfect medication adherence (over 95% of doses) was needed to suppress blood levels of the virus and prevent progression to AIDS (Paterson et al., 2000). Later, research showed that not all classes of drugs required the same stringency of adherence; (Bangsberg, 2006a) and added evidence that the relationship between adherence to treatment and drug resistance was not linear (Bangsberg et al., 2003, 2004, 2007). Whatever the adherence level required, it was evident that HAART, only 15 years old, had saved millions of lives (Palella et al., 1998); and treatment has subsequently been shown to reduce rates of transmission (Cohen & Gay, 2010), but only in those with the ability to access and adhere, long term, to the drugs.

Raising the Alarm: Medication Nonadherence in HIV

Initial concern about medication nonadherence in HIV and the risk of primary and secondary drug resistance arose with the advent of HAART. Physicians in New York City had observed an epidemic of drug resistant TB as a consequence of poor adherence to anti TB drugs. Since the risk factors for nonadherence were poor mental health, addiction to substances and unstable housing, there was a perception that these factors were causal and some physicians withheld treatment from AIDS-affected individuals who fit this demographic (Sontag & Richardson, 1997), thereby providing one of the earliest examples of discrimination or enacted stigma in HIV/AIDS. However, the relationship between antiretroviral adherence, viral suppression, and progression to AIDS related mortality is now well established, although the unique adherence-resistance relationship of ARVs (Bangsberg et al., 2004) has broad implications for prescribers (Figure 10). The reason for this, in part, is that unique
patterns of pill-taking behaviours affects NRTI, NNRTI and PI classes differently in terms of the consequent signature mutations (Bangsberg, 2003, 2006). Specifically, this has to do with drug class characteristics such as the potency of the drug, half life in plasma (Hardman, Limberd & Gilman et al., 2001), and site of action, for example, distance from target enzyme and capacity to develop cross resistance (Bangsberg et al., 2004). Understanding this important relationship is critical to ensure viral suppression and prevent rebound viraemia. Furthermore, given the difficulty of maintaining high levels of adherence, it is necessary to know the threshold values for individual drugs so as to tailor regimens to suit individual requirements including. These include: host genetics; concomitant medications that might interact with ART; and factors in the individual’s environment that may be dynamic over time, known as ‘pharmacoecologic’. For example, patient preference for dosing schedules and side effects that they are willing to tolerate (Heath, Singer, O'Shaughnessy, Montaner & Hogg, 2002; O'Brien, Clark, Besch, Myers & Kissinger, 2003; Pavlos & Phillips, 2011; Pham, 2009).

Figure 10: Relation between individual drug classes, levels of adherence and risk of resistance mutations. Adapted from Bangsberg, Moss & Deeks (2004)

Abbreviations: PI = protease inhibitors; NNRTI = non-nucleoside reverse transcriptase inhibitors.
The Pharmacokinetics of Commonly Prescribed Antiretroviral Drugs

People with variable access to ART or who choose to interrupt their treatment, for whatever reason, are particularly vulnerable to the effects of non-persistence arising from the less than therapeutic exposure to the drugs (The Strategies for Management of Antiretroviral Therapy (SMART) Study Group, 2006) and this effect is cumulative (Knobel et al., 2009). Some specific examples follow. Nevirapine (NVP), an NNRTI, remains detectable one week after discontinuance whereas abacavir and lamivudine, drugs which are commonly used in combination with NVP, have serum half lives of 1.5 hours and 6 hours, respectively. The intracellular concentration of the active metabolite of abacavir becomes undetectable within 72 hours of the last dose. (Bae et al., 2011; Mackie et al., 2004; Mirochnick et al., 1998; Johnson, Moore, Yuen Bye & Pakes, 1999; Kumar et al., 1999). Therefore, if this combination is ceased together then an extended period of monotherapy (under NVP) results and resistance to nevirapine (which has a low genetic barrier to resistance) can ensue (Richman et al., 1994). Efavirenz, another commonly used NNRTI has a serum half life of 40 - 55 hours and can remain at a therapeutic level for 21 days after it is ceased. However, although efavirenz and nevirapine can continue to suppress HIV if they are stopped or missed for a short time they are more likely to develop resistance when they are stopped for longer periods. The ‘permissible gap’ for a NNRTI is estimated to be between 2 and 7 days for an efavirenz containing regimen (Bangsberg et al., 2003; Bangsberg et al., 2004; Parienti et al., 2008; Ribaudo et al., 2006). In contrast, ritonavir boosted PI regimens have a high genetic barrier for resistance so that even at a lower serum concentration, potency is maintained and the occurrence of resistance mutations less common (Swindells et al., 2006). Thus giving rise to the concept discussed earlier that such a regimen is ‘forgiving’.
Non-persistence with medication can arise from factors intrinsic or extrinsic to the patient or regimen. Intrinsic factors include: pill burden, adverse side effects, underlying resistance and cost of the drug. Extrinsic factors are those that might influence the practitioner to alter the regimen including: findings from clinical trials, treatment guidelines, and choice predicated by regional access to particular treatments (Bae et al., 2011).

**Measurement of Adherence**

No single method for measuring adherence has been widely accepted (Nachega et al., 2011), however, methods for measuring both adherence and persistence can be summarised as:

- Directly observed therapy (DOT) (Lucas, Flexner & Moore, 2002; Ford, Nachega, Engel & Mills, 2009)
- Medication event monitoring system (MEMS Cap) *(Figure 9)* (Bangsberg, 2001)
- Patient recall, with or without a validated questionnaire (Morisky, Green & Levine, 1986; Chesney et al., 2000; Wagner, 2004)
- Pharmacy refill data, which does not discriminate patient persistence but is useful to indicate whether a regimen persists *(Figure 11)* and in Australian settings was found to correlate with viral load and self-reported adherence (Fairley et al., 2005; Herrmann et al., 2008)
- Medical record review which should indicate record of side effects or other reasons for difficulties with adherence or patient-initiated treatment interruptions, and start and stop dates of regimens
- Database search (Andrade, Kahler, Frech & Chan, 2006; Vrijens et al., 2008)
The Challenge ofPersisting with Lifelong HIV Treatment

Bae and colleagues (2011), in an editorial review, commented that patient nonpersistence to ART in HIV had been insufficiently addressed given its association with adverse clinical outcomes. They went on to report a series of studies beginning from 2002 (Hogg et al., 2002) that showed that intermittent use of ART, from gaps exceeding 48 hours onwards, resulted in drug resistance and increased mortality.

Significantly, the authors differentiate between patient and regimen persistence or durability, which has increased in recent years alongside the development of fixed-dose co-formulations (FDCs) and is associated with the greatest likelihood of sustained virological suppression (Willig et al., 2008). Klein et al (Klein, Willemot, Murphy & Lalonde, 2004). The authors report that NNRTI-based initial or ‘first-line’ regimes were more likely to be durable than PI-based combinations. Should first regimens fail, salvage regimens, although improved over recent years, may not be as successful as the initial combination, be associated with a more complicated dosing schedule, and be less tolerable and therefore influence likely successful adherence and persistence. Regimen persistence is a particular issue in resource poor settings where ART choices are limited, stock outs are not an uncommon occurrence and food insecurity prevalent (Bae et al., 2011; Nachega et al., 2011; Weiser et al., 2010). For

Figure 11: Adherence correlates with pharmacy refill data (Designed by Bethy McKinnon)
people who may move from region to region and across jurisdictions and health services, such as temporary visa holders, and non-citizens in general, the challenges are evident. While the influence of medical insurance coverage on adherence to ART has been reported and although there have been some studies in migrants, asylum seekers, and illegal immigrants there has been less research on the circumstances of temporary visa holders with HIV and none to date in Western Australia.

![Figure 12: Schematic of fundamental domains which encompass factors influencing adherence to medication. (Ickovics & Meisler, 1997; Ickovics & Meade, 2002a, 2002b)](image)

**Factors that Influence Adherence to and Persistence with ART**

Medication adherence behaviour is complex and dynamic (Carrieri et al., 2001; Ickovics & Meade, 2002a; Ickovics & Meisler, 1997). Although certain characteristics have predicted adherence in some studies, particularly relating to substance use and psychiatric illness (Golin, Liu, et al., 2002; Paterson, et al., 2000; Wagner, 2004) as well as past history of non-adherence (Wilson, Doxanakis, & Fairley, 2004), some clinicians and researchers prefer to think in terms of patterns and correlates of medication non-adherence (Atkinson & Petrozzino, 2009; Beusterien et al., 2008b; Fumaz et al., 2008; J. S. Gonzalez, Batchelder, et al., 2011; Gordillo et al., 1999; Heath, et al., 2002; M. O. Johnson et al., 2005; Murphy et al., 2000; O’Brien et al., 2003; Spire et al., 2002). This
requires a focus on identifying ‘potential barriers’ to achieving good adherence and
developing interventions tailored to individuals, treatment settings and patient
providers as well as an awareness of current best practice guidelines (De Bruin et al.,
2010; Fairley et al., 2003; Harman et al., 2005; Sidat, Fairley & Grierson, 2007).
Adherence is conceptualized as pertaining to aspects of (a) the individual, (b) the
treatment regimen, (c) the patient–provider relationship, (d) the clinical setting, and
(e) the disease (Ickovics & Meisler, 1997). Figure 12 provides a simple schema.

This paradigm has been widely accepted but assumes unfettered access to ART.
Striking reasons for medication nonadherence and patient nonpersistence are drug
dosing schedules, pill burden and side effects such as diarrhoea and fatigue. These are
frequently cited physiological ‘de- motivators’ that result in reduced adherence and
self-cession of treatment without any reference to health care providers (Atkinson &
Petrozzino, 2009; Heath et al., 2002; Murphy et al., 2000). A range of idiosyncratic
psychosocial and behavioural factors also contribute to episodes of missed medication.
These include younger age, substance use, sleep disturbance, depression, non-
disclosure of HIV status (Glass et al., 2006; Golin et al., 2002a; A. Gonzalez et al., 2011;
J. S. Gonzalez et al., 2011; Gordillo, del Amo, Soriano & Gonzalez-Lahoz, 1999;
Herrmann et al., 2008b; Phillips et al., 2005), fear of stigmatization and notions of self-
punishment or reward (Safren et al., 2001).

Indeed the presence of physical and psychological symptoms has been demonstrated
as strongly predictive of viral rebound in those with previously suppressed infection
(Lampe et al., 2010). Personal health literacy and numeracy are also important
components of successful medication management (Kalichman et al., 2008; Waldrop-
Valverde, Jones et al., 2010), although this finding is not universal (Paasche-Orlow et
al., 2006), and neurocognitive functioning plays a significant role (Waldrop-Valverde, et al., 2010).

**The role of environing conditions**

Clinic-related factors which influence attendance have in turn been associated with improved adherence within cohorts. It is now widely accepted that institutions delivering HIV clinical services should support a standard of care that incorporates a minimum of interventions to support acceptance of treatment; and long-term maintenance of medication adherence. The standard of care should be measurable and comparable between settings (De Bruin et al., 2010; Harman et al., 2005). In the Royal Perth Hospital outpatient hospital setting adherence care is based on research conducted in that context (Herrmann et al., 2008b) and is conceptualised by Figure 13. However, disease-specific dimensions of HIV related to treatment side effects, and less tangible constructs, such as stigma, in the absence of immunopathology, can interact with context-specific factors. These dimensions can affect the health and well-being of people by interfering with the appropriate use of health services (Weiss, Ramakrishna & Somma, 2006) by way of delaying HIV testing; delaying or preventing the acceptance of treatment; and threatening adherence (Sayles, Ryan, Silver, Sarkisian & Cunningham, 2007) and persistence with treatment. Finally, engagement with health care providers and long-term medical management can be threatened.
Health-related Quality of Life

The psychosocial and physical effects of HIV/AIDS and treatment affect health-related quality of life, despite the effectiveness and potency of antiretroviral drugs in ameliorating the condition. Adverse side effects, pill burden, inhospitable dosing schedules and psychosocial effects of the disease make diligent adherence and persistence with the treatment challenging. Despite some normalisation of quality of life indicators in patients with poor health pre-HAART (Carrieri et al., 2003), in general, common side effects such as nausea, diarrhoea and peripheral neuropathy, and disease-related symptoms distressed and limited the lifestyles of people, particularly around relationships and employment, and this had socially detrimental outcomes (Ammassari et al., 2002; Blaschke, 2008; Chesney et al., 2000; Duran et al., 2001; Eriksson, Bratt & Nordstom, 2005; Fumaz et al., 2002; Harmon, Barroso, Pence, Leserman, & Salahuddin, 2008; Maticka-Tyndale, Adam & Cohen, 2002; Mocroft et al., 2001; Murphy et al., 2000; Murri et al., 2000; O’Brien et al., 2003; Trotta et al., 2002; K.J Wilson et al., 2004).
Shortly after the advent of HAART, it became apparent that medication adherence and drug resistance were important issues in the successful management of HIV infection and, as the search for tolerable but potent ARVs continued, measuring health-related quality of life (HRQL), and understanding its relationship with medication adherence became a major focus for interdisciplinary research. However, many HRQL measures used in HIV research up until recently were developed either before, or in the early HAART era, including the MOS-HIV, FAHI, HOPES, HAT-QOL, AIDS-HAQ, and the MQOL-HIV (Cella, McCain, Peterman, Mo & Wolen, 1996; Ganz et al., 1993; W. C. Holmes & Shea, 1998; Smith, Avis, Mayer & Swislow, 1997; Wu, Revicki, Jacobson & Malitz, 1997; Wu et al., 1991). On this basis these measures could be construed as not attuned to the impact of contemporary treatments, not sensitive enough to detect HRQL changes in HIV, or to account for the long-term experience of living with HIV. Indeed, some critics of general HRQL measures recommended that they be abandoned altogether, citing that they lack the specificity and diagnostic utility of conceptually discrete scales (Cummins, Lau & Stokes, 2004). That a contemporary, global HRQL measure was needed was also indicated by the steep increase in access to ART in low and middle-income countries (UNAIDS, 2009). It became evident that such a measure should be equally useful and valid in those regions, as well as the higher income countries.

To address this need, a team from the Patient Reported Outcomes Unit (PRO) at the Hôpital de Saint-Louis in Paris in collaboration with institutions internationally, developed the PROQOL-HIV health-related quality of life questionnaire with the participation of PLWH across 11 countries, including patients from Royal Perth Hospital in Western Australia. Two manuscripts, published recently, describe the international study and can be found in an appendix to this thesis. The preliminary data gathered in 2007-2008, in the developmental phase, informed the direction of the thesis and is
therefore discussed, in brief, to provide background information. The data was presented at national and international conferences (Duracinsky et al., 2008; Herrmann et al., 2009b) prior to publication in 2012.

The development of the PROQOL-HIV study followed a 4-stage process (1) development of a conceptual model and item generation; (2) development of source questionnaires; (3) linguistic validation and (4) psychometric validation. In phase 1, thematic analysis of semi-directed interviews with 152 patients across nine countries was used to develop a questionnaire item bank from which a pilot questionnaire was constructed. There were 11 underlying themes that emerged to represent a conceptual model of HIV-specific HRQL and these were: general health perception, social relationships, emotions, energy/fatigue, sleep, cognitive functioning, physical and daily activity, coping, future, symptoms and treatment. Seven issues in particular, subsumed into the main themes, were important to participants but not represented in any existing QOL instrument and these were: fear of infecting others, concerns for the future, satisfaction with care, self-esteem problems, sleep problems, work disruption and treatment issues (Duracinsky et al., 2012). As expected, differing epidemiological patterns of HIV transmission and inter-country, socio-cultural and linguistic differences moderated the themes and subsequently influenced the item construction.

**Across country thematic comparisons**

The idea of general health was widely understood as important for quality of life and people considered even small changes in their general health as important to them. Nuances were related to areas such as physical activities, social relationships and treatment. Although the ability to work was important for people in all countries,
physical activity was often centred on sports in developed countries and around work, chores and the ability to walk long distances in developing countries – leisure was not a concept well understood in low income countries. Work was also linked to social status, the ability to pay for treatment and the availability of resources and services in low and middle income countries.

Issues of energy and fatigue appeared more evident in people in low income countries perhaps because the disease is often diagnosed at a later stage. The ability to drive a car was cited as important for Australians, and international travel was mentioned as another important activity. The former was sometimes restricted by lack of concentration and the latter around restrictive HIV-focused international laws. It was notable that blood spills were concerning to Australians who often visualised themselves involved in a car accident, or some other situation that involved exposing others (unwittingly) to their blood.

Social relationships by way of family life were important in the USA, Senegal, China and India. In Western Australia, it was evident that friendship could be as important as family. While social stigma was felt universally, for participants in Senegal, India, China, Thailand and Cambodia, it extended to involving the family in the aura of discrimination which ensued from disclosure. In general, psychological burden was observed to be heavier in Asia but most participants described negative self perceptions and emotions, for example: shame, guilt, inferiority, embarrassment, sadness, anxiety, irritability and stress. However religious and/or spiritual beliefs were beneficial to coping and described by participants in Australia, Brazil, the USA, Thailand and Senegal. Significantly, there were distinctions between religion and spirituality in that religions were seen to impose constraints or boundaries on behaviour.
Symptoms and side effects were another key quality of life issue but, while universally felt, adverse effects of treatment received more attention from the higher income countries (France, the USA, Australia, Brazil) where access to ARVs was less of an issue. In India, Thailand, Cambodia, China and Senegal treatment was viewed as lifesaving and lack of access to ARVs was feared. It is also the case that in these countries there was less criticism of health care providers. There were general concerns around medication related to the stress around managing good adherence but, in addition to this, there was the perceived need to take medication privately to protect from exposing their HIV status.

Finally there were three other issues that were frequent points of discussion for participants and these were: satisfaction with health care services; financial and employment problems; and worries about conceiving and raising children. This last topic came up more frequently in Thailand and Cambodia.

**Health-related Quality of Life and Adherence**

A number of studies have found a relationship between ART medication adherence and HRQL or HIV-AIDS specific quality of life either directly or indirectly (William Holmes et al., 2007; Mannheimer et al., 2005). It was often the case that adherence was associated with toxicity to early HAART regimens and lipodystrophy was a good example of this (Guaraldi et al., 2003; Guaraldi et al., 2008). **Figure 14** is a vignette of how one man manages his ART regimen. I carried out this assessment in 2005 when the man participated in an earlier study (Herrmann et al., 2008b). It was notable that despite the detrimental effects (self-reported) on the patient’s lifestyle of what is a disruptive dosing schedule, and a marginal immunological response to the treatment, the patient showed reluctance to switch to a simpler, more tolerable regimen. In a
post script to this narrative, the patient went on to improve adherence to his IDV/d4T/3TC regimen and developed nephrolithiasis (kidney stones) as an adverse effect of indinavir. As a consequence he was motivated to accept a change of treatment to a BD regimen in 2006. This led to an improvement in his ability to manage the regimen and he achieved an undetectable viral load for the first time in eight years.

<table>
<thead>
<tr>
<th>Dosing schedule:</th>
<th>4 times/day for 7 days/week &amp; 5 times/day for 2 days/week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pill burden:</td>
<td>10-14 pills/day</td>
</tr>
<tr>
<td>Regimen 1996-2006</td>
<td>Adherence = erratic</td>
</tr>
<tr>
<td>Employment:</td>
<td>Shift worker in supermarket</td>
</tr>
<tr>
<td>Waking and sleeping: Wakes by alarm at 0800 to take indinavir, goes back to sleep and wakes (if has set alarm) at 1200 and takes d4T and 3TC. Usually gets up then. Goes to bed anytime between 2400 (when takes last dose of d4T and 3TC) and 0500.</td>
<td></td>
</tr>
<tr>
<td>Reasons for missing doses: Forgetting a dose, busy with other things, sleeping through dose time, change in routine, had difficulty taking pills at specified times (food restrictions) and misses when feeling depressed or over whelmed. At work does not have medication and if does forgets to take it.</td>
<td></td>
</tr>
<tr>
<td>Facilitators of adherence: Motivation - although regimen is challenging and has resulted in adverse effects (lipatrophis and dyslipidemia) pt committed to making it succeed. Uses a dosette box, a pill box and a bedside alarm. Close relationship with parent.</td>
<td></td>
</tr>
<tr>
<td>Barriers to adherence identified: Frequency of dosing, food restrictions, memory lapses, low mood, daily routine challenged by shift work.</td>
<td></td>
</tr>
</tbody>
</table>

Figure 14: The impact of treatment regimen and lifestyle on medication adherence

Despite some studies reporting increased drug toxicity with better adherence in the early HAART era, health-related quality of life dimensions in people with HIV while dynamic, also have a co-dependent relationship with medication adherence by way of (1) improved clinical outcomes and (2) increased tolerability of ART (Carrieri et al., 2003; J. S. Gonzalez et al., 2011; Mannheimer et al., 2005; Swindells et al., 1999; T. E. Wilson et al., 2002).
However, it remains difficult to tease out the effects of ART on HRQL since there may be ‘noise’ from other influential biopsychosocial factors affecting PLWH concurrently: including experience of stigma and discrimination, depression, and relationship issues (J. S. Gonzalez et al., 2011). There is a sound case for an instrument that can account for the emotional and social effects of treatment beyond objective observation of side effects. In addition, focused interventions could be informed by research that examines the potential mechanisms connecting adherence with depression (J. S. Gonzalez et al., 2011). By exploring and addressing, where possible, common aspects of HIV that have traditionally been associated with diminished HRQL in PLWH, a secondary benefit in improving or sustaining medication adherence may ensue. Qualitative research methods support this approach.

In Australia the publication of The HIV Futures Surveys, the latest of which is ‘Futures 6’ (Grierson et al., 2009) funded by the Commonwealth Department of Health & Ageing at intervals since 2004; and activities of the Australasian Society of HIV Medicine (ASHM) as well as NAPWA, AFAO and other national HIV organisations, gives a profile to issues that impact on the quality of life of people living with HIV, among other useful information. However, the population represented in the latest Futures 6 Survey (2009) while national, may not be reflective of the WA demographic of PLWH or reflect the priority populations identified in the 6th National HIV Strategy (Government of Australia, 2010), particularly with regard to mobile populations. Therefore, a study that reflects the contemporary issues for PLWH in Australia, regardless of their ethnicity or citizenship status, is timely.
Medication Adherence in the WA HIV Cohort

The concern about sub-optimal adherence to ART in the USA and Europe (Bangsberg et al., 1997; Bangsberg et al., 2001; Carriero et al., 2001; Chesney et al., 1999; Paterson et al., 2000) was also shared by those in the field of HIV clinical management in Australia (Fairley, et al., 2003). At Royal Perth Hospital, ART and AIDS prophylaxis is dispensed free from the hospital pharmacy to those with Medicare access, with no concomitant copayment, although this is likely to change in the near future to bring ARVs in line with other drugs dispensed by hospital pharmacies. The results of the study of medication adherence in the APROCO cohort (Carriero et al. 2001) were sufficient to alert health care providers that similar, sub-optimal adherence levels were likely contributing in the WA HIV cohort to: poor viral suppression or viral rebound, drug resistance, AIDS-associated or defining illnesses such as cryptococcal meningitis, and premature death (personal communication (nd), Professor Martyn French). Furthermore, it was recognised that sub-optimal adherence could confound the validity of toxicity and therapeutic outcome data (Ickovics & Meisler, 1997; Urquhart, 1991), and impact on the quality of longitudinal data retained in the HIV Cohort Database since 1983 when the first cases of HIV were identified in WA (Mallal, 1998). The RPH Immunology Department had a long history of conducting clinical observational and basic science research, and participating in clinical trials, so aside from the deleterious health effects of poor adherence on the patient there was a perceived threat to data integrity. Therefore, implementing a program of assessment and improvement of adherence was imperative. After obtaining Royal Perth Hospital Ethics Committee approval we began the research in September of 2002.
Conceptual framework

The theoretical underpinning of the program was based on the assumptions that: adherence is a complex and dynamic behaviour fluctuating across the disease continuum for any individual; therefore interventions to improve adherence should be supported by a maintenance program and lastly; that evidence-based research should be embedded in clinical practice to facilitate maintenance and evaluation of feasible and effective programs of care. Because many of the bio-psychosocial factors impacting on adherence identified in the literature fell within the domain of nursing, social work, psychology and dietetics, a multi-disciplinary, multi-component approach to adherence care was undertaken (Figure 13). This approach appeared to be a good ‘fit’ with the management of patients at that time. Our findings and recommendations are detailed in an article published in the Internal Medicine Journal in 2008 (Herrmann, McKinnon, John, Hyland et al., 2008) but preliminary findings were presented at national conferences in 2003-4 (Herrmann et al., 2003, 2004).

Summary of original findings

The original survey identified reasons for missing medication and these reasons can be seen as the antecedent contexts. We grouped these into four categories or contexts: ‘forgot’, ‘circumstance’, ‘psychosocial’ and ‘regimen’ issues. These findings were similar to those seen in the French and US studies. We found that diminishing adherence correlated with younger age and substance use which could primarily be attributed to reasons of unplanned circumstance. Perceived stress and indicators of depression were particularly associated with missing medication for psychosocial and regimen related reasons. Ongoing monitoring of adherence was facilitated by the derivation of medication scores based on self-reported adherence at routine
consultations with the physician. This measure was found to correlate with viral suppression and restoration of CD4 T-cells and indicated an improvement in adherence over the period of observation. We later went on to examine the role of once daily dosing and side effects in medication adherence and conduct a review of substance use (Herrmann et al., 2008a, 2012) to further characterise our cohort. However, the limitations of the early studies and the audits that followed became evident with the passing of time, primarily because of newer treatments and the changing epidemiology of the epidemic as outlined in the introduction to this thesis. Of the 162 patients with complete data who participated in the first survey, 140 were men, 135 identified as Caucasian, six Aboriginal and 21 (unidentified), most were living in the metropolitan area and only 18 were listed with the Rural and Remote HIV service and travelled to attend the clinic. Transmission of HIV was primarily between men having sex with men (MSM, 106/140). Should the survey be repeated today the demographic would be quite different. So in summary, the survey reflected the WA epidemic in 2002 - Caucasian men who were infected by other men and living mainly in the metropolitan area. Therefore, arguably, findings of the earlier study cannot be fully generalised to the current demographic of the WA HIV Cohort although at the time the demographic was seen to be representational and the sampling method sound. Most notably, the cohort reflected a population with unfettered access to free antiretroviral drugs and a low proportion of people living and working in regional areas.

**The Critical Role of Antiretroviral Drug Access**

**AIDS Activism Influenced Drug Access**

The HIV/AIDS epidemic has been characterised by civilian activism, so much so that biology and sociology are said to have converged and shaped the global epidemic
(Ford, Wilson, Chaves, Lotrovska & Kijtiwatchakul, 2007; Killen, 2008; Nguyen, Ako, Niamba, Sylla & Tiendrebeogo, 2007). The juxtaposition of drug discovery and advocacy for access to treatment created a momentum for change in the way experimental drugs are regulated. In the USA an alliance between the Food and Drug Administration (FDA), the Department of Health and Human Services (DHHS) and the Burroughs Wellcome Company resulted in an unprecedented access program known as ‘treatment IND’ which effectively accelerated access to zidovudine as a monotherapy for HIV. At the same time, social activists were demanding the inclusion of women, children and ethnic minorities who were generally considered to be under represented in clinical trials. This social activism encouraged by research ethicists gave impetus to the creation of the AIDS Clinical Trial Group (ACTG) in 1987, a national multicentre clinical trials network under the governance of the National Institute for Allergy and Infectious Diseases (NIAID) (Killen, 2008). Internationally, concern over limited access to ARVs spilled over in 2000 at the 13th International AIDS Conference in Durban, driven by: the clinical evidence that ART could prevent deaths from AIDS; and a law suit filed in 1998 brought by 41 pharmaceutical companies against the South African Government which sought to amend the Medicines Act to make medicines more available to its citizens (‘t Hoen, 2009). Even up to five years after HAART became the standard of care in developed countries, less than 8,000 HIV infected people in Sub Saharan Africa received treatment due to the high cost of drugs under patent protection and, subsequently the difficulty accessing cheaper generic, bioequivalent alternatives, the first of which was made in India in 2001 (Satyanarayana & Srivastava, 2010).

Today a global network of scientists, civilians and activists, many of whom are affected by or infected with HIV underpins a drug development program that has seen, in the
last decade, the licensing of more than 30 antiretroviral drugs under patent, and around 30 generic formulations, produced mainly in India followed by Brazil and Thailand (Satyanarayana & Srivastava, 2010). Sovereign government and activist responses to the high cost of first-line ARVs, estimated to be >10,000 US dollars per patient per year in 2000 have resulted in falls in prices to 87 US dollars in 2010 (Satyanarayana & Srivastava, 2010). However, the prices between countries vary significantly depending on the success of negotiations between governments and pharmaceutical companies and the complexity of other trade agreements between those countries ('t Hoen, 2009; Ford et al., 2007).

**Access to Medication: the Socio-Political Context and TRIPS**

India was able to become a major producer and exporter of generic drugs and their component substances because the Indian government did not introduce patent protection until 2005 ('t Hoen, 2009), and had challenged the 1994 international trade agreement constructed by the World Trade Organisation (WTO). This mandated Governments who were signatory, to issue exclusive intellectual property rights to inventors of new technological products. The agreement was called: Agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS) ('t Hoen, 2009).

The TRIPS agreement mandates the lowest level of protection that each government has to give to the intellectual property of the other WTO members ('t Hoen, 2009). Prior to the agreement between the WTO and signatories to the agreement, medicines and food could be excluded from patenting however since the TRIPS Agreement all forms of technology including medicines, now defined as *medical products*, are included; and the life of patents or patent terms, were standardised to a time frame of usually 20 years ('t Hoen, 2009).
A basic premise behind patenting is that exclusive licenses offer incentives to individuals that foster innovation and the enhancement of the quality of human life (World Intellectual Property Organisation, 2010). An expectation of the TRIPS Agreement was that the higher levels of Intellectual Property (IP) protection afforded by patents would result in an exchange of Research and Development (R & D) with developing countries but this was not realised (The National Institute for Health Care Management Research and Educational Foundation (NIHCM), 2002). A second more immediate and unresolved issue was how to export products manufactured in one country, under a compulsory license to a country in need of the product but lacking the capacity to produce it themselves. These and other unresolved concerns led to the Fourth WTO Ministerial Conference held in Qatar (2001) which adopted the Declaration on TRIPS and Public Health, later known as the ‘Doha Declaration’, which affirmed the sovereign right of governments to protect public health. Therefore governments, who are WTO members, can legally make exception to patent licensing and also use a WTO dispute settlement system when intellectual property rights are contentious between members.

One important component of the Doha Declaration was the enabling of TRIPS flexibilities which allowed the least developed countries to defer granting or enforcing pharmaceutical product patents up to 2016. This is significant because it then facilitated negotiation on prices between governments and pharmaceutical companies which resulted in huge price reductions. A later amendment which came to be known as the August 30th decision, was taken by the WTO in 2003 which established an export process between those countries manufacturing generics and those in need of them but with no domestic production capacity. Over 60 developing countries have exploited these so-called TRIPS flexibilities (’t Hoen, 2009) with India the most
successful player (Satyanarayana & Srivastava, 2010). Although the administrative processes required to invoke the TRIPS waiver are a disincentive to its use, China, Canada, Norway and the European Union have all sought to access changes to TRIPS allowed by the August 30th decision to their advantage.

Among the sovereign measures available to governments are the use of compulsory licensing and parallel importation. In her thesis on “The global politics of pharmaceutical monopoly power”, ’t Hoen (2009, p. xvi) defines these succinctly:

1. **Compulsory licensing** enables a ‘competent government authority’ to license the use of a patented invention to a third-party or government agency without the consent of the patent-holder against a payment of ‘adequate remuneration’.

2. **Parallel imports** are cross-border trade in a patented product, without the permission of the manufacturer or publisher. Parallel imports take place when there are significant price differences for the same good in different markets.

**Delivery of Antiretroviral Drugs to the People**

The mechanisms of delivery of drugs to individuals world-wide varies between countries who supply patented ART to citizens for a price, to those that offer free universal access to patented drugs for their citizens. Middle income countries such as India, Brazil and Thailand manufacture and supply generic drugs either under universal access schemes or via regional projects to their own citizens and those of other countries (Ford et al., 2007; Satyanarayana & Srivastava, 2010; ’t hoen, Berger, Calmy & Moon, 2011). The Clinton Health Access Initiative and the President’s Emergency Plan for AIDS Relief (PEPFAR) began distributing ARVs in 2005 and by 2008 most of these were generic, purchased from India, at an estimated cost saving to the donors of
approximately 323 million USD (Figure 15) (C. B. Holmes et al., 2010; Waning, Diedrichsen & Moon, 2010).

![Countries reporting purchase of Indian-produced generic ARVs in 2008](image)

Figure 15: Countries with highest purchase volumes (donor funded) from India of generic ARVs: Tanzania, Nigeria, Ethiopia, Mozambique, Zambia, Namibia, Congo, Kenya, and Cameroon (Waning et al., 2010)

The rights of non-citizens

The right of access to ARVs for non-citizens varies between countries. The Netherlands, Belgium and Italy are among the few countries to offer free medical care, including ARVs, to all immigrants whether or not their status is legal (Elinav et al., 2012; C. B. Holmes et al., 2010; Pollard & Savulescu, 2004; Romero-Ortuno, 2004; Waning et al., 2010). In the least developed countries access to usually generic drugs manufactured in India is via patchy philanthropic governance although in South Africa, arguably hardest hit by the epidemic, coverage is almost complete. But in many of the least developed countries ‘stock-outs’ are common, supply chains tenuous and, in regions like Papua New Guinea, inhospitable topography limits access to essential drugs (Ford et al., 2007; Satyanarayana & Srivastava, 2010; ‘t hoen et al., 2011). It is also the case
that people move within countries for largely economic reasons (internal migration) and in regions where coverage is patchy access to ARVs will be compromised by population mobility.

**The need for more antiretroviral drugs is pressing**

Although over 10 million people with HIV are currently identified as in need of treatment under the current guidelines for commencement of first-line ART, only 5 million are receiving it, although this represents a more than twelve-fold increase in access in the last eight years and particular gains over the last three years (WHO et al., 2010). By 2010, Rwanda, Botswana and Namibia achieved between 76 and 88% treatment coverage among adults. But another eleven countries (Cameroon, Côte d’Ivoire, Ghana, India, Indonesia, Mozambique, South Africa, Ukraine, United Republic of Tanzania, Viet Nam and Zimbabwe) reported treatment to less than 40% of people in need. Significantly for the Asia Pacific region, Indonesia, like the Ukraine reported that less than 20% of adults were receiving ART (UNAIDS, 2010). Furthermore, since worldwide ARV coverage reaches only about 10% of children eligible under treatment guidelines, there is a pressing need to develop suitable, affordable and accessible drugs (Satyanarayana & Srivastava, 2010). Importantly, access to second-line treatment is rare in low and middle income countries since these drugs are expensive and require supply chain management and complex clinical monitoring (Ford et al., 2007). The World Health Organisation (World Health Organisation, 2005) estimates that in Thailand alone, second-line therapy for a quarter of all patients will take up three quarters of the budget, and the total budget for ART should prices remain at current levels, will arrive at 500 million USD per year by 2020 (‘t Hoen, 2009; Ford et al., 2007).
India, the pharmacy of the modern world

India continues a strong and independent stand rejecting patent applications (2009) for tenofovir, a commonly used (and often in co-formulation) first-line NRTI, and darunavir a PI. The governments of other countries who also reject licensing these drugs and therefore avoid patent infringement, are then able to import the generics from India (Reuters 2009). The cost of all four of the fixed-dose coformulated generic drugs approved as first-line regimens by the World Health Organisation in 2009 is cheaper purchased from India (Waning et al., 2010). The country has also succeeded in limiting the number of patents issued by establishing criteria that must be met before a patent licence is granted. For generic drugs released between 1995 and 2005 licensing was automatic. However, authorisation for the production and export of generic drugs is a separate process for each new order and there is evidence that the sector is moving towards the export of generic ARVs that are already off patent to countries that are relatively affluent (‘t Hoen, 2009) because this is more fiscally attractive. In addition, since 2005, for each new drug, India is compelled under the TRIPS Agreement to subject these to 20 year patent terms (‘t Hoen, 2009). According to Satyanarayana & Srivastava (2010) India’s capability is under threat and ‘t Hoen (2011) cites Oakeshott (2009) as stating fears of a ‘treatment timebomb’.

The international community redoubles efforts

UNITAID was established in 2006 and is closely associated with organisations such as the Clinton Health Access Initiative (CHAI). UNITAID supports existing efforts to achieve the some of the United Nations Millenium Development Goals by establishing a stable drug purchasing facility. Funded by a tax on airline tickets, UNITAID negotiates with large pharmaceutical companies to facilitate the reduction in costs by, in part,
supporting ‘tiered pricing’, which is based on using the average income per head – obviously less in developing countries (www.avert.org/generic.htm). Another international initiative established The Global Price Reporting Mechanism in 2005; this website provides regional and country specific information on ARV prices (http://www.who.int/hiv/amds/gprm/en/). Therefore, low income countries are assisted, in an administrative way, with ordering large shipments of largely donor funded or subsidised ARVs.

However, currently the most viable mechanism to promote universal affordable access to ARVs is the Medicines Patent Pool. Supported by UNITAID, this scheme aims to improve access to patents by creating a repository that can be accessed to enable competitive generic manufacture in exchange for royalty payments to the original patent holders. It is thought that this strategy will facilitate the production of FDCs, which has been hampered by the complexities of patenting law, and paediatric formulations (’t Hoen, 2009; Satyanarayana & Srivastava, 2010). Importantly the scheme will support India in the production of affordable, generic second-line drugs (Oakeshott, 2009).

In summary, although the Doha Declaration created an environment in which the least developed countries could manoeuvre within the TRIPS flexibilities, middle income countries in Latin America and Asia are under increasing pressure from pharmaceutical companies to comply rigidly because of their growing market potential as purchasers of medicines in general. Furthermore, the capacity of these countries to manufacture generic medicines and supply their own demands as well as that of Africa, and countries that lack manufacturing capability, is under threat. Improving access to ART will require addressing international regulatory issues, financial remuneration,
strengthening procurement and supply chains to prevent stock outs, and pharmacovigilance to ensure quality products ('t Hoen, 2009).

**Australia’s position with regard to the importation of drugs**

In Australia, the Therapeutic Goods Administration (TGA) is the body which regulates pharmaceutical goods and medical devices, including the importation of drugs for personal use under the Personal Import Scheme. People with HIV, ineligible for the universal health access scheme, Medicare, but needing anti-retroviral treatment can import generic medicines from overseas via internet vendors provided they have a script written by a doctor with authority to prescribe Section 100 pharmaceuticals. A Canadian-based company: AIDS Drugs Online [www.aids-drugs-online.com](http://www.aids-drugs-online.com) is the recommended internet vendor listed on the NAPWA website. In theory ARVs can be purchased in Australia if a prescription is dispensed but only patented drugs are available and these are costly. The range of generic drugs available from internet vendors is limited to approximately 15 drugs including didanosine, stavudine and zidovudine, which are unlikely to be prescribed in Australia, and seven fixed-dose combinations. This is in contrast with the antiretroviral drugs available for prescription to Medicare eligible individuals which number over 25. The generic drugs available for legal import are usually older drugs manufactured in countries such as India that were able to evade the constraints of TRIPS until 2005. Although, stavudine (also known as d4T) was removed from the World Health Organisation’s guidelines for ART 2009 because the evidence of its toxicity was unarguable, and replaced with tenofovir.

People importing generic drugs via internet vendors can and do face logistical problems relating to delay of shipments and confiscation by customs in the absence of a prescription accompanying the package. Some medications can be received through
Australia Post but others use reliable couriers. Unfortunately and perhaps relating to the regulations surrounding the import and export of generic drugs, previously reliable providers may become unreliable, and access may be discontinued. Interruptions to treatment of this nature have been shown to result in virological rebound on NNRTI therapy (Parienti et al., 2008) and are associated with increased morbidity and mortality.

In order to optimise treatment success and avoid treatment interruptions it is necessary for the HIV infected person to engage with continuous medical care. This requires a lifestyle commitment to attending medical centres, as well as accessing and accepting drug treatments available at a given location. This ability favours those in geographical proximity to treatment, and those with citizens’ rights. The ability of people who live in remote locations, lack citizens’ rights or lead a peripatetic lifestyle, to engage with HIV care, access and adhere to medication is compromised.

**Migration, Mobility and HIV**

Before the 20th Century, lack of legal and administrative restriction facilitated the movement of people across borders and, historically, a migrant was someone who left one country and settled permanently in another (Williamson, 2006). Current migrants or mobile populations are made up of a number of subgroups, such as refugees and asylum seekers fleeing their countries because of civil strife or environmental catastrophe; temporary migrants such as guest workers (a term originally coined by the Germans – *Gasterbeiter*); or international students and complex groups of irregular or illegal migrants, including those who have arrived through smuggling or human trafficking. These groups are subject to differing national and international restrictions
upon their movements and their rights as non-citizens, including their access to health services.

Therefore, the migration pattern of the ‘modern migrant’ may be something quite different from this idea of a person or family setting off from one country and settling in another and it is this ‘pattern’ that has wide ranging implications for health, not only for the destination country but for the country of origin, and countries transited through to that destination (Gushulak & MacPherson, 2004).

In many countries migrants, driven by economic hardship or aspirations for a better life, work legally and illegally receiving lower rates of pay. Arguably, societal protections in health are reduced for migrants. Non-citizens may lack the protections afforded to citizens, for example, in terms of workers compensation/union representation, and access to subsidised health care (Ahonen et al., 2007; Sousa et al., 2010). The ‘migrant’ encapsulates health impacts from their country of origin, the travel phase or transitioning country and the country of destination. For example, the prevalence of endemic disease, access to and awareness of care as well as cultural attitudes to health and illness are likely to be different in another country (Bhopal & Rafnsson, 2012). A migrant carries attitudes and expectations to the destination country (Gushulak & MacPherson, 2004). If one accepts this view then it follows that, in the case of HIV, people are going to bring their experience, knowledge and attitudes to HIV to a destination country; and that these will need to be identified and acknowledged in the health setting. Furthermore, Kesby et al, (2003, pp1588) assert the necessity of exploring, ‘discourses, practices and material conditions that create particular subject positions, structure the relationships between individuals and frame
the possible limits of decision-making within particular communities’. These authors refer to the need to understand the ‘social embeddedness’ of HIV in Africa.

Forcible displacement in the example of refugees can impact on health in a number of ways. Refugees may be subject to irregular movement resulting in environmental exposures such as to extremes of weather; and exposure to coercion and violence such as rape. However, people can also find themselves ‘between’ countries which can affect their engagement with health care resulting in inadequate or absent vaccination, and for people with chronic illness dislocation from services can have a most detrimental effect (Gushulak & McPherson, 2004).

The legal status, economic status, personal behaviour and cultural practices or beliefs of an individual and their family members on arrival, within the context of the host country’s social and environmental ecology, can also have a health impact (Ahonen, 2007). In particular, the meaning attributed to certain illness, for example, in some cultures it is unacceptable to talk about death. This can make fraught communication between health care providers and their patients when talking about cancers, for example. HIV is associated with behaviours that are taboo in some cultures and this may make people feel deeply ashamed and reluctant to seek help if they suspect they are ill. That this is the case has been demonstrated in studies that show fear prevents people, especially people of migrant status, seeking help (Burns et al., 2007; Adler et al., 2009). It is a challenge for migrants of all categories to ‘read’ the culture of the destination or ‘guest’ country. Finally, return travel can have consequences for health of migrants, particularly when situations have grown worse in the country of origin and when, for example, children born in the guest country are taken to a place where their immunity leaves them vulnerable to diseases (Gushulak & McPherson, 2004).
Migrant groups tend to have a higher labour participation and, importantly, migrations tend to self select young adults as it is they who may stand to gain most from migration (Williamson, 2006). Economic migrants in their young to middle years, often fall into the age group where HIV is most prevalent.

Foreign workers tend to be stigmatised because it may be perceived that they displace a local workers. As a group, migrant workers are fearful of antagonising the local population and drawing negative attention to themselves. The idea of foreigners introducing contagion has been used to vilify immigrants in the past. As such HIV would increase the likelihood of stigmatisation especially for people working illegally (Ahonen et al., 2007; J. Anderson, 2008; Bhopal & Rafnsson 2012).

In 2010 the United Nations Development Programme (UNDP) published jointly with the Secretariat of the Pacific Community, a report which provided an assessment of migration and mobility as key drivers of the distribution and spread of HIV in the Pacific. The authors of the report note that in the Pacific region appropriate interventional responses to address the vulnerabilities created by population mobility have yet to be developed. The report specifically recognises workers engaged in ‘circular migration’, which as the expression suggests, are those people who return at some stage to their country of origin. These people are commonly working in mining and construction, transport, plantations, the military and seafaring occupations (Connell & Negin, 2010).

While populous countries like China (Scheineson, 2009) have large numbers of internal migrants, most of whom leave their homes to find work elsewhere in the country, it is estimated that there are over 200 million international migrants. These migrants could constitute the world’s fifth most populous country. An International Labour
Organisation Report in 2004 (Gushulak & MacPherson, 2006) estimated that there were 90 million people working outside their country of origin. Historically, labour migration rates were higher than population migration rates and were driven, typically, by young adult males (Williamson, 2006). Current access to international travel opportunities supports population exchanges, and the number of international journeys in 2004 exceeded 760 million. However, in the present day, legal, administrative and health requirements shape migration and, significantly, people with HIV may be subject to the HIV-related restrictions on entry, stay, and residence of a large number of countries (Figure 16). In fact, 52 countries, territories and areas impose some sort of restriction on the entry, stay and residence of people living with HIV based on their serostatus, including Australia, despite evidence to suggest that restrictions do not protect public health (UNAIDS, 2008). While 124 countries have no specific restrictions, 22 deport individuals once their HIV positive serostatus is discovered (UNAIDS, 2010).

![Figure 16: Countries, territories that have some form of HIV-related restriction on entry, stay or residence, retrieved from “Mapping progress towards universal access” (UNAIDS, 2010).](image-url)
Immigration and HIV in Australia

In 1985 The Human Rights Commission reviewed the Migration Act of 1958 (Cth). In their report they stated that permitting ‘same sex’ migration, i.e. the permanent entry into Australia of an interdependent couple of the same gender, was likely to increase the threat of AIDS. In 1989 the Australian Government introduced the requirement that all applicants for permanent residency aged 15 years and over be screened for HIV infection (Department of Immigration & Citizenship, 2010c, cited by Szaraz, 2005). At the time of writing, successful immigration is contingent on satisfying the Health Requirement (Department of Immigration & Citizenship, 2010b) under the Schedule 4 of the Migration Regulations 1994 (Cth). This involves a series of health tests and an assessment of the likely implications of those results for current Australian health standards. The Australian Government, through a decision maker in the Department of Immigration and Citizenship, who takes advice from the Medical Officer of the Commonwealth (MOC) (Department of Immigration & Citizenship, 2008), assesses whether the applicant satisfies the Requirement and can waive the Requirement at their discretion. Between 2007 and 2009, 205,940 permanent resident visas were issued; and 1532 temporary visa applications were refused on health grounds. A subset of these (244 applications for the waiver), were refused on the basis of undue expense to the Australian economy, and people with HIV were the most highly represented in this subset, according to the National Association of People Living with HIV/AIDS (NAPWA) (2009). Although 59 people with HIV infection were granted waivers of the Requirement in the financial year 2009-10 (Australian Immigration News, 2010) this was thought to be because of the intrinsic value of their skills category. Should a visa application be refused by the Department of Immigration and Citizenship (DIAC), the Migration Review Tribunal (MRT), can be accessed to consider
new evidence in support of an application to stay in Australia but time limits apply and these are purportedly inflexible (Turner Coulson Immigration Lawyers, 2011).

The primary health condition of concern to the Australian Government is tuberculosis, recognised by the World Health Organisation as a global public health issue (DIAC, 2010a, 2010b, 2010c, 2010d) in contrast to HIV/AIDS, which is not considered to be a public health risk of the same order. In theory, applicants (with HIV infection) for permanent entry are considered for assessment on the same basis as others with pre-existing conditions, as it is the economic cost of the ‘condition’, in terms of public expenditure, which is of overriding concern to the government. This consideration of cost is also extended to the ‘availability’ of health services so that no Australian citizen or permanent resident is displaced or prejudiced by a non-resident and is widely inclusive of clinical and community services (DIAC, 2008). Examples of this might be access to surgery and radiotherapy for cancer treatment. The term condition is also broad, extending itself to physical, mental and health ailments, intellectual disabilities and blood-borne infections such as hepatitis B, C and HIV (Szaraz, 2005). Significant cost is defined as 50% above the average per capita health care and community services cost for Australians over a five year period (DIAC, 2008). A person is assessed against these criteria, regardless of their ability to pay for these services and regardless of whether they will access them in any case. Someone with HIV, at minimum, would access health care for monitoring of immune status, specifically CD4 T-cell count and detection of virus, and review of any efficacy and toxicity related to antiretroviral drug treatment. The current assessment policy however, includes a ‘lifetime’ estimate of medicines, hospitalisations and end-of-life care. This is currently estimated at $240,000. Therefore, people with HIV applying for residency cannot meet the Requirement and rely on the award of the Health Waiver. This option is open to:
partners, fiancé(e)s, including same-sex and de facto relationships; dependent children of an Australian Permanent Resident; refugee and humanitarian visas granted overseas; and temporary humanitarian stays. But it is not open to student visa holders (Forbes & Godwin, 2011).

**Australian HIV/AIDS Organisations Action on Behalf of Immigrants with HIV**

The National Association of People Living with HIV/AIDS is the peak body representing organisations of HIV positive people in Australia. Along with partner organisations such as the Australian Federation of AIDS Organisations (AFAO) and the National Ethnic Disability Alliance (NEDA), NAPWA submitted their viewpoint and recommendations (National Association of People Living With HIV/AIDS (NAPWA), 2009) to the Joint Standing Committee on Migration Inquiry into Immigration Treatment of Disability in October 2009. Among their recommendations were the following:

1. The Health Requirement should be removed for diseases or conditions that do not present as a serious public health threat
2. Generic estimates of cost should not be used as a basis for assessments
3. Costs should be relevant to the applicant
4. For those seeking visas on humanitarian grounds – applications should not be denied on the basis of failing a health test

Major stressors have been identified in those seeking permanent residency in Australia, some of which are in common with the migrant experience in general:

- The uncertainty of successful migration: uncertainty concerning legal status, threat of deportation, financial uncertainty, and language proficiency
And these intersect with HIV specific factors:

- The immediate effects on health, treatment success, implications for the future, stigma within communities and stigma from the host population

The influence of the health environment of country of origin can compound these uncertainties since in the experience of many CALD communities, HIV is highly stigmatized and presently, without treatment, a terminal infection (Körner, 2005). More recently the experience of African-born Australian residents living with HIV in Victoria has been described, including their experiences of migration HIV screening. Most found the migration screening ‘coercive’ and a major barrier to accessing information, as was concern about the stigma attached to HIV from within African communities (Lemoh, 2010a; Lemoh, et al.,2010b).

**Applications for Temporary Visas for Work or Study**

Visa application is a universal condition of entry to Australia for work, study or holiday and there are currently over 100 different categories which carry varying entitlements to health, social services and the right to access employment (DIAC, 2010g). When there is a demand for skilled workers that cannot be met by Australian residents, employers recruit workers from overseas often through third party agencies. The most commonly used program to sponsor overseas workers to fill skilled positions on a temporary basis is the Subclass 457 Visa or more formally, the Temporary Business Long Stay Subclass 457 Visa (DIAC, 2010g). This visa allows the successful, business-sponsored applicant to live and work—with or without their immediate family— in Australia for up to four years. After two years an employer can nominate the recipient for permanent residency. For lower skilled positions in regional areas, special conditions can be accessed by employers to meet the demand for labour.
Current statistics on temporary entrants

In December 2010 there were just over one million temporary entrants in Australia including tourists and those on business, and these numbers were swelled by over 500,000 New Zealanders. There were nearly 300,000 students, while slightly less than that number were temporary residents of which just over 100,000 were 457 visa holders. Of the 457 visa holders 11,037 (10%) were from sub-Saharan Africa and 3000 (30%) were in Western Australia. The guest workers typically support the resource industry labour market which is largely structured around fly in fly out or drive in drive out workers. Of the just over 20,000 (21,078) category 457 visa holders working in WA at the end of 2010, around 5000 worked in the mining, construction and manufacturing industries in comparison with the other states where most of the business visa entrants were working in the health sector. In 2009, of all states after New South Wales, WA had the highest number of 457 visa holders (Department of Immigration and Citizenship, 2010d).

Health cover for temporary visa holders

Unlike refugees and asylum seekers, applicants for temporary visas are required to take out private health insurance since they are not eligible to access the Medicare system or drugs listed on the Pharmaceutical Benefits Scheme (PBS), in contrast with applicants for permanent residency who may be awarded interim access. Indeed, an important and obvious issue for 457 visa holders and for those on student visas (Subclass 572, 573, 574) is lack of Medicare cover which is universal for Australian and New Zealand citizens and residents of countries that have reciprocal health care agreements with the Australian Government, specifically those from the United Kingdom, Sweden, Finland, Norway, the Netherlands and Malta (Department of
Immigration & Citizenship). Employers of temporary workers can offer to take responsibility for their employees’ health costs but this is at the employer’s discretion. Furthermore it is the conditions attached to a particular visa which will determine the DIAC assessments of application for waiver of the Health Requirement and, in the case of 457 applications, the employer must sign to undertake responsibility for health costs should the waiver be granted. With regard to worker’s compensation, subclass 457 visa holders are subject to the same legislation and obligations and therefore protection, as all other employees of Australian employers operating in Australian workplaces. However, if a visa holder is sponsored offshore or the employer company is based in another country, it is very difficult for regulatory bodies such as Occupational Health and Safety to follow up on breaches of the legislation, making workers vulnerable in the case of workplace injury (DIAC, 457 Integrity Review, 2008).

**Temporary Visa Holders and HIV in Australia**

Unlike people seeking permanent entry to Australia, including migrants, refugees or asylum seekers from those same regions, it is not a condition of 457 visa or student visa access to be screened for HIV infection unless the intention is to work or study as a doctor, dentist, nurse or paramedic (Department of Immigration and Citizenship, 2010b, 2010d), and this clause includes pregnant women. In effect, health checks for those seeking a temporary visa depend on the type of employment, prevalence of TB in country of origin and length of stay in Australia. However, if a student is found to be HIV seropositive there is no Health Waiver that can be applied to that visa category under the *Migration Regulations 1994* (Cth).

In Australia, people with HIV from CALD Communities; including new migrants, refugees and those on temporary visas, face issues that may dramatically impact on
their well-being. In 2003, 30% of new notifications were in people born in non-English speaking countries; and many of these were late presentations (Körner et al., 2005, Körner 2007b). These data are similar to those observed in other settings internationally (Burns & Fenton, 2006; Burns, 2001; Burns et al., 2007; Fakoya, Reynolds, Caswell & Shiripinda, 2008; Staehelin et al., 2003); and were later supported by Lemoh’s observations (2010), again in Australia. Of concern is the disparate level of knowledge about HIV/AIDS among populations living in WA in whom HIV prevalence is comparatively higher than the background population (Drummond, et al., 2008).

Summary

In Western Australia there has been an increase in notifications of HIV acquired in countries with a high prevalence of the infection, against the national trends, and these cases are distributed across regional WA. There is also an increase in citizens living and or working in rural areas where access to treatment and HIV services may be challenged by distance and lack of familiarity with health care services. Testing for HIV in those applying for work or student visas is not current practice and diagnosis is often made when an application for residency status is lodged. This means that there may be a burden of undiagnosed HIV infection in visa holders working or studying in WA. Compounding this may be low levels of knowledge about HIV transmission and treatment, and as yet unknown health beliefs that may impact significantly on how people access and respond to medical care. Stigma associated with the disease impacts on health-related quality of life for people with HIV universally, and may be particularly difficult for people living in rural areas, complicating the process for non-citizens. Access to appropriate antiretroviral drugs is compromised since temporary visa holders are not eligible for Medicare and private health insurance does not cover
costs of ART. The influence that this has on medication adherence and persistence and resultant clinical outcomes is not known. Finally, the experience in other countries indicates that care is more complex in migrants however, whether this is the case in temporary visa holders with HIV in the WA health system has yet to be established.

Migration is an outstanding feature of human history and evolution and has been recorded since the biblical era. People and populations now move further and more rapidly than ever before between and within countries. This movement has implications for the spread of infectious diseases. HIV prevalence rates are higher in immigrant populations and even higher in ‘internal’ migrants moving from one region to another (Soskolne & Shtarkshall, 2002). Australian studies of rural resident and immigrant populations with HIV infection are limited, despite the topical subjects of immigration and workforce mobility. To date, there is no published study that has focused on the impact of HIV on people whose access to care and treatment may be compromised by lack of citizens’ rights and/or distance from HIV services, in Western Australia. This work will address these gaps in the literature and contribute to an understanding of these issues from the personal perspectives of individuals who find themselves, by virtue of circumstance, in such situations.
CHAPTER TWO

METHODS
CHAPTER TWO  METHODS

Activities only make sense when you know what they are a response to, what phenomena provide inputs and necessary conditions for the thing you want to understand.

(Becker, 1998, p. 44)

Introduction

The primary methodological approach to achieving the aims of this thesis is qualitative and I have chosen ethnography as a theoretical framework. In this chapter I will justify that choice, consider the ethical issues that arise from the research, and detail the qualitative, quantitative, clinical audit and biological methods that were employed. This section will also include a description of the research setting and will draw on background given by key informants. Since the study was conducted primarily at the Royal Perth Hospital, the description of the setting is focused on that hospital and the services of other teaching hospitals are not detailed.

The specific methods, and study design used to frame and gather the data on health-related quality of life in the WA HIV Cohort in Chapter Three are presented in a journal format within the chapter as they were prepared for submission. My contribution is detailed at the beginning of this thesis. Chapter Three provides an explanatory rather than a predictive approach to understanding the relationship between HRQL and physical, social and psychological distress in this particular context. The data set the scene and provide a real and relevant setting for the subsequent observations concerning people living or working in rural areas; and those people whose visa status complicates their experience of HIV in Western Australia. The detailed methodology of the larger international study was published in two manuscripts early in 2012 and
these manuscripts (which I co-authored) are included as appendices to this thesis. Findings of the international study relevant to the background of this thesis are outlined in the literature review, although it was the preliminary data gathered in 2007-2008, and the preceding adherence studies, which gave direction to the contemporary studies in rural living and temporary visa holders.

**Methodological Considerations**

**Qualitative Research**

Qualitative research is a scientific approach that uses observation, interviews and verbal exchanges as methods to gather in depth information to describe and explain complex social issues (Sankar, Golin, Simoni, Luborsky & Pearson, 2006). Qualitative methods such as phenomenology and grounded theory have been employed usefully to describe sexual practices, reveal cognitive representations of illness behaviour in HIV/AIDS, and illuminate adherence behaviour generally and in the context of uncertainty of attribution related to treatment side effects and illness ideology (Anderson & Spencer, 2002; Crane et al., 2006; Lewis, Colbert, Erlen, & Meyers, 2006; Sankar et al., 2006; Sidat et al., 2007; Vervoort, Borleffs, Hoepelman & Grypdonck, 2007; H. S. Wilson, Hutchinson & Holzemer, 2002). Although the value of early quantitative research, including survey methods, into HIV medication adherence is not disputed, without qualitative research in the field, a limited understanding of the behaviour would have resulted in potentially ineffective interventions. For example, the research of Hill and her colleagues (2003) who, not long after the use of HAART became widespread in regions with access to the drugs, interviewed 78 PLWH and identified nine distinct, non-exclusive and unstable patterns of adherence which, respondents reported, had different causes and consequences. This study offered rich
behavioural description which assisted practitioners to develop interventions to improve medication adherence behaviour. Later Beusterien, Davis, Flood, Howard and Jordan (2008) developed a conceptual framework for adherence based on data from focus groups using qualitative methods that could be translated, feasibly, into clinical practice. Qualitative research can allow the study of people in their social milieu, and some qualitative enquiries are in themselves interventions, for example the method of cooperative inquiry whereby participants develop and explicate the investigation and formulate agreed interventions as part of the process (Heron, 1996).

**Ethnography**

Ethnography has been defined most simply as ‘a holistic approach to the study of cultural systems’ (Whitehead, 2004), but Bruce Berg (2009) notes that the opinions of social scientists vary with regard to how it is both conceptualised and applied. Most however, seem to agree that it is an approach to research that is especially concerned with description and with research questions that demand explanation and prediction (Miles & Huberman, 1994). While not synonymous with qualitative research (Troman et al., 2006), it can involve both quantitative and qualitative research methods. More than a method, ethnography has epistemological and ontological properties (Whitehead, 2004). The focus of ethnography is on the description of the local particularities and the individual’s perspective and interpretations of their world (Miles & Huberman, 1995) including socio-cultural contexts, processes, and meanings within those contexts and cultural systems (Whitehead, 2004). Ethnography can be the study of an intact social group or an individual or individuals within the group. In 1987 Wolcott wrote that extensive reference to cultural groups and culture help differentiate ethnography from other qualitative research (Wolcott, 1987). However,
the use of ethnography as a theoretical perspective in the study of culture in health systems is more recent. As Long, Hunter and van der Geest (2008, p. 71) wrote in the journal *Anthropology and Medicine*: “It was not until post-colonialism moved the anthropological focus from the exotic of the Other to shine a light on the exotic of the Self that hospitals became of interest to anthropologists.”

Despite the acknowledged contribution of qualitative methods in behavioural research it is argued that qualitative methods to date have been under utilised in the field of medication adherence in HIV (Sankar et al., 2006), and that ethnography, in particular, offers a valid and useful research approach to the field, being especially concerned with description and in questions that demand explanation and prediction (Beebe, 2001). Observations by ethnographers of the physical and social environments of intravenous drug users have assisted with understanding the epidemiology of AIDS and designing interventions (Sankar et al., 2006), and are considered to be well fitted to research in a clinic setting as well as in the community. Ethnographic studies in sub-Saharan Africa explicating patient perspectives have also been reported (Merten et al., 2010; Mitchell, Kelly, Potgieter & Moon, 2009; Nachega et al., 2006; Nguyen et al., 2007; Penn, Watermeyer & Evans, 2011), and ethnographic principles incorporated into patient-based cross cultural curriculum frameworks to educate health practitioners (Carrillo, Green & Betancourt, 1999).

Ethnography arose from social anthropology at a time when communities were studied with the aim of exploring shared (within those communities) cultural beliefs and practices, which were often presumed static. Shifts in attitude away from the idea of ethnographers as neutral observers and the notion of social coherence as a dominant feature of cultures, has led ethnography to become a powerful research
approach incorporating a range of methods and an explicit acknowledgement of the role and influence of the ethnographer as data gatherer in the fabric of the research outcome (Savage, 2000). Therefore, within ethnography is the explicit recognition of the potentially positive and negative interaction that an ethnographer can have within the setting. In effect, ethnography is currently viewed as a constructivist epistemology, in that meaning is constructed from the outcomes of interactions between, and within individuals and their environments (Whitehead, 2004). Another key aspect of ethnographic research which emerged in the 1970s, is the concept of the researcher as participant observer rather than an ‘observer of participants’ (Tedlock, 1991). In effect, the researcher is both participant and observer, although Gitte Wind (2008) proposes that ‘negotiated interactive observation’ may be a more appropriate way to describe ethnographic fieldwork that is conducted in hospital settings. Notwithstanding, the influence of the ethnographer in the fabric of the research outcome is aligned with the idea that the researcher is a primary research instrument and such an instrument is generally calibrated to avoid or account for bias in a scientific study. Accordingly, the practice of including field notes becomes an essential part of the study methodology.

Relevant features of ethnography include the consideration and involvement of information from key informants. Geoffrey Walford (2009) cites (Bryman, 2002) to explain further features: the interaction of the researcher with the participants and with the environment in which the research takes place; the high value assigned to the participants’ verbatim concerning the meanings and attributions that arise within discourse; and the consequent internal validity of the study. In this study I have applied the concepts expounded by Becker (1998, p. 44) so that rather than viewing participants as analytic units that are fixed entities immune to context and situational
variations, I have posited adherence behaviour as an activity within the illness experience. Accordingly, I have focused the analysis on the circumstances in which the participants found themselves with their attendant and critical antecedents and connections such as access to medication, citizen status and psychosocial aspects of HIV infection that may influence health outcomes. In concordance with that stance, I also hold the understanding that culture is a constantly shifting and multifaceted construct with many attributes (Sands, Bourjolly & Roer-Strier, 2007).

Methodological issues arising from concepts of ethnicity and race

A culture that arises from shared activities and a sense of identity or belonging to a common origin in language, religion, race and or ancestry, underpins the concept of ethnicity, however, Ragin & Hein (1993, p. 255) remind us that:

...ethnicity is profoundly contextual (it takes many forms, depending on associated conditions) and deeply interactive (it is closely entwined with political and economic institutions, events, and processes).

In contrast Howard Becker (1998, p. 2) cites his teacher and mentor Everett Hughes (1971, 1984, p. 153-4) as stating:

An ethnic group is not one because of the degree of measurable or observable difference from other groups; it is an ethnic group, on the contrary, because the people in and the people out of it know that it is one; because both the ins and the outs talk, feel, and act as if it were a separate group.

As is often the case literature can illuminate ideas. A character in Teju Cole’s recent novel ‘Open City’ (2011, p. 118) says (of communitarianism):

White is a race, he said, black is a race, but Spanish is a language. Christianity is a religion, Islam is a religion, but Jewishness is an ethnicity. It makes no sense. Sunni is a religion, Shiite is a religion, Kurd is a tribe, you see?
The terms race and ethnicity are often used interchangeably and although intertwined, race is sometimes viewed as a variant of culture. But ethnicity tends to be socially situated (Ragin & Hein 1993) and race, biologically or ancestrally (Salzman & Rice, 2011). Both are relevant in the context of HIV disease since HIV is a biological condition, socially situated, and influenced by host genetic factors. Stanfield and Dennis (1993) assert that data collected in ethnographic research, and pertaining to race and ethnicity, are often presumptive and confounded by a priori ideological and cultural biases. Furthermore, it has been argued that racial and ethnic issues in the social sciences are embedded in societal folk beliefs and can impede or confound research studies, particularly qualitative, which rely on the researcher as the data collection instrument. As a researcher, I acknowledge the potential influence of social and cultural stereotypes of ethnicity and race derived from historical influences and my own personal experience as confounding biases in this research.

If ethnicity is accepted as deeply contextual and interactive, the methodological consequences are considerable. It then becomes illogical (because it weakens the research design) to group and compare cases based on race or ethnicity which it follows could then be used, erroneously, to predict or assign those constructs. Therefore, I sought to overcome this by focusing on the circumstances in which the participants found themselves; and by describing commonalities; highlighting points of difference; and setting the limits on generalisations that could be made.

Another issue for the social scientist is that discourse is constrained by the conservative style imposed by the discipline. Stanfield and Dennis (1993) argue that some of the most compelling and influential accounts of issues arising from the concept of race can be found in the field of literature. I sought to overcome this
methodological challenge by using qualitative methods to facilitate the participants’ voices while I grappled with data validity and reliability, or credibility and dependability respectively; and by (Bloomberg & Volpe, 2008; Stanfield & Dennis, 1993) using a combination of research methods to achieve data triangulation.

Notwithstanding the preceding comments, a cultural competency framework was referenced to query the participants’ social context, socio-cultural beliefs and behaviours. This method of questioning was developed to assist physicians to avoid socio-cultural stereotyping and improve their ability to understand, communicate and deliver clinical care to patients from diverse backgrounds. This is in contrast to learning presumed cultural characteristics of certain ethnic groups (Carrillo et al. 1999). However, in a research setting it should be recognised that the researcher’s questions are often responses to observations made in the field, and by the participants, so that the construction of meaning arises from both etic and emic sources. To explain this further, emic understanding is based on the categories local people use for compartmentalising their reality and identifying the terms that they use for these categories—an insider perspective. Etic understanding, however, is based on the categories used by the researchers or outsiders to divide up perceived reality, in effect an outsider perspective (Beebe, 2001).

Research Problem, Purpose and Aims

Research problem

People with HIV residing in WA on temporary visa status or living and /or working in rural areas face issues that may dramatically impact on their experience of living with HIV and managing the condition at a number of biopsychosocial levels, including health-related quality of life. Temporary visa holders are not eligible for Medicare or
drugs listed on the PBS and must import generic treatments from internet vendors at commercial rates. In addition, evidence in migrants and people living in rural environments suggests that these groups are heavily affected by the stigma surrounding HIV/AIDS at a structural and personal level.

**Research purpose**

The purpose of this research is to describe (1) the experience of managing HIV in a rural or remote environment; (2) the impact of HIV in people on temporary visas; and (3) the outcome of ARV treatment for those individuals. Specific topics of access and adherence to ART are given prominence; the research positioned in the context of current service delivery and health provider perspective; and referenced to a study of health-related quality of life in PLWH carried out in the WAHCS in 2007-2008.

**Research goal**

I hope that this research will achieve a greater understanding of factors that are impacting and potentially disadvantaging PLWH in Western Australia, from their perspective, particularly those factors that are unjust or unfair, and that will lead to appropriately targeted interventions. A secondary objective is to delineate pathways of therapeutic care, again from a patient perspective, and contribute this information to an evidence based practice framework.

**Research questions**

1. What factors influence HIV health outcomes in the current Western Australian epidemic and in terms of barriers and facilitators to clinical care and treatment?

2. Do visa status, or rural remote living/working status influence access and uptake of antiretroviral drugs and clinical outcomes of treatment?
The Research Setting: HIV Services in Western Australia

Funding

Under the National HIV/AIDS strategy there is dedicated funding for the provision of services for HIV prevention, education and clinical services. Since 1996, funding for HIV/AIDS has been State and Territory specific under the Public Health Outcomes Funding Agreements, and because the Commonwealth government enters into individual negotiations, service provision between states varies. Although patients with HIV in Australia can choose to have their HIV care managed in a variety of health care facilities, including public or private hospitals, a sexual health clinic, or at a private HIV S100 prescribing GP practice, opportunities are limited, since most services developed became HIV-specific. In Western Australia, these are primarily public hospital-based funded by the WA Health Department.

Non-Government sector services: The West Australian AIDS Council

The Western Australian AIDS Council (WAAC) is a community based, not-for-profit organisation incorporated in 1985 in response to the HIV/AIDS epidemic in WA. The primary objectives of the organisation are (1) the prevention of HIV, and education of people at risk of acquiring HIV; and (2) the provision of care and support to people living with HIV. The Council receives State, Federal and Local government funding as well as sponsorship from local non-government organisations like Lotterywest and Healthway.

The WA HIV Cohort Study

The WA HIV Cohort Study (WAHCS) was established in 1983 (Mallal, 1998) as a long-term clinical observational study of HIV infected people in Western Australia. The
majority of HIV infected individuals in WA, approximately 80%, receive specialist care from a team of immunologists and infectious disease physicians at RPH. The service incorporates a Rural and Remote HIV Program delivering outreach care state-wide. A similar service model operates from Fremantle Hospital with approximately 120 outpatients and at Sir Charles Gairdner Hospital with 20-30. The remaining patients are followed up by GPs qualified to prescribe S100 antiretroviral drugs. At RPH comprehensive demographic, clinical and laboratory data are collected at the patient’s first presentation, and updated at subsequent physician reviews. Laboratory results are downloaded and linked with treatment and other relevant patient information (adherence, nicotine use, weight, blood pressure). This information is entered into a database after the patients’ clinic visits and contributes to individualised patient management plans. Patient support nurses, a social worker, clinical psychologist and dietitian as well as immunologists, infectious disease and sexual health physicians, provide a multidisciplinary HIV service to PLWH attending Royal Perth Hospital.

At the time of writing approximately 10% of patients in the WA HIV Cohort held temporary visas and were ineligible to receive Medicare and access the PBS. This represents a steady increase in number since 2002 (Combs & Giele, 2009). An audit in May 2011 reported that 48% of the patients ineligible for Medicare were 457 visa holders (30 primary applicants, 10 spouses), the majority from Eastern Africa and employed in the mining industry. Another 20% were spouses of Australian residents, primarily women from South-East Asia who are progressing through application for permanent residency; a further 16% were student visa holders. Most patients were based in the metropolitan area and 32% lived in the regions. Many were diagnosed during health screening for continuation of visas and applications for residency (Williams, L. K., Foley & Cain, 2011).
Shifts in epidemiology have influenced clinic core activities

According to the anecdotal narratives of staff working in the clinic, an increased and varied workload has arisen as a consequence of this emergent epidemiological pattern. Temporary visa holders seek ongoing education, counselling and support from medical and allied health staff. First, they seek to alleviate their distress around the diagnosis of HIV since, in addition to the fear of illness and death experienced by many people diagnosed with HIV, visa holders are concerned that they will be deported. Secondly, there is fear that employment may be terminated; and thirdly, there is concern about preventing HIV status being disclosed to extended families or local communities. Following this phase further assistance is sought as medical personnel are called upon to support and provide documentation for visa applications and continuations. In addition to pre-treatment medication education provided routinely to all patients, nurses teach Medicare ineligible patients how to procure generic antiretroviral drugs using links to vendors of generic drugs on the internet. They also prepare letters seeking compassionate access to largely unaffordable patented medicines until generic supplies are established; or when generic ARVs are unsuitable for a particular patient because of resistance or hypersensitivity. Staff also note that since temporary visa holders tend not to access the WA AIDS Council which traditionally offers education, low cost counselling and support to HIV positive individuals, as will be demonstrated in this study, this role is borne largely by the outpatient service. Furthermore, people with temporary visas, (particularly category 457) are often likely to be living or working in rural areas and distance can potentially increase the complexity of their care. The perceived need for confidentiality of those working in the mining and health sectors may further complicate health service delivery.
Section 100 pharmaceutical prescribing authority

This centralisation of HIV care in Western Australia has been shaped by the way antiretroviral drugs are classified or scheduled by the Pharmaceutical Benefits Scheme (PBS) as Section 100 (S100) pharmaceuticals. This scheduling means that medical practitioners must receive training and accreditation through the Australasian Society of HIV Medicine in order to become prescribers of ARVs. Since there are currently only two S100 prescribers aside from the Perth Teaching Hospital HIV Physicians and both are Perth based GPs, there are no physicians certified to prescribe ART outside the metropolitan area. To compound the difficulties, ART is only dispensed by pharmacies at Royal Perth and Fremantle Hospitals. This is in stark contrast to the other Australian states where, in 2009, New South Wales listed 103 prescribers; Victoria 36; Queensland 25; South Australia 20. WA was more akin to the Northern Territory (3); and Tasmania with just one authorised prescriber (McLean & Savage, 2009a).

Services to PLWH in Regional Western Australia

The Western Australian Rural and Remote HIV Program at RPH was established in 1998 in response to the increase in number of HIV infected people living and/or working in country areas. Approximately 30-35% of PLWH in WA live and work in rural areas including many migrants and those on Long Stay Business (457) visas (32% of all visa holders), although they may return to their country of origin periodically. The enrolment in 2009 was 198 patients although the number accessing the program since its inception is 274. Three Immunologists, and an Infectious Diseases Physician participate in this service as part of their substantive positions and a Clinical Nurse Specialist (1.0 FTE) holds a dedicated position. The person in this role liaises with regional health professionals state-wide and also provides a clinical point of contact for
people with HIV infection through the Department of Justice (Prisons) and in the management of pregnancy. Outreach clinics to two regional areas in the North-West and the Goldfields have been held *ad hoc* about twice a year since 1998 and 2005, respectively, and, more recently, a clinic was held in Broome in liaison with the Public Health Physician in that centre. The role of the Rural Remote Nurse is to support patients, their partners/families and health professionals, coordinate bloods, and dispatch antiretroviral medication from Perth to patients. Although the service is delivered in selected regional areas many patients take the opportunity to come to the city for business or recreational reasons. Others prefer to access the service in Perth to avoid inadvertent disclosure of HIV serostatus in their rural communities, and some simply prefer to see the health care providers in person. Approximately half of the rural cohort, about 100 people, see a doctor in their region and attend the service at RPH about once a year. The main regional centres are Kalgoorlie-Boulder and two North-West Towns but there are established shared care relationships with GPs in the Great Southern region although these are not S100 prescribers.

**Accessing the Research Setting**

Before beginning my PhD candidature I had worked in the field of HIV for 12 years as a researcher and research coordinator in a group of clinician immunologists and scientists. My first research project in 1997 was a study of lipodystrophy, a serious drug-induced adverse effect of what was thought to be protease inhibitors. This study was my introduction to field of HIV, the world of ARVs and their impact on the lives of PLWH. It was carried out in a university research facility situated alongside RPH but my subsequent research was conducted in the Immunology Outpatient Clinic at RPH. My experience in lipodystrophy, which was a focus of our group, led to an interest in
medication adherence which, by then, had become a primary concern in HIV clinical care. In 2002 I formed an ‘adherence’ working party with allied health professionals in the Department of Immunology, and a number of studies related to medication adherence followed.

It was the findings of the 2007-2008 study on health-related quality of life (PROQOL-HIV) which led me to believe that we needed to extend our understanding of people with HIV/AIDS from backgrounds other than the, largely Caucasian male, city-based demographic I had studied previously. I had informal discussions with a clinical immunologist about her perceptions of the difficulties facing migrants from Asian backgrounds and people working in the mining industry. From my association with the working party and attendance in the clinic conducting other research activities, I was aware there had not been any rigorous research involving non-indigenous rural-based patients. Therefore, conversations with my hospital-based colleagues and supervisors assisted the development of the proposal, informed the study design and shaped my approach to the interview material. In addition, the data from the PROQOL-HIV study provided me with access to contemporaneous and relevant sociocultural data to use as a reference point for the studies in regional and mobile populations. This long association with the service at RPH and the natural progression of the research meant that my hospital-based colleagues, many of whom were co-authors on collaborative research activities, were familiar with my presence in the clinic so there was a degree of trust and rapport which facilitated the acceptance of my PhD proposal.

My primary supervisor was also a hospital-based HIV Physician, as were three members of my supervisory committee. However, in order to access the RPH site, I circulated my research proposal to the Heads of Department, the Rural and Remote
Service and the Clinical Nurse Specialists. I met with them subsequently to seek their individual approval, and advice with regard to the proposal. Contact was also made with the Head of the Infectious Diseases Department at Fremantle Hospital and senior nursing staff to gauge their interest in offering clients attending the clinics participation in the study. The proposal was also sent to Public Health Physicians in the North-West and Goldfields’ regions.

**Engaging with the community and GIPA principles**

The term GIPA refers to the Greater Involvement of People with HIV/AIDS, and derives from a principle embedded in the Paris AIDS Summit Declaration of 1994 where leaders of 42 nations met to determine how they could effectively respond to the AIDS crisis. The underlying principle is that PLWH should have a central and active role in developing policies to address the issues related to the epidemic. This principle is based on the idea that HIV-positive people have a unique perspective of their experience:

*Positive people can perform valuable functions. They can be very powerful AIDS educators, counsellors, and policy makers. Their involvement in the response also builds up the morale of other positive people. The essential link between protecting human rights and promoting public health suggests that a greater pool of positive activists must be encouraged.*

(Asia Pacific Network of People Living with HIV/AIDS, 2004)

Although there had been representation of migrants and refugees via non-government organisations (NGOs), at the time of the study, there was no formal representation for temporary visa holders as a community. However, the HIV service providers had assigned temporary visa holders a ‘virtual’ group status based on their ineligibility for Medicare, despite their heterogeneity in gender, country of origin, ethnicity, mode of
transmission, and employment or student status. More commonly they held Long Stay Business Visa and were categorised by workers in the field as ‘457s’ rather than the more ‘wordy’ temporary visa holders. According to Salzman and Rice, (2011) temporary visa holders might be represented as a contingent group i.e. only called into existence and action in response to certain circumstances or contingencies. Therefore, it could be argued that there was no formal support or community representation for visa holders as a recognised group or community. Notwithstanding these limitations, I recognised the WA AIDS Council (WAAC) as a potential and legitimate stakeholder in this research and accordingly, the proposal with an invitation for comment and participation was sent to the Director, who circulated it within the organisation. I also contacted the Migrant Resource Centre (on the recommendation of Professor Peter Drummond at Murdoch University) which had been funded by the Department of Health to employ a Youth Worker for a Sexually Transmitted Infections awareness and prevention program who was subsequently interviewed. She had initiated HIV educational sessions for men (HIV status unknown) in the African Community in partnership with WAAC. A number of other stakeholders were interviewed, including a worker with the Integrated Humanitarian Settlement Strategy Scheme in WA and the President of the Australian Federation of AIDS Organisations (AFAO), who subsequently (in February 2011), authorised my access to a confidential report on the subject. In addition, the results of my investigation in the temporary visa holders were presented at the annual conference of the Australasian Society for HIV Medicine (ASHM) in September 2011, thus offering any party who believed they had a stake in the outcome of the study to comment or contact the researcher. And finally, an executive summary of a detailed report on temporary visa holders was sent shortly
after that to WAAC, AFAO and NAPWA. No response was received from those organisations.

Engaging with other communities

With the principles of community engagement in mind, in October 2010 I took the opportunity to attend a Community Consultation Forum on the topic of “Living with cancer in the country” convened by The Cancer Council of WA, a team of researchers from the University of Western Australia and the WA Department of Health. I declared my interest as a PhD student conducting a research study which involved people in regional areas, without disclosing my interest in HIV to the participants (although I did so to the convener). I therefore attended as an observer. This level of participation enabled me to reflect on the commonalities and differences between the experiences of cancer vs HIV/AIDS in rural areas and gave me access to a wider variety of views than I was to have from a rural HIV ‘community’ which could be argued does not exist.

Data Collection

Interviews with Key Informants

I contacted the informant/stakeholders identified in Table 2 by email to invite their participation and attached a copy of the research proposal. If they agreed, then a face to face, informal interview was arranged and conducted at their venue of choice, most commonly the workplace. This ensured that people were given the opportunity to be met on their own terms and within an environment in which they were comfortable, their own ‘territory’ in effect. For this reason, I went to Kalgoorlie-Boulder and a North-West Town to interview regional staff in these towns and to the offices of the non-clinical participants. I travelled to Kalgoorlie by train for the first visit in May 2010,
a seven hour journey one-way. I wanted to experience the journey as would a local making the trip to and from Perth for medical care. As it happened, I struck up a conversation with a fellow passenger, a New Zealander who, with her husband, had been attracted by the work available in the Goldfields. That journey and the return a day later gave me a sense of the distances to be traversed and a snapshot of the demographic (including people with evident mental health problems) using the train as a mode of transport (since air travel is significantly more expensive). The next visit to Kalgoorlie-Boulder was in August 2010 when I flew from Perth, a one hour flight. In September I travelled to the North-West Town, a two hour journey by air.

I asked those interviewed for advice as to other informants who could be approached to ensure the adequate representation of people who felt they had a stake in the research. The interval between the participants receiving the proposal, and discussions with me ensured that by the time the interviews took place the participants had had ample time to consider their participation. Some of the interviews with clinical personnel were rescheduled up to four times.

Table 2: Sampling frame of key informants and stakeholders/constituents

<table>
<thead>
<tr>
<th>Key constituency</th>
<th>Roles</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>*Clinical</td>
<td>Immunology Consultant</td>
<td>Perth Teaching Hospital</td>
</tr>
<tr>
<td></td>
<td>Clinical nurses (3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychologist</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social Workers (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dietitian</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pharmacist</td>
<td></td>
</tr>
<tr>
<td>Public Health</td>
<td>Public Health Physicians (2)</td>
<td>Kalgoorlie Boulder</td>
</tr>
<tr>
<td></td>
<td>Public Health Nurses (2)</td>
<td>North-West Town</td>
</tr>
<tr>
<td></td>
<td>Aboriginal Health Care Worker</td>
<td>Population Health Units</td>
</tr>
<tr>
<td></td>
<td>Secretary</td>
<td></td>
</tr>
<tr>
<td>Health Promotion/Prevention</td>
<td>Executive Director</td>
<td>WA AIDS Council</td>
</tr>
<tr>
<td></td>
<td>CALD Counsellor</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Treatments Officer</td>
<td></td>
</tr>
<tr>
<td>Migrant Health</td>
<td>Migrant Health Workers</td>
<td>IHSS and Migrant Health Unit</td>
</tr>
<tr>
<td>Health Policy</td>
<td>President</td>
<td>Australian Federation of AIDS Organisations</td>
</tr>
</tbody>
</table>

*The Study was approved by the Fremantle Hospital Ethics Committee but no participants were recruited at that centre.
The interview questions were topic based and framed by the occupation of the informant, but access to medication and engagement with care were consistent themes. More generally, roles within organisations, specific patient or client-centred responsibilities and relationships with other members of their team and/or other HIV service providers were explored. Participants were advised that the information they gave would not be shared with any other informants but should they wish to discuss their interviews with others that was acceptable to the researcher. The interviews lasted between 40 and 80 minutes, were recorded, transcribed verbatim and returned to the interviewees for verification and additional comment, none were forthcoming.

**Recruitment of ‘Patient’ Participants**

**Eligibility Criteria**

People were eligible for inclusion in my research if: (1) they had HIV-infection and lived or worked in a regional area; (2) may have been at some stage, ineligible for Medicare; and (3) were eligible to give written consent. Since the research focus was not based on any particular ethnic group (including Aboriginal and Torres Strait Islander people) or gender, no one was excluded or included on the basis of ethnic background, or minority status. In 2009 there were approximately 50 patients on temporary visas distributed across both metropolitan and country areas attending the Ambulatory HIV Services at RPH at intervals of 3-6 months. Of the approximately 168 adults enrolled in the Rural and Remote Service (RRS) around 25 were classified as ‘fly in fly out’ workers and 19 lived overseas or ‘offshore’. However, I subsequently discovered that many FIFO workers were not listed with the service and during my candidature their status as enrolled in the RRS was revised.
Method of recruitment

There are four outpatient clinics held each week at RPH to care for PLWH. I knew from experience that these clinics were extremely busy and that there were no rooms available for dedicated research purposes. I was also advised that one of these clinics was too busy to accommodate my research activity at all. However, rooms in an adjacent clinic were frequently unoccupied and the regular clinic staff and clerks helped me secure peripatetic accommodation that would normally remain disused at those times. Therefore, during the data collection phase between April 2010 and October 2011, I attended at least two of the four clinics held each week at RPH in order to recruit participants.

I reviewed the clinic lists prospectively and then sought advice from the Consultant or Clinical Nurse supervising that particular clinic as to the potential eligibility of patients on the list for that day. If it was thought that a patient might be eligible, I accessed the case notes during the clinic to confirm the fact. For each case reviewed I sought advice from the Clinical Nurse as to whether there might be some reason which might make an approach by a researcher, at that time, inappropriate, and this was sometimes the case. For example, it happened that some patients (potential participants) were recently diagnosed or undergoing a personal crisis. Subsequently, patients were introduced to me by the Nurse or Consultant Immunologist. I then explained the study and provided an information sheet. At this stage I endeavoured to establish rapport and trust so that participants understood the purpose of the study and my role in it. Many patients who cited being busy or being unlikely to return to the clinic for some months asked if they could do the interview straight away. However, to ensure that the patient had time to consider the implications of their participation and potentially
discuss the study with a person(s) that they cared about, I explained why that was not possible (with regard to the condition for informed consent) and a follow-up appointment was made either then, or by phone subsequently. Written informed consent was obtained at the next appointment. A second issue here is that from an ethical perspective, the participant exercises choice, and separating the interview from the initial encounter maximises the likelihood of freedom of choice (Morse et al., 2008).

The pre-arranged interviews were held either in the outpatient clinic, often during the lunch break between the morning and afternoon clinics; a research office elsewhere in the hospital; at the participants’ homes (two participants); by phone (two regional participants); and at a regional Population Health Unit (three participants).

At the beginning of 2011, I became concerned that I was not reaching sufficient numbers of rural-based or offshore workers. After discussions with my supervisor I sought a project amendment from the two ethics committees. This would allow the RRN nurses at RPH and Fremantle Hospital to send an email to clients who did not attend the hospital-based clinics, and with whom they had established patterns of electronic communication, to offer the clients information about the study and my email contact details. However, the nurses subsequently declined to do this.

**Outcome of recruitment**

Between April 2010 and October 2011 I met with over 45 people including the three seen at Kalgoorlie-Boulder Population Health Unit. Three patients declined to participate, one citing that he feared jeopardising his visa application in some way, another felt too busy with work and family commitments, and a third refused after discussion with her husband. Another 12 patients expressed interest and spoke freely
with me at our initial encounters however, for reasons related to their busy lives or work away, follow-up appointments proved too challenging. Two patients (both FIFO workers) agreed to field notes as one was not clear about when he would be able to return to the clinic and the other said that it would be difficult since he was a sole parent on his ‘off weeks’. Therefore, the data used for analysis was gathered from interviews with 30 participants (9 women) with HIV-infection: 22 had been granted temporary work or student visas, fourteen were current business or student visa holders, and nineteen lived or worked in rural areas. The other participants lived or worked in the metropolitan area. Interview data from nine participants was used in Chapters’ Four and Five, with the focus on Chapter Four related to issues of geographical remoteness; and in Chapter Five, were pertaining to visa status. Group data from the two rural-based cohorts was obtained from the WA HIV Cohort Study clinical records at RPH.

**Interviews with ‘Patient’ Participants**

The face to face interviews were of 40 to 90 minutes duration. The participants were again briefed on the aims of the research and assured of confidentiality. I had prepared a list of questions which were submitted to the ethics committees as part of the original submission. The questions were largely open-ended and participants were invited to qualify their responses (e.g. *could you describe to me...? Would you like to say more about that?*), and because I wanted the participants to ‘own’ the interview as much as possible, the questions became more of a cue to me to indicate whether we had covered the subject matter relevant to the research problem than a systematic, structured interview. The interview schedule was therefore based on broad topics and themes (*Table 3*) which had emerged from the PROQOL-HIV study, and informed by
the cross-cultural approach described by Carrillo and colleagues (Carrillo, et al. 1999) and was revised in December 2012 following the early analysis. Participants were free to direct the interview time so that the issues important to them were articulated, however, I ensured that access to treatment and adherence to medication were thoroughly addressed in the conversations. All interviews from consenting participants were recorded using a digital recorder and transcribed verbatim by a professional secretary with extensive experience in the process and in managing confidential material. All identifying features were removed from the transcripts. Field notes and observations prompted by the interviews were retained in a separate electronic file.

Table 3: Evolution of themes derived from the PROQOL-HIV Study. Seven issues important to participants not covered by any single existing HIV HRQL instrument: These issues were subsumed within 11 broader underlying themes

<table>
<thead>
<tr>
<th>Themes revealed by PROQOL analysis</th>
<th>Broad underlying themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of infecting others</td>
<td>General health perception</td>
</tr>
<tr>
<td>Concerns for the future</td>
<td>Social relationships</td>
</tr>
<tr>
<td>Satisfaction with care</td>
<td>Emotions</td>
</tr>
<tr>
<td>Self esteem problems</td>
<td>Energy (fatigue)</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>Sleep</td>
</tr>
<tr>
<td>Work disruption</td>
<td>Cognitive functioning</td>
</tr>
<tr>
<td>Treatment issues</td>
<td>Physical and daily activity</td>
</tr>
<tr>
<td></td>
<td>Coping</td>
</tr>
<tr>
<td></td>
<td>The future</td>
</tr>
<tr>
<td></td>
<td>Symptoms</td>
</tr>
<tr>
<td></td>
<td>Treatment</td>
</tr>
</tbody>
</table>

**Language considerations**

Most of the participants used English competently or fluently. English language competency is also a requirement attached to 457 and student visa status. Three South-East Asian women had limited English but were able to communicate with the researcher given sufficient time during the interviews. Two were accompanied by their husbands and one had an interpreter present, this participant’s English improved upon subsequent clinic visits as she was attending English language classes. I gave written
information about HIV/AIDS to the women in their language. To account for potentially low literacy, most questionnaires were administered by interview.

**Use of Diverse Forms of Data: The Reflective Diary and Field Notes**

In social science, data triangulation is a metaphor for the use of data from different sources. In this research I have aimed to achieve perspective by positioning reference data from the PROQOL-HIV study, interviews with key informants, a mix of clinical and fixed demographic data and finally my own observations recorded between August 2010 and October 2011. I also present two small case studies, one of which appears in the literature review and the other appears in Chapter Four. The information for these came from case notes, electronic records from the Cohort Study database and interviews with the participants themselves.

Keeping the project goal in mind I took opportunities, particularly while I was waiting for long periods in the Outpatient Clinic during recruitment opportunities (the ‘field’), to interact with staff, and record observations and discussions. As time passed I could see that these notes became valuable in providing context and detail to the research issues and useful reference data when I came to discuss the findings. I also planned and scoped a focus group on the topic of health literacy with nursing staff from three hospitals but did not achieve the participation necessary to make the activity feasible.

**Clinical Data**

**Socio-demographic characteristics**

I recorded socio-demographic characteristics including: country of birth; visa status; professional activity; level of studies; marital status; ethnic identity; year of diagnosis, mode of transmission; and place of infection if known. Use of alcohol, nicotine and
other drugs were assessed using the questionnaire adapted by Chesney and colleagues (2000) and used in previously in our unit (Herrmann et al., 2008b, 2012).

**Biological markers**

Plasma HIV RNA levels were determined using a polymerase chain reaction assay with a lower limit of detection of 40 copies/mL. The Taqman 48 assay which detects virus in the range of 40-10,000,000 copies/mL was used for testing since 2007. The kit used for the assay includes primers which detect A, B, C, D, E, F and G HIV subtypes. Where the information was available, the HIV subtype (or clade) was recorded. The HIV RNA level was dichotomized as detectable (copies/mL) or not. The CD4 T-cell lymphocyte count was measured using the current standard flow cytometry using Trucount Tubes (Becton Dickinson) and recorded as the absolute number (mm3) and the percentage (%) of total lymphocytes.

**Antiretroviral Medication History, Access and Adherence to Treatment**

History and recent changes (within the last 3 months), in anti-retroviral therapy, current AIDS prophylaxis, and treatment of co-morbidities, was collected from the participants’ medical records and cross referenced with participant self-report. Symptoms and side effects were assessed, in all the studies, using a modified version of an HIV symptom index (Justice et al., 2001), adjusted to include questions sensitive to side effects of current drugs. A history of AIDS diagnosis, depression, self-reported and clinically diagnosed, and other co-morbidities were collected and verified using the patients’ medical records. Use of complementary therapy, pill burden and dose scheduling was also confirmed with the participant. The way in which the participants accessed ART and the cost of the medication was recorded. Adherence to ART was assessed by self-report using the Adult AIDS Clinical Trial Group Adherence
Instruments (Chesney et al., 2000), and discussed with the participants within the interview, except in the second stage of the PROQOL Study, where it was assessed by asking the participant if they had missed doses of medication in the two weeks preceding their visit.

**Data Analysis**

Once identifying features were removed from the transcripts they were imported into NVivo 8 (QSR International Pty Ltd). I used the software to create broad categories (free nodes) into which I put selected text from the transcripts. I coded nearly all the verbatim and included positive and negative responses within the same coding node, for example, comments concerning the topic future included concerns about the future but also optimistic statements. This approach allowed me to assess balances and trends within the participants’ responses. I later coded from the free nodes into a more hierarchical structure (tree nodes). Table 4 provides more detail. I conceptualised the impact of HIV as emotional, social and physical but also coded for eight other topics: access to and experience of health services, prior experience of illness; personal history, which allowed the participants to share information about themselves; thoughts and feelings about the future; moderators of HIV impacts; use of alcohol and other drugs; attitudes to the future; and treatment related impacts. Because of interrelationships between the themes some verbatim appears in more than one node.

An interim analysis of the text at the end of 2010 provided key data to refine the questionnaire schedule and informed the focus of the latter data collection which started in early 2011. I then began refining the coding e.g. from stigma as a broad subcategory of emotional and social impacts into ‘stigma manifestations’. I also
considered how people perceived that having HIV infection limited their lives now and in the future. The themes of access and adherence became intertwined with aspects of stigma but also the functional constraints posed by non-citizen status.

In addition to the qualitative software, I used simple pen and paper data summary tables in order to do a close and textual analysis of the transcripts and field notes (Bloomberg & Volpe, 2008) which helped in recording frequencies. Some of this was later transcribed to Excel to be collated with the clinical data. The NVivo program was also useful as a project management tool and linked the ethics committee submission, assessment tools and project proposal. Demographic, symptom, adherence and clinical outcome data was entered into Excel version 7 and summarised.
Table 4: Topics and themes drawn from the interviews. Themes incorporate positive and negative utterances e.g. continuity of care or lack of.

<table>
<thead>
<tr>
<th>TOPICS</th>
<th>THEMES</th>
<th>TOPICS</th>
<th>THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Emotional impact of HIV</td>
<td></td>
<td>Social impact of HIV</td>
</tr>
<tr>
<td>Experience of diagnosis</td>
<td>Shock &amp; distress</td>
<td>Visa &amp; immigration issues</td>
<td>Partner impact/Physical intimacy/</td>
</tr>
<tr>
<td>Diagnosis adjustment</td>
<td>Confusion</td>
<td>HIV in home country</td>
<td>Childbearing/rearing</td>
</tr>
<tr>
<td>Feelings about HIV</td>
<td>Constraints of the disease</td>
<td>Employment</td>
<td>Limited opportunities, e.g. work &amp;</td>
</tr>
<tr>
<td></td>
<td>Leading a ‘normal’ life</td>
<td>Impact on relationships &amp; family</td>
<td>relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Employment health screening</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health cover and cost</td>
<td></td>
</tr>
<tr>
<td><strong>Stress</strong></td>
<td>General stress &amp; due to HIV</td>
<td><strong>Personal histories</strong></td>
<td>Reason for being in Australia</td>
</tr>
<tr>
<td>Confidentiality concerns</td>
<td>HIV in rural area/heightened disclosure</td>
<td></td>
<td>Work/workplace issues</td>
</tr>
<tr>
<td></td>
<td>Confidentiality concerns</td>
<td></td>
<td>Cultural/diff epidemiology</td>
</tr>
<tr>
<td><strong>Stigma</strong></td>
<td>Fear</td>
<td></td>
<td>Travel to country of origin</td>
</tr>
<tr>
<td>Cultural nuances</td>
<td>Fear of testing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enacted/actual</td>
<td>Fear disclosure/discrimination/shame</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived/anticipated</td>
<td>Fear transmitting HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalised</td>
<td>Future/health/residency</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Moderators</strong></td>
<td><strong>Treatment related impacts</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>Coping/adjustment</td>
<td>Access medication</td>
<td>Frustration</td>
</tr>
<tr>
<td>HIV Knowledge</td>
<td>Partner/spiritual</td>
<td>Adherence/missed doses</td>
<td>Determination, motivation, access</td>
</tr>
<tr>
<td></td>
<td>Positive thinking</td>
<td>Treatment interruption</td>
<td></td>
</tr>
<tr>
<td>Alcohol &amp; other drugs</td>
<td>Previous experience of HIV in home country</td>
<td>Adverse side effects</td>
<td></td>
</tr>
<tr>
<td>Physical impact of HIV</td>
<td>Use and impact on adherence</td>
<td>Beliefs about medication</td>
<td></td>
</tr>
<tr>
<td>Appetite</td>
<td>Belief in healthy lifestyle</td>
<td>Beneficial effects of treatment</td>
<td></td>
</tr>
<tr>
<td>General health</td>
<td></td>
<td>Complementary therapy</td>
<td></td>
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<tr>
<td>Health Beliefs</td>
<td></td>
<td>Facilitators of adherence</td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td></td>
<td>HIV treatment experience</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Managing medication at work</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Organisation</td>
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<tr>
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<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Patterns of secrecy</td>
</tr>
</tbody>
</table>
Sample size or *How Many Interviews Are Enough?*

Guidelines for the size of non-probabilistic samples in qualitative research usually rely on the concept of data saturation i.e. the situation in which the data has been heard before. Guest and colleagues (Guest, Bunce & Johnson, 2006) used data from in-depth interviews conducted with sixty women from two West African countries to document the degree of data saturation and variability observed during their thematic analysis, and to demonstrate how to apply the concept of saturation. They found that saturation occurred within the first twelve interviews. A different approach is adopted by Howard Becker who discusses aspects of sampling at length, arguing that the aim of theoretical sampling (Glaser & Strauss, 1967) is to capture and describe variety and exceptions, in contrast with probabilistic random sampling which aims to reduce data to its common features (Becker, 1998). Nixon’s assessment is that if the qualitative research is focused on a homogeneous population then ten individual interviews is enough (Nixon & Wild, 2010), yet the issue arises in the definition of homogenous. The essential feature of the participants with whom I researched was that they were not an homogenous or easily definable group. The information on hand when I prepared the research proposal (at the end of 2009) indicated that there were approximately 198 active patients registered with the Rural and Remote Service, 25 were fly in fly out workers, 19 held visas, and 19 were living or working offshore. Approximately 50 patients attending the Immunology Outpatient Clinic at RPH were on temporary visas. After considering the feasibility of the project, I aimed to interview 40-60 patients with the goal of describing the issues important for people living and/or working in rural areas and those on temporary visas, while theorising that there would be three ‘contingent’ groups, termed loosely as: rural, FIFO, and temporary visa holders.
Validity or issues of trustworthiness

In qualitative research, data validity and reliability undergo a semantic change to become credibility, dependability, and transferability, respectively (Bloomberg & Volpe, 2008). These are the criteria for evaluating the trustworthiness of qualitative research. In this setting I have sought to represent the reality of the persons involved in my research and I have done this, in part by using multiple methods of data collection and providing an auditable trail of data. On completion of my field diary I kept a notebook of observations made during the data analysis and thesis writing phase. I also prepared three peer reviewed publications during the course of the candidature which required me to scrutinise details of my work repetitively. One of my supervisors cross checked the interpretation and analysis of several interviews. In addition, my long immersion in the field facilitated my understanding of the context in which the participants of the study are involved.

It is generally understood that in qualitative research by comparison with quantitative research, ‘generalisability’ is limited. Transferability, in this sense, relates to how useful the data is to another researcher or setting. For example, if the data is richly described it can offer a vicarious experience to a reader, thereby allowing them the opportunity to expand and develop new theories that can be used in relation to other research avenues (Bloomberg & Volpe, 2008). Whether or not this is achieved in this thesis will be expounded in the final chapter and judged by the reader.

Ethical Considerations

In the first ethics committee submission to RPH and Murdoch University, I indentified ethical issues that might arise in the course of the research and how I proposed to manage these risks. The relevant issues were: (1) consent, privacy, confidentiality; (2)
potential harm related to distress arising from the interview process which is of particular import in qualitative research; and (3) people in potentially dependant or unequal relationships, including visa holders and health professionals. Both committees gave approval conditional to receiving clarification on a number of points. These were related, primarily to: the security of the study data; the involvement of visa holders; the implications of asking people to reveal illicit substance use; and issues of consent. The study was subsequently submitted to the Fremantle Hospital Ethics Committee and was approved. Finally approval for protocol amendment was sought (and later approved) to seek more efficient access to ‘hard to reach’ but potentially eligible participants.

**Particular issues conducting research in PLWH**

Writing in the *Oxford Textbook of Clinical Research Ethics*, John Killen (2008) observes that the HIV/AIDS epidemic has had a profound impact on almost every aspect of research ethics. This revolution in ethics played out in community advocacy as access to care and treatments for the social communities most affected by HIV/AIDS was sought. Killen notes that as a consequence of community activism, the concepts of autonomy and justice have been broadened by recognising the important role that humans with life-threatening diseases play in assessing the potential harms or benefits of their participation in research as opposed to this decision being made by others with no personal ‘stake’.

An overriding concern when conducting research in the field of HIV/AIDS is to protect the privacy of the participant and take prescribed steps to avoid harm (the principle of maleficence) in the form of unauthorised, inadvertent disclosure of the participant’s HIV serostatus to others. Of course, protecting the privacy of participants in any
research setting is a prime concern. However, it is generally the case in mainstream research that given ethics committee project approvals, participants can be feasibly and inoffensively contacted by post, telephone or newspaper advertisement. However, in HIV research these practices can lead to inadvertent disclosure of HIV serostatus which can occur in a number of ways for example, by leaving messages on answering machines that reveal the nature of the inquiry or by sending documentation through the post that contain content with explicit reference to HIV or HIV/AIDS. This may be opened by neighbours if incorrectly addressed or by people living with the person who may unaware of their serostatus. The consequences of inadvertent disclosure of HIV serostatus for an individual can be distressing and result in real or perceived stigmatisation of that person. However, one of the downsides of this vigilance is that a health care worker can reinforce the stigma attached to the condition by implying that the patient has something of which to be ashamed. Careful communication is required to avoid this situation, especially around decisions made concerning to whom and when the decision is made to disclose HIV serostatus.

Similar issues around ensuring confidentiality can also constrain how educational material is disseminated. It is standard practice to use brochures to inform and educate patients about health disorders and drug treatments. Frequently people with HIV are reluctant to retain hard copy material (and this was also the case for people with cancer who may or may not have told family members about their cancer diagnosis) that may be viewed by visitors to their homes. Even those patients who are unconcerned about privacy at home may be reluctant to carry material on their persons away from the unit. This has practical implications for how patients are educated about HIV/AIDS on a number of levels, including how they interact with the health care system. This study was not designed to be an educative intervention,
however, wherever possible I took the opportunity to correct any knowledge deficits that I uncovered and used educational material during the interview, for example, the pill identification chart and graphic representation of the virus and targets for ART. I also assessed participants’ access to particular HIV/AIDS websites and directed them to those appropriate to their needs. In this way I dealt with the ethical dilemma that can arise when conducting research when a problem is uncovered: should the researcher act when they discover a deficit that may influence an outcome for a participant? In this way I also ‘gave something back’ to the participants.

The particular sensitivities around HIV disease complicated my access to patients in the regions. Traditionally clinicians act as advocates for their patients, and this is explicit in nursing codes of professional conduct. In research, this behaviour can be construed as functional ‘gate-keeping’. I had expected that my credentials as a qualified, experienced researcher in HIV over a ten-year period and my widely circulated, ethically approved proposal, would overcome some of the initial barriers to conducting the PhD research project. However, the extreme concerns of the Public Health Physicians and the Rural and Remote Clinical Nurse Specialist around privacy considerations, limited access to patients in regional areas. Just before this thesis was submitted I was asked by the Mid-West PHP responsible for the North-West Cohort to suppress the name of the town out of which the cohort is managed. Since all the patients in the cohort were Aboriginal it was necessary to obtain approval from the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC) in order to invite Aboriginal people, as a targeted group, to participate in any research studies. However, this was not part of my proposal and I would not be offering participation to this population. I visited the Goldfields twice; at the first visit I interviewed the Public Health Physician and the Public Health Nurse.
informed me of his confidentiality concerns and suggested that I attend the next outreach clinic and recruit patients by the invitation of the Rural and Remote Nurse during the clinic, which is what happened. All of these negotiations involved lengthy communications over weeks. Just before this thesis was submitted for examination, I sent Part 1 of Chapter Four to the Public Health Physicians from both the regions that I visited, as a courtesy and in order to invite their comments. Other than the request from the PHP to suppress the name of the North-West ‘Town’, both were happy to approve the presentation of the data.

The preceding comments and observations are drawn from my field notes and correspondence with providers. They serve to illustrate the realities of conducting research in populations assigned as vulnerable, and the current context for conducting qualitative research in Western Australia and they are not in any way a reflection of personal resentment.

**Summary**

In this chapter I have delivered a comprehensive description of how I conducted the research, the rationale behind those decisions and their theoretical bases, and some of the methodological aspects pertaining to qualitative research in general and ethnography in particular. I have described the social context of the research and pertinent details that contribute to context and the principle of thick description.
CHAPTER THREE

HEALTH-RELATED QUALITY OF LIFE
CHAPTER THREE  HEALTH-RELATED QUALITY OF LIFE

Introduction

This study was reported in a manuscript submitted to the journal Health and Quality of Life Outcomes under the title of: “HIV-related stigma and physical symptoms have a pervasive influence on health-related quality of life in Australians with HIV infection”. The manuscript is under revision, following the receipt of reviewers’ comments. The study outcomes are discussed in this section of the thesis but further explicated and placed in context in Chapter Six. I have acknowledged the contribution of co-authors in the preliminary section of this thesis.

Background

Antiretroviral therapy (ART) has slowed progression of HIV infection to AIDS, and significantly reduced morbidity and mortality in people with HIV who have access to the treatment (Palella et al., 1998). However, symptomatic HIV infection, effects of treatment, stigma and other psychosocial features of the condition continue to exert a considerable influence on health-related quality of life (HRQL) (Abboud, Noureddine, Huijer, Dejong & Mokhbat, 2010; Bouhnik et al., 2008; Jia et al., 2007; Logie & Gadalla, 2009; Protopopescu et al., 2007; Xianhong, et al., 2011). Measures to assess the effect of ART on health status and wellbeing were introduced in 1991 (Wu et al., 1991). Underpinning these measures was the hypothesis that adverse symptoms would impact on respondents’ perception of their Physical, Social and Mental Health functioning and quality of life. This pragmatic perspective of HRQL shifted in the mid-nineties when the World Health Organization broadened the concept to encompass ‘an individual’s perceptions of their position in life in the context of the culture and values systems in which they live and in relation to their goals, expectations, standards
and concerns’ (1995). A priority for long-term clinical management of HIV, and a critical endpoint, is to improve quality of life indicators. Increased tolerability of ART, reduced pill burden and dosing frequency have been positive influences on quality of life facilitated by medication adherence (Mannheimer et al., 2005). However, these and other disease-specific dimensions of HIV such as stigma and treatment idiosyncrasies can impact on individual and public health and may not be captured using the current instruments. A new Patient-Reported Outcomes (PRO) questionnaire to measure the HRQL in people living with HIV was developed in eight countries; and later validated in our centre and others (Duracinsky et al., 2012a, 2012b). The aim of the study was to enhance understanding of the major factors impacting health-related quality of life in our cohort. By focusing on this local perspective, the work provides an explanatory rather than predictive approach to understanding the relationship between HRQL and physical, social and psychological distress, including HIV-related stigma, on a specific sample in a particular context. Here I present the results from the Australian arm of the PROQOL-HIV Study: a summary of themes from in-depth interviews (Stage One); the results of the psychometric testing (Stage Two); and present the factors most relevant in influencing HRQL in the WA HIV Cohort.

**Specific Methods**

**Study design and setting**

Semi-structured interviews with fifteen patients and survey data from 102 (out of 106 administered) respondents were analysed. It had been determined that fifteen interviews were sufficient for a within-country analysis based on the research of others into qualitative data saturation [24]; and the sample size for a within-country analysis of the PROQOL-HIV questionnaire had been powered for 100 patients. This figure
considered the number of conceptual dimensions needed to ensure a final factor model with reliable factor loadings in exploratory factor analysis (Duracinsky et al., 2012a; Guest et al., 2006). Patients with HIV infection, over the age of 18 years and able to give informed consent, were eligible for inclusion in the study. Patients were recruited during scheduled clinic visits to the Immunology Clinic at Royal Perth Hospital, a tertiary ambulatory facility. The fifteen interviewees were informed about the study by the unit social worker and patients subsequently contacted the researcher to arrange an appointment at an agreed venue. These participants were chosen to reflect a mix of age, gender and mode of HIV transmission. Recruitment for the survey phase was conducted at consecutive clinics from June to October 2008. Patients with sufficient time before their appointment with the physician were invited to complete the survey. Of 109 patients approached two patients declined to participate and data from five surveys were not included in the final analysis because they were incomplete. The study was approved by the Royal Perth Hospital Ethics Committee (2007/115).

**Interviews Stage One**

The two interviewers, this author and a Clinical Psychologist, reviewed the English version of the interview guide for fluency and use of the Australian vernacular. We then conducted semi-directed interviews of 60 to 120 minutes duration which were recorded and transcribed verbatim. The interview guide comprised 107 questions of which the first five were open-ended seeking participants’ experiences of the impact of HIV on their daily lives and their quality of life in general. The latter 102 questions were categorised into topics of self and body care, daily activities, physical activities, health perception, energy/fatigue, cognitive functioning, social relationships, emotions and
treatment. Participants were invited to qualify their responses. Hard copies of the transcripts were printed and patient interview data were examined by the two interviewers, independently, and several themes were identified and discussed. I subsequently imported the transcripts into the NVivo 8 qualitative software programme (QSR International Pty Ltd) where the verbatim was catalogued under theme headings called nodes. Analysis in NVivo facilitated the exploration of recurring themes and concepts, and drew attention to commonalities and variation between the verbatim of the interviewees.

**Questionnaires administered in Stage Two**

Two HRQL instruments were administered: (1) the 70 item pilot PROQOL questionnaire and (2) the Medical Outcomes Study HIV-Health Survey (MOS-HIV) (Wu et al., 1997; Wu et al., 1991), together with an HIV symptom index modified to include common side effects of current regimens (Justice et al., 2001). Psychometric analysis of the pilot PROQOL-HIV questionnaire across all participating cohorts arrived at an eight-factor solution, based on 39 items, explaining 60% of the variance in HRQL. The eight subscales were identified as follows: Physical health and symptoms (PHS), emotional distress (ED), treatment impact (TI), health concerns (HC), body change (BC), intimate relationships (IR), social relationships (SR) and stigma (ST). Each Likert item score (range 0-4 points) was summed and expressed as a final score on a 0-100 scale where each item contributed equally, and with higher values indicating better HRQL. The main properties including the validity and reliability of the questionnaire are described in the publications found in the appendix, but briefly, the score’s reliability was assessed using Cronbach’s alpha (0.936, 95% CI = 0.929-0.943) and the intra-class correlation coefficient (ICC) was assessed in 34 participants (ICC=95%, 95% CI=0.701-
Analysis was conducted on the 8 subscale scores corresponding to the 8 factors of the final solution, and two composite scores derived by averaging over the subscales with and without the treatment impact domain (termed the global 8-factor and 7-factor scores respectively). The two main composite scores derived from the MOS-HIV SF36 were also assessed within this study: the physical health summary (PHS) and the mental health summary (MHS).

**Clinical measures**

Plasma HIV RNA levels were determined using a polymerase chain reaction assay with a lower limit of detection of 40 copies/ml (Roche). The CD4+ T cell lymphocyte count (mm$^3$) was measured by flow cytometry using Trucount Tubes (Becton Dickinson). A history of HIV/AIDS diagnosis, co-morbidities, current anti-retroviral therapy, AIDS prophylaxis, and other treatments were collected and verified against the participants' medical records. Adherence to ART was measured as the number of self-reported missed doses in the two weeks preceding the study visit. This was concordant with the standard clinic practice of recording level of adherence, longitudinally, for all PLWH attending the clinic (Herrmann et al., 2008b) and work published by others (Gao & Nau, 2000; Lu et al., 2008).

**Analysis**

Sociodemographic, biomedical and psychometric data obtained from the PROQOL participants were compared across treatment groups using Fisher or Kruskal-Wallis tests as appropriate. PROQOL composite and subscale scores, and MOS-HIV composite scores, were analysed within a linear regression framework, with model $R^2$ values utilized to obtain the percent of score variability explained by inclusion of specified variable sets. Pearson correlations were calculated, with Fisher’s z transformation used
for calculation of 95% confidence intervals. Analyses were undertaken using TIBCO Spotfire S+ 8.2 for Windows (TIBCO Software Inc., Palo Alto, CA).

Results

Results of Interviews (Stage One)

Clinical and demographic data

Most of the 15 interviewees were Caucasian men, three were South-East Asian and two identified as being of Aboriginal ancestry. The median year of HIV diagnosis was 2001, and the mean (± SD) age was 41yrs (±10.5); CD4 T-cell count 542 copies/ml (±332.2), and percent lymphocyte count 25.5% (±9.7) (Table 5). Of the 3/15 participants who had a detectable viral load, two were not on current ART and one had a history of poor adherence. Symptoms were frequently reported (1-20 symptoms/31) at an average of eight symptoms per person. The most common were gastrointestinal (11 patients) followed by sleep difficulties (10), fatigue (10), and skin dry/itching (9).

Eight participants smoked and eleven reported current use of alcohol. Seven lived alone, five in a couple, two with family members and two with children. Six participants were in paid employment and two were students. All completed school to at least age fifteen and six were tertiary educated. Co-morbidities were described by 4/15 (26%): hepatitis C (HCV) (2 participants); pulmonary hypertension (1); Type 2 diabetes (1); and chronic back pain (1); and four (26%) reported current depression, two were treated. Three participants had lipodystrophy attributed to previous treatment with thymidine analogue nucleoside reverse transcriptase inhibitors.
Interview Verbatim: Aspects of Living with HIV

Quotes illustrating four dimensions of living with HIV are presented in Table 6: (1) emotional/social, (2) physical, (3) impact of treatment and (4) understanding of quality of life. Most participants perceived HRQL as having HIV or non-HIV influences. For some it involved feeling happy, and having supportive networks of family and/or friends, a satisfactory income and access to potent and effective treatments. The participants who experienced lower HRQL described co-morbidities, a high frequency of stigma fears, adverse symptoms and were more likely to be receiving disability pensions.
Table 5: Characteristics of the 15 interviewees who participated in Stage One of the PRO-QOL HIV Study

<table>
<thead>
<tr>
<th>Patient</th>
<th>Age (yrs)</th>
<th>Gender m/f/o</th>
<th>Transmission mode</th>
<th>Year</th>
<th>CDC</th>
<th>CD4 count</th>
<th>CD4 (%)</th>
<th>Viral Load (log)</th>
<th>HAART*</th>
<th>Duration (mths)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>48</td>
<td>m</td>
<td>msm</td>
<td>1985</td>
<td>C</td>
<td>1295</td>
<td>35</td>
<td>&lt;40</td>
<td>3TC/AZT/ABC</td>
<td>109</td>
</tr>
<tr>
<td>2</td>
<td>31</td>
<td>m</td>
<td>msm</td>
<td>2004</td>
<td>A</td>
<td>600</td>
<td>30</td>
<td>&lt;40</td>
<td>3TC/AZT/EFV</td>
<td>42</td>
</tr>
<tr>
<td>3</td>
<td>41</td>
<td>f</td>
<td>unknown</td>
<td>1987</td>
<td>B</td>
<td>330</td>
<td>22</td>
<td>&lt;40</td>
<td>FTC/TDF/LPV/RTV</td>
<td>180</td>
</tr>
<tr>
<td>4</td>
<td>66</td>
<td>m</td>
<td>hetero</td>
<td>1997</td>
<td>C</td>
<td>540</td>
<td>20</td>
<td>&lt;40</td>
<td>3TC/DDI/RTV/ATV</td>
<td>114</td>
</tr>
<tr>
<td>5</td>
<td>28</td>
<td>f</td>
<td>hetero</td>
<td>1994</td>
<td>C</td>
<td>&lt;6</td>
<td>&lt;6%</td>
<td>4.8</td>
<td>no current HAART</td>
<td>156</td>
</tr>
<tr>
<td>6</td>
<td>36</td>
<td>m</td>
<td>msm</td>
<td>2003</td>
<td>A</td>
<td>392</td>
<td>28</td>
<td>1.84</td>
<td>3TC/AZT/NVP</td>
<td>33</td>
</tr>
<tr>
<td>7</td>
<td>55</td>
<td>m</td>
<td>msm</td>
<td>1988</td>
<td>A</td>
<td>612</td>
<td>34</td>
<td>&lt;40</td>
<td>3TC/ ABC/ LPV/RTV</td>
<td>78</td>
</tr>
<tr>
<td>8</td>
<td>47</td>
<td>m</td>
<td>msm</td>
<td>2002</td>
<td>A</td>
<td>416</td>
<td>26</td>
<td>&lt;40</td>
<td>3TC/ ABC/ LPV/RTV</td>
<td>36</td>
</tr>
<tr>
<td>9</td>
<td>45</td>
<td>m</td>
<td>msm</td>
<td>2001</td>
<td>C</td>
<td>784</td>
<td>28</td>
<td>&lt;40</td>
<td>3TC/TDF/NVP</td>
<td>72</td>
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<tr>
<td>10</td>
<td>38</td>
<td>m</td>
<td>msm</td>
<td>2006</td>
<td>A</td>
<td>340</td>
<td>17</td>
<td>&lt;40</td>
<td>3TC/AZT/EFV</td>
<td>9</td>
</tr>
<tr>
<td>11</td>
<td>26</td>
<td>f</td>
<td>hetero</td>
<td>1998</td>
<td>A</td>
<td>1127</td>
<td>49</td>
<td>&lt;40</td>
<td>3TC/AZT/EFV</td>
<td>72</td>
</tr>
<tr>
<td>12</td>
<td>32</td>
<td>f</td>
<td>IDU</td>
<td>2001</td>
<td>A</td>
<td>384</td>
<td>32</td>
<td>3.92</td>
<td>no current HAART</td>
<td>72</td>
</tr>
<tr>
<td>13</td>
<td>44</td>
<td>m</td>
<td>msm</td>
<td>1986</td>
<td>C</td>
<td>336</td>
<td>21</td>
<td>2.16</td>
<td>3TC/AZT/ABC</td>
<td>156</td>
</tr>
<tr>
<td>14</td>
<td>37</td>
<td>m</td>
<td>msm</td>
<td>2005</td>
<td>A</td>
<td>690</td>
<td>30</td>
<td>&lt;40</td>
<td>3TC/ABC/RTV/ATV</td>
<td>26</td>
</tr>
<tr>
<td>15</td>
<td>42</td>
<td>m</td>
<td>msm</td>
<td>2002</td>
<td>C</td>
<td>280</td>
<td>20</td>
<td>&lt;40</td>
<td>3TC/AZT/EFV</td>
<td>63</td>
</tr>
</tbody>
</table>

Abbreviations: msm=men who have sex with men, hetero=heterosexual, IDU=intravenous drug use. HAART=highly active antiretroviral therapy; 3TC=lamivudine, FTC=emtricitabine, AZT=zidovudine, ABC=abacavir, TDF=tenofovir, DDI=didanosine, NVP=nevirapine, EFV=efavirenz, LPV=lopinavir, RTV=ritonavir, ATV=atazanavir; 8/13 patients on a BD regimen, mean number of pills = 3.4, median=3. CDC = stage at first presentation
Emotional and social impact

Feelings of social stigma triggered by HIV were associated with fear and anxiety in 11 out of the 15 interviewees despite a degree of self-reported adjustment to living with HIV. A fear of transmitting HIV inadvertently or in a situation where one was powerless to protect others, for example during a car accident, was intense for some individuals. A minor cut while preparing food resulted in interviewees repeating the food preparation from the beginning. One participant abandoned a profession in catering because of this concern. There was an aversion to disclosing HIV sero-status in any circumstance and a fear of being ‘outed’ by the appearance of ill health or being seen attending the hospital clinic. Anxiety about disclosure to employers, sexual partners and parents and for two of the women, their children, was considered most stressful. Some perceived career options to be limited. Attitudes of others featured strongly; stigma related to disease but also sexual identity, for example a heterosexual man feared homophobia. HIV impacted on work opportunities for those with ill health and choice of work generally. Feelings of sadness, shame and inferiority were common. The greatest restrictions for over half of participants were around sexuality: reduced spontaneity and avoidance of sexual intercourse. The legal and moral requirement to disclose to prospective partners and, potentially, employers weighed heavily. Restrictions to travel opportunities were perceived, compounded by concerns over travelling with medication, disclosing HIV sero-status on entry to some countries, and fear of becoming ill while holidaying. Some withdrew by degrees from social activities. The loneliness of chronic illness was described by one participant who perceived that friendships had fallen away since illness has altered his appearance and relationships.
with health care providers were tense because of his inability to ‘get well’ despite their ‘efforts’.

**Physical impact**

With regard to physical activity, some participants were limited by disability related to co-morbidity, whilst in others symptoms of pain and/or fatigue limited activity and affected motivation, resulting in feelings of social isolation. Activity that might result in transmission of HIV was avoided by interviewees and some had given up pleasurable body contact sports which they perceived might lead them to spill blood.

**Impact of treatment**

The interviewees who started ART pre-2000 described effects of pill burden, frequent dosing and residual side effects. One developed immune restoration syndrome and a disfiguring skin condition, not necessarily related. His experience of high-dose steroids and frequent changes of ART were debilitating and he felt unable to work or maintain an intimate relationship. Another interviewee had a long-standing history of non-adherence to ART and was hospitalised with severe immunodeficiency. This respondent took medication secretly, as did others. However, the majority viewed ART positively, as improving their health despite the effects of long term toxicities.
Table 6: Interviews: themes emerging from narratives (N=15)

<table>
<thead>
<tr>
<th>EMOTIONAL AND SOCIAL IMPACT</th>
</tr>
</thead>
<tbody>
<tr>
<td>The fact that (it’s, a) it’s a scary thing for people that don’t have it and a scary thing for people that do have it, it’s just a terrifying thing... (woman, 28yrs).</td>
</tr>
<tr>
<td>What disturbs me most about HIV is even though there is a lot of information out there, there are a lot of people that still are quite ignorant and they’re still quite fearful of HIV (man, 31yrs).</td>
</tr>
<tr>
<td>That my mother will find out...(man, 42yrs).</td>
</tr>
<tr>
<td>I am scared that I tell them and then it will be different. They would treat me differently (woman, 28yrs).</td>
</tr>
<tr>
<td>I’m afraid of dying...getting sick and not being able to take care of my children. I’m afraid of my children finding out like that’s probably my biggest fear in this world is when my children find out (woman, 32 yrs).</td>
</tr>
<tr>
<td>Oh massively restricted in the sexual sense (woman, 26yrs).</td>
</tr>
<tr>
<td>The fear that something may happen to me and I’m in a car accident....and someone tries to help me and I’m bleeding profusely and I pass it on to them (woman, 32yrs).</td>
</tr>
<tr>
<td>Sometimes if I’m cooking... silly thoughts of cutting myself (man, 37 yrs).</td>
</tr>
<tr>
<td>When they talk about people there is a disgust in the way they talk there’s disgust and it really deeply hurts because I have HIV and I don’t think that I’m disgusting (woman, 28yrs).</td>
</tr>
<tr>
<td>Sometimes it’s really difficult... like can be very isolating. Sometimes I feel like no one really understands and it’s very secretive as well like no one really knows, I don’t want people knowing (woman, 32 yrs).</td>
</tr>
<tr>
<td>...the friends that I did have put distance between us.... Separated themselves from me because it’s all got a bit hard or whatever (man, 47yrs).</td>
</tr>
<tr>
<td>That fear of possibly infecting him. I think the guilt eventually killed it (man, 42 yrs).</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>PHYSICAL IMPACT</th>
</tr>
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<tbody>
<tr>
<td>I went straight back to work as soon as I could- (work) was just a very lucky distraction to have (man, 38yrs).</td>
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<tr>
<td>I get tired very quick but don’t generally stop me doing anything I want to do...my problem is not wanting to do anything...it’s the motivation I don’t have (woman, 41yrs).</td>
</tr>
<tr>
<td>Tired and exhausted both (man, 66yrs).</td>
</tr>
<tr>
<td>I might have three or four bad days in a row and I have to ring up and take it off work and there’s no employer... they can’t put up with that for too long (man, 47yrs).</td>
</tr>
<tr>
<td>...any sort of activity that involves danger, all the risk of you know getting cut or something like that I just don’t do (woman, 32yrs).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IMPACT OF TREATMENT</th>
</tr>
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<tbody>
<tr>
<td>I look at them making me sick, making me vomit like just want to vomit already just looking at them (woman, 28yrs).</td>
</tr>
<tr>
<td>The drugs, the drugs are great. I can’t complain I haven’t had any side effects (man, 55yrs).</td>
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<tr>
<td>None... problem is just taking them in front of people (man, 37yrs).</td>
</tr>
<tr>
<td>I never had a eight hour sleep... there was not such a thing as an eight hour sleep (man, 44yrs).</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>PERCEPTIONS OF QUALITY OF LIFE</th>
</tr>
</thead>
<tbody>
<tr>
<td>The way you do to get to do the things you like to do, like what kind of barriers do you face like - do you have the support networks and all that sort of stuff (man, 66 yrs).</td>
</tr>
<tr>
<td>... means enjoying yourself, being happy... feeling good within yourself and about the people around you. I don’t have that any more (man, 47 yrs).</td>
</tr>
<tr>
<td>I think within the realms of HIV itself, I would think that my health is good... um... but within the realm of the general population, I would say that my health is quite bad...(man, 42yrs).</td>
</tr>
<tr>
<td>Since my medication my life’s actually been enhanced (man, 37 yrs).</td>
</tr>
<tr>
<td>I’ve got the best drugs, good treatment at the hospital - I can still work (man, 38yrs).</td>
</tr>
<tr>
<td>It’s been up and down but it’s now it’s pretty good according to all the numbers and results and things, I’m pretty well normal...(woman, 41 yrs).</td>
</tr>
<tr>
<td>I realised it’s all psychological really (woman, 32yrs).</td>
</tr>
<tr>
<td>I suppose for two thirds of my life, because ... I have been living with HIV for a third of my life, I lived a quality of life where I didn’t have to think about everything I just did what I wanted to do basically within ones responsibilities and obligations. Now through HIV my quality of life has changed in that now everything I do has to be considered (man, 45yrs).</td>
</tr>
</tbody>
</table>
Results of the Psychometric Testing of HRQL (Stage Two)

Sociodemographic and clinical attributes

Data were collected from 102 participants (15% female) aged between 24 and 71. Socio-demographic characteristics can be found in Table 7. Transmission was mainly through sexual contact (94%) and nearly 40% of participants lived alone. All but two participants reached at least secondary school level, and 80% were employed. The most common co-morbidity was depression (24%), followed by HCV (17%), psychiatric disorder (5%), cardiovascular disease (3%) and hepatitis B (2%). Of the participants with depression, 30% had Hepatitis C. Most participants were treated with ART (87/102), two participants had stopped previous treatment, and 13 were naive to ART. Amongst treated participants, 76% reported 100% adherence over the last two weeks, and of the 47% on a protease inhibitor (PI) based regimen, 56% were taking ART once daily compared with 83% of those on a non-nucleoside reverse-transcriptase inhibitor (NNRTI) regimen. An undetectable viral load was recorded in 85% of patients and the average CD4 T-cell count was 26%.

Health-related quality of life outcomes

Health-related quality of life outcomes were assessed in terms of both the global PROQOL score and the 8-subscale scores. The global 7-factor score had an observed mean (SE) of 60.62 (2.01), with mean subscale scores ranging from 43.32 (ST) to 72.55 (SR). Restricting to the treated participants only, scores were slightly higher across all domains except the physical health score, with the highest subscale being that measuring treatment impact. Inclusion of this latter domain resulted in an increase of the global mean from 61.66 (2.21) for the 7-factor score, to 64.07 (2.06) for the 8-factor score. On average, participants scored higher on the MOS Physical Health Scale
(mean (SE) = 52.5 (1.2)) than the Mental Health Scale (48.0 (0.9)) (p<0.001, paired t-test).

Univariate regression analyses of demographic associations with the PROQOL global and subscale scores are presented in Table 8, with covariates grouped according to indication of sociodemographic, treatment, biological and clinical factors. Of sociodemographic factors considered, the most discerning was professional activity, with patients who were unemployed or on sickness benefits reporting consistently lower HRQL across the domains. Those living alone were significantly more impacted by difficulties with intimate relationships compared with those living with others (p=0.006), whereas older age (>45yrs) was associated with higher HRQL scores in this domain. Worry over HIV and other health outcomes, for example test results and catching other infections, was less common in Caucasians (p=0.003) and older patients (p=0.02). However, those recently diagnosed (<2 years) were more likely to express health concerns (p=0.001) and, with lower scores in the stigma domain, indicate fear of disclosing their HIV status and infecting others (p=0.02). Duration of ART was considered as a treatment-related factor.

Participants not on treatment had significantly lower HC and ST scores (p<0.01) than those treated. Accordingly, having a detectable viral load correlated with increased health concerns and treatment impact on HRQL. In contrast, those receiving protease inhibitor-based ART who, on average, had been on therapy for 3 years longer than participants receiving NNRTI-based therapy, appeared less affected by issues of stigmatization. A small number of participants infected via IDU (mean = 12 years ago) reflected this trend since they scored most highly in this domain. However, PI regimens per se, having a higher daily pill burden and inducing more treatment-related
symptoms, were associated with both worse PHS scores and greater treatment impact on total HRQL. Negatively impacting on HRQL across many of the subscale scores were clinical factors: suffering from depression, another comorbidity or sexual dysfunction and frequency of experienced symptoms. The number of symptoms, in particular, was highly predictive of reduced HRQL across all domains except stigma. Symptoms were more prevalent amongst participants receiving PI regimens (mean (SE) number = 8 (0.85)) compared with those on NNRTI regimens (5.48 (0.80), p=0.005, Mann-Whitney test) but were not confined to participants receiving ART. Symptoms of malaise, particularly, were common across all three groups, as were insomnia and skin problems. Reflecting the observed consistent effect across most of the subscales, the clinical variables were also strongly associated with lower global PROQOL scores (Table 8). When considered together in multivariable models, these clinical factors explained over 30% of the variability in the global scores, contrasting with about 20% for the sociodemographic factors alone, 10% for the treatment factors and about 5% for the biological parameters.

After accounting for the clinical predictors, the contribution of the sociodemographic variables to observed score variability reduced to 12%, whereas that of the treatment factors and biological parameters dropped to 6% and 2.5%, respectively, in sequential models. The additional contribution of behavioural indicators such as smoking and alcohol consumption was negligible. With quality of life being a global concept, a total of 55% of the PROQOL score variation could be explained by the combined covariate sets. This compares with 75% and 70% of the variation in the MOS HIV PHS and MHS scores, respectively, each of which could attribute over 50% to the clinical outcomes alone.
Correlations between the composite scores and the PROQOL subscale scores are presented in Table 9 (restricting to treated patients only). Whilst the global PROQOL correlated most strongly with the subscale encompassing emotional distress (R [95%CI] = 0.86 [0.79-0.91]), both MOS HIV composites correlated particularly strongly with the physical health and symptom subscale (MOS-MHS: R [95%CI] = 0.80 [0.71-0.87]; MOS-PHS: R [95%CI] = 0.85 [0.78-0.90]). Conversely, the stigma subscale, which recorded the lowest mean of all the subscales, had the lowest correlation with the MOS scores (MOS-MHS: R [95%CI] = 0.25 [0.04-0.44]; MOS-PHS: R [95%CI] = 0.09 [-0.13-0.30]), unsurprisingly, since MOS-HIV does not purport to measure stigma.

The stigma subscale of the PROQOL instrument is comprised of items pertaining to fear of disclosure of HIV status and transmitting the infection. There was a strong correlation between having a high frequency of these two fears (p=0.0001), with 33% of participants reporting that fears of both disclosure and infecting others were often/always on their mind. These participants had consistently lower scores spread across subscales other than the stigma domain, particularly in the areas of emotional distress (p=0.02), intimate relations (p=0.0007), social relationships (p=0.04) and health concerns (p<0.0001). Whilst there appeared to be some attenuation of stigmatization with time, a substantial proportion of participants with these issues frequently on their mind had been on treatment for some time: 50% for at least 3 years and 25% for more than 7 years.
Table 7: Characteristics of participants (n=102) who took part in the PRO-QOL psychometric testing

<table>
<thead>
<tr>
<th>Variables</th>
<th>ALL N = 102</th>
<th>Not on Rx N = 15</th>
<th>NNRTI N = 46</th>
<th>PI N = 41</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>15 (14.7%)</td>
<td>4 (26.7%)</td>
<td>7 (15.2%)</td>
<td>4 (9.8%)</td>
<td>p=0.3</td>
</tr>
<tr>
<td>Age</td>
<td>46 (37-53.8)</td>
<td>41 (32.5-49.5)</td>
<td>48 (37-56.5)</td>
<td>45 (40-53)</td>
<td>p=0.4</td>
</tr>
<tr>
<td>Transmission</td>
<td></td>
<td></td>
<td></td>
<td>p=0.08</td>
<td></td>
</tr>
<tr>
<td>Heterosexual/other</td>
<td>42 (41.2%)</td>
<td>10 (66.7%)</td>
<td>21 (45.7%)</td>
<td>11 (26.8%)</td>
<td></td>
</tr>
<tr>
<td>IDU</td>
<td>6 (5.9%)</td>
<td>0 (0%)</td>
<td>3 (6.5%)</td>
<td>3 (7.3%)</td>
<td></td>
</tr>
<tr>
<td>MSM</td>
<td>54 (52.9%)</td>
<td>5 (33.3%)</td>
<td>22 (47.8%)</td>
<td>27 (65.9%)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>34 (33.3%)</td>
<td>5 (33.3%)</td>
<td>17 (37%)</td>
<td>12 (29.3%)</td>
<td>p=0.7</td>
</tr>
<tr>
<td>Caucasian</td>
<td>80 (78.4%)</td>
<td>9 (60%)</td>
<td>37 (80.4%)</td>
<td>34 (82.9%)</td>
<td>p=0.2</td>
</tr>
<tr>
<td>Living alone</td>
<td>40 (39.2%)</td>
<td>8 (53.3%)</td>
<td>16 (34.8%)</td>
<td>16 (39%)</td>
<td>p=0.5</td>
</tr>
<tr>
<td>Post-secondary</td>
<td>37 (36.3%)</td>
<td>6 (40%)</td>
<td>17 (37%)</td>
<td>14 (34.1%)</td>
<td>p=0.9</td>
</tr>
<tr>
<td>Unemployed/sickness benefits</td>
<td>18 (17.6%)</td>
<td>2 (13.3%)</td>
<td>3 (6.5%)</td>
<td>13 (31.7%)</td>
<td>p=0.007</td>
</tr>
<tr>
<td>Smoker ≥ 2 cigarettes/day</td>
<td>41 (40.2%)</td>
<td>4 (26.7%)</td>
<td>19 (41.3%)</td>
<td>18 (43.9%)</td>
<td>p=0.0002</td>
</tr>
<tr>
<td>Alcohol ≥ 2 glasses/day</td>
<td>15 (14.7%)</td>
<td>1 (6.7%)</td>
<td>7 (15.2%)</td>
<td>7 (17.1%)</td>
<td>p=0.5</td>
</tr>
<tr>
<td>Diagnosed &lt; 2 years</td>
<td>16 (15.7%)</td>
<td>8 (53.3%)</td>
<td>6 (13%)</td>
<td>2 (4.9%)</td>
<td>p=0.7</td>
</tr>
<tr>
<td>Time since diagnosis (years)</td>
<td>7.3 (2.9-15.6)</td>
<td>1.5 (0.8-3.8)</td>
<td>6.8 (3.2-11.9)</td>
<td>13.2 (6.2-18.9)</td>
<td>p&lt;0.0001</td>
</tr>
<tr>
<td>Body mass index</td>
<td>24.3 (22-28)</td>
<td>23.6 (22-28)</td>
<td>25.4 (23-28)</td>
<td>23.9 (22-27)</td>
<td>p=0.5</td>
</tr>
<tr>
<td>CD4 T-cells</td>
<td>530 (376-733)</td>
<td>546 (512-695)</td>
<td>591 (386-853)</td>
<td>455 (323-638)</td>
<td>p=0.1</td>
</tr>
<tr>
<td>Undetectable VL</td>
<td>77 (75.5%)</td>
<td>2 (13.3%)</td>
<td>43 (93.5%)</td>
<td>32 (78%)</td>
<td>p&lt;0.0001</td>
</tr>
<tr>
<td>Time on ART (years)</td>
<td>4.2 (0.8-11.8)</td>
<td>-</td>
<td>4.4 (2.1-9.9)</td>
<td>10.7 (3.2-13.6)</td>
<td>p&lt;0.0001</td>
</tr>
<tr>
<td>On non-ART medication</td>
<td>38 (37.3%)</td>
<td>3 (20%)</td>
<td>15 (32.6%)</td>
<td>20 (48.8%)</td>
<td>p=0.1</td>
</tr>
<tr>
<td>ART pill burden (tablets/day)</td>
<td>3 (2-5)</td>
<td>-</td>
<td>2.5 (2-3)</td>
<td>4 (3-5)</td>
<td>p&lt;0.0001</td>
</tr>
<tr>
<td>Non-adherent to ART</td>
<td>18 (17.6%)</td>
<td>-</td>
<td>7 (15.2%)</td>
<td>11 (26.8%)</td>
<td>p=0.2</td>
</tr>
<tr>
<td>Depressive</td>
<td>26 (25.5%)</td>
<td>3 (20%)</td>
<td>8 (17.4%)</td>
<td>15 (36.6%)</td>
<td>p=0.1</td>
</tr>
<tr>
<td>Other comorbidity</td>
<td>56 (54.9%)</td>
<td>8 (53.3%)</td>
<td>20 (43.5%)</td>
<td>28 (68.3%)</td>
<td>p=0.07</td>
</tr>
<tr>
<td>Sexual dysfunction</td>
<td>25 (24.5%)</td>
<td>4 (26.7%)</td>
<td>9 (19.6%)</td>
<td>12 (29.3%)</td>
<td>p=0.5</td>
</tr>
<tr>
<td>Number symptoms (total)</td>
<td>5 (2-10)</td>
<td>4 (1-10.5)</td>
<td>5 (1-8)</td>
<td>8 (5-12)</td>
<td>p=0.01</td>
</tr>
</tbody>
</table>

For categorical variables, values are N(%) and the p-value corresponds to a Fisher exact test of equal proportions across treatment groups; for continuous variables, values are median (interquartile range) with the p-values reflecting differences across the treatment groups as assessed by a Kruskal-Wallis test.
Table 8: Linear regression estimates of univariate predictors of mean (SE) increase/reduction (+/-) in PROQOL subscale and global scores (body of table), together with the percent of the score variances explained by fitting joint models of covariates blocks as grouped according to indication of sociodemographic, treatment, biomedical or clinical factors (R²×100).

<table>
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</thead>
<tbody>
<tr>
<td>All patients: Mean (SE)</td>
<td>64.89 (2.63)</td>
<td>54.90 (2.64)</td>
<td>72.55 (2.58)</td>
<td>51.63 (2.98)</td>
<td>43.32 (3.10)</td>
<td>66.48 (2.58)</td>
<td>71.36 (2.14)</td>
<td>-</td>
<td>60.62 (2.01)</td>
<td>-</td>
</tr>
<tr>
<td>Treated patients: Mean (SE)</td>
<td>65.16 (2.88)</td>
<td>57.69 (2.80)</td>
<td>73.41 (2.79)</td>
<td>52.01 (3.17)</td>
<td>46.66 (3.40)</td>
<td>66.52 (2.73)</td>
<td>71.05 (2.27)</td>
<td>81.08 (1.63)</td>
<td>61.66 (2.21)</td>
<td>64.07 (2.06)</td>
</tr>
<tr>
<td>Sociodemographic factors</td>
<td></td>
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</tr>
<tr>
<td>Male gender</td>
<td>+8.18 (7.43)</td>
<td>+13.56 (7.36)</td>
<td>+2.01 (7.33)</td>
<td>-9.81 (8.41)</td>
<td>+9.77 (8.71)</td>
<td>+4.18 (7.32)</td>
<td>+3.09 (6.05)</td>
<td>+7.36 (4.86)</td>
<td>+4.29 (5.67)</td>
<td>+4.50 (6.18)</td>
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<tr>
<td>Transmission (ref: heterosexual/unknown)</td>
<td></td>
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<tr>
<td>IDU</td>
<td>+11.61 (11.65)</td>
<td>+14.29 (11.65)</td>
<td>-0.89 (11.49)</td>
<td>+2.28 (13.14)</td>
<td>+27.39 (13.43)*</td>
<td>+1.64 (11.49)</td>
<td>+1.29 (9.48)</td>
<td>+3.46 (6.77)</td>
<td>+8.51 (8.89)</td>
<td>+7.60 (8.57)</td>
</tr>
<tr>
<td>MSM</td>
<td>+3.51 (5.49)</td>
<td>+3.17 (5.49)</td>
<td>-2.28 (5.42)</td>
<td>-8.60 (6.19)</td>
<td>+8.41 (6.36)</td>
<td>+2.56 (5.42)</td>
<td>-3.01 (4.47)</td>
<td>+4.34 (3.46)</td>
<td>+0.82 (4.21)</td>
<td>+2.20 (4.41)</td>
</tr>
<tr>
<td>Caucasian race</td>
<td>+11.38 (6.33)</td>
<td>+18.93 (6.16)**</td>
<td>+4.84 (6.29)</td>
<td>-2.75 (7.29)</td>
<td>+5.98 (7.52)</td>
<td>+10.87 (6.22)</td>
<td>+4.29 (5.20)</td>
<td>+11.34 (4.04)**</td>
<td>+7.52 (4.84)</td>
<td>+9.16 (5.23)</td>
</tr>
<tr>
<td>Age &gt;45 years</td>
<td>+9.04 (5.22)</td>
<td>+12.21 (5.16)*</td>
<td>+8.24 (5.13)</td>
<td>+12.32 (5.87)*</td>
<td>+11.00 (6.13)</td>
<td>+5.18 (5.17)</td>
<td>+6.27 (4.25)</td>
<td>+9.25 (3.12)**</td>
<td>+9.02 (3.95)*</td>
<td>+9.23 (4.02)*</td>
</tr>
<tr>
<td>Living alone</td>
<td>-0.33 (5.42)</td>
<td>-2.15 (5.42)</td>
<td>-11.91 (5.18)*</td>
<td>-16.74 (5.91)**</td>
<td>-6.87 (6.36)</td>
<td>-2.18 (5.32)</td>
<td>-6.44 (4.35)</td>
<td>+2.82 (3.38)</td>
<td>-7.05 (4.1)</td>
<td>-4.23 (4.29)</td>
</tr>
<tr>
<td>Diagnosed &lt;2 years</td>
<td>-0.98 (7.27)</td>
<td>-22.96 (6.91)**</td>
<td>-2.65 (7.13)</td>
<td>-3.79 (8.24)</td>
<td>-18.98 (8.32)*</td>
<td>+4.54 (7.13)</td>
<td>+6.54 (5.86)</td>
<td>-7.04 (5.61)</td>
<td>-5.34 (5.52)</td>
<td>-3.04 (7.12)</td>
</tr>
<tr>
<td>Post-secondary education</td>
<td>+8.44 (5.44)</td>
<td>+3.18 (5.5)</td>
<td>-0.4 (5.4)</td>
<td>-0.8 (6.24)</td>
<td>-0.65 (6.47)</td>
<td>+3.03 (5.39)</td>
<td>+8.22 (4.39)</td>
<td>-0.92 (3.42)</td>
<td>+3.2 (4.19)</td>
<td>+2.17 (4.31)</td>
</tr>
<tr>
<td>Substance use over previous 2 weeks</td>
<td></td>
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<tr>
<td>Tobacco</td>
<td>+1.1 (5.4)</td>
<td>+1.49 (5.4)</td>
<td>-8.65 (5.22)</td>
<td>+6.95 (6.08)</td>
<td>+1.75 (6.37)</td>
<td>-4.62 (5.28)</td>
<td>-7.68 (4.31)</td>
<td>-0.81 (3.31)</td>
<td>-1.69 (4.13)</td>
<td>-1.09 (4.2)</td>
</tr>
<tr>
<td>Alcohol</td>
<td>-3.29 (7.46)</td>
<td>-10.37 (7.41)</td>
<td>+0.06 (7.33)</td>
<td>-0.96 (8.76)</td>
<td>+4.12 (7.32)</td>
<td>+1.92 (6.06)</td>
<td>+3.18 (4.44)</td>
<td>+1.88 (5.69)</td>
<td>+3.57 (5.6)</td>
<td></td>
</tr>
<tr>
<td>Proportion of variance explained by sociodemographic factors</td>
<td>18.01%</td>
<td>22.49%</td>
<td>19.64%</td>
<td>20.7%</td>
<td>18.74%</td>
<td>20.69%</td>
<td>32.63%</td>
<td>20.6%</td>
<td>22.61%</td>
<td>21.22%</td>
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<tr>
<td><strong>Treatment factors</strong></td>
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</tr>
<tr>
<td>On ART</td>
<td>+1.82 (7.47)</td>
<td>+18.94 (7.24)*</td>
<td>+5.92 (7.31)</td>
<td>+2.57 (8.47)</td>
<td>+22.49 (8.46)**</td>
<td>+0.27 (7.33)</td>
<td>2.08 (6.06)</td>
<td></td>
<td>+7.00 (5.65)</td>
<td></td>
</tr>
<tr>
<td>Current ART (ref: NNRTI)</td>
<td></td>
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<td></td>
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<td></td>
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<tr>
<td>none</td>
<td>-3.79 (7.96)</td>
<td>-19.27 (7.74)*</td>
<td>-7.50 (7.80)</td>
<td>-6.44 (8.98)</td>
<td>-15.00 (8.80)</td>
<td>-2.09 (7.82)</td>
<td>-2.99 (6.30)</td>
<td></td>
<td>-7.95 (6.04)</td>
<td></td>
</tr>
<tr>
<td>PI</td>
<td>-4.16 (5.75)</td>
<td>-0.70 (5.59)</td>
<td>-3.35 (5.63)</td>
<td>-8.23 (6.48)</td>
<td>+15.71 (6.37)*</td>
<td>-3.86 (5.65)</td>
<td>-10.76 (4.55)*</td>
<td>-9.93 (3.10)**</td>
<td>-1.99 (4.37)</td>
<td></td>
</tr>
<tr>
<td>Time on HAART (per year)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>+0.23 (0.5)</td>
<td>+1.38 (0.47)**</td>
<td>-0.07 (0.49)</td>
<td>-0.04 (0.56)</td>
<td>+1.44 (0.57)*</td>
<td>-0.12 (0.4)</td>
<td>+0.36 (0.28)</td>
<td>+0.43 (0.38)</td>
<td>+0.42 (0.36)</td>
<td></td>
</tr>
<tr>
<td>PI</td>
<td>-2.78 (2)</td>
<td>-0.68 (1.96)</td>
<td>-2.06 (1.94)</td>
<td>-3.74 (2.18)</td>
<td>+3.06 (2.36)</td>
<td>-2.12 (1.9)</td>
<td>-3.06 (1.55)</td>
<td>-3.36 (1.08)**</td>
<td>-1.56 (1.14)</td>
<td></td>
</tr>
<tr>
<td>ART non-adherent</td>
<td>-2.48 (7.16)</td>
<td>+2.13 (6.96)</td>
<td>-3.26 (6.93)</td>
<td>-7.21 (7.84)</td>
<td>-2.8 (8.4)</td>
<td>-1.57 (6.79)</td>
<td>-6.58 (5.58)</td>
<td>-9.22 (3.91)**</td>
<td>-2.95 (5.46)</td>
<td></td>
</tr>
<tr>
<td>On non-ART medication</td>
<td>-8.00 (5.41)</td>
<td>-2.57 (5.47)</td>
<td>-6.05 (5.34)</td>
<td>-6.45 (6.17)</td>
<td>+8.08 (6.38)</td>
<td>-11.07 (5.26)*</td>
<td>12.39 (4.26)**</td>
<td>-1.19 (3.34)</td>
<td>-5.35 (4.14)</td>
<td></td>
</tr>
<tr>
<td><strong>Proportion of variance explained by treatment factors</strong></td>
<td>8.33%</td>
<td>20.27%</td>
<td>4.02%</td>
<td>5.39%</td>
<td>17.01%</td>
<td>8.51%</td>
<td>14.28%</td>
<td>26.55%</td>
<td>10.18%</td>
<td>10.18%</td>
</tr>
<tr>
<td><strong>Biological factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Body mass index (per unit)</td>
<td>-0.01 (0.58)</td>
<td>-0.35 (0.58)</td>
<td>-0.29 (0.57)</td>
<td>+0.20 (0.66)</td>
<td>+0.02 (0.68)</td>
<td>+0.08 (0.57)</td>
<td>-0.18 (0.47)</td>
<td>+0.16 (0.35)</td>
<td>-0.07 (0.44)</td>
<td></td>
</tr>
<tr>
<td>CD4 count (per 100 T cells)</td>
<td>+0.25 (0.82)</td>
<td>+1.50 (0.81)</td>
<td>+0.30 (0.81)</td>
<td>+1.90 (0.91)*</td>
<td>+0.22 (0.97)</td>
<td>+0.80 (0.80)</td>
<td>+0.42 (0.66)</td>
<td>+0.88 (0.47)</td>
<td>+0.81 (0.62)</td>
<td></td>
</tr>
<tr>
<td>Detectable viral load</td>
<td>-9.13 (6.08)</td>
<td>-17.09 (5.92)**</td>
<td>-10 (5.95)</td>
<td>-6.36 (6.94)</td>
<td>-13.05 (7.10)</td>
<td>-5.94 (6.01)</td>
<td>-0.87 (4.99)</td>
<td>-10.52 (4.61)*</td>
<td>-8.79 (4.6)</td>
<td></td>
</tr>
<tr>
<td><strong>Proportion of variance explained by biological factors</strong></td>
<td>2.99%</td>
<td>11.15%</td>
<td>3.31%</td>
<td>4.57%</td>
<td>3.47%</td>
<td>2.07%</td>
<td>2.49%</td>
<td>10.00%</td>
<td>4.80%</td>
<td>5.51%</td>
</tr>
<tr>
<td><strong>Clinical factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive</td>
<td>-27.84 (5.41)***</td>
<td>-11.26 (5.95)</td>
<td>-19.64 (5.63)***</td>
<td>-20.76 (6.51)**</td>
<td>+4.91 (7.12)</td>
<td>-17.22 (5.69)**</td>
<td>24.26 (4.27)***</td>
<td>-6.49 (3.67)</td>
<td>-16.48 (4.29)***</td>
<td></td>
</tr>
<tr>
<td>Other comorbidity</td>
<td>-10.5 (5.21)*</td>
<td>+0.27 (5.32)</td>
<td>-3.97 (5.2)</td>
<td>-3.95 (6.02)</td>
<td>+9.49 (6.2)</td>
<td>-7.59 (5.16)</td>
<td>-8.61 (4.23)*</td>
<td>-3.35 (3.27)</td>
<td>-3.35 (4.06)</td>
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</tr>
</tbody>
</table>
Emotional Distress
Health Concerns
Social Relationships
Intimate Relationships
Stigma
Body Changes
Phys. Health & Symptoms
Treatment Impact
GLOBAL

Symptoms

Sexual dysfunction
-26.02 (5.57)***
-22.06 (5.57)***
-6.69 (6.00)
-23.14 (6.58)***
-12.38 (7.11)
-14.88 (5.85)***
-23.6 (4.40)***
-7.86 (3.73)*
-18.29 (4.31)***
-16.03 (4.49)***

Gastrointestinal (per number)
-6.73 (1.53)***
-3.99 (1.63)*
-4.2 (1.59)**
-5.38 (1.82)**
-0.31 (1.97)
-5.63 (1.54)***
-8.57 (1.05)***
-8.57 (1.54)***
-3.3 (0.94)***
-4.95 (1.18)***

Malaise (per number)
-8.11 (1.58)***
-4.75 (1.71)**
-6.44 (1.62)***
-4.28 (1.97)*
+0.17 (2.09)
-8.29 (1.53)***
-9.18 (1.11)***
-2.21 (1.12)
-5.95 (1.22)***
-5.84 (1.3)***

Morphological (per number)
-4.71 (1.36)***
-2.2 (1.42)
-2.75 (1.38)*
-5.29 (1.54)***
-1.04 (1.68)
-4.81 (1.33)***
-4.97 (1.05)***
-1.76 (0.84)*
-3.65 (1.03)***
-3.66 (1.01)***

Other (per number)
-8.39 (2.5)**
-4.6 (2.6)
-5.32 (2.53)*
-4.34 (2.96)
-0.8 (3.15)
-11.06 (2.34)***
-9.17 (1.93)***
-2.48 (1.58)
-6.71 (1.93)***
-7.01 (1.91)***

Proportion of variance explained by clinical factors
37.25%
19.37%
19.68%
21.82%
6.7%
29.97%
62.04%
14.2%
31.92%
33.31%

Proportion of variance explained by all factors
63.64%
49.81%
37.24%
46.31%
33.07%
41.26%
75.36%
47.83%
53.01%
55.4%

P-values: ***<0.001<**<0.01<*<0.05. †Analysis restricted to treated patients only.

Table 9: Pearson correlations (95% CI) of PROQOL subscale scores with the global PROQOL 8-factor score and the MOS Mental health and Physical Health Scales. Scores are obtained from patients receiving anti-retroviral therapy: N = 87 (PROQOL), N = 85 (MOS).
Discussion

We have gathered data on health-related quality of life in our cohort using qualitative and quantitative methods, validated instruments and the new PROQOL HIV patient report outcomes measure. This is the largest study of HRQL in Western Australia since the HIV epidemic began thirty years ago. The results from these surveys, supported by the interview material, demonstrate that HIV disease influences HRQL across the spectrum of biological, social and psychological domains that comprise the complex continuum of measures of health (I. B. Wilson & Cleary, 1995). In particular, people reporting unemployment, depression, and a higher frequency of symptoms, especially those impacting negatively on sexual expression, scored a poorer quality of life overall, independently of other factors and regardless of ART status. Interview respondents struggling with romantic relationships described feelings of loss around cessation of sexual practices relinquished to prevent transmission; opportunities to engage in sexual activity without the burden of disclosure; fear of rejection and the potential for transmission despite use of safer sex strategies. Accordingly, the novel instrument captured dimensions of stigma, by way of an individual’s fear of disclosing their HIV serostatus and/or transmitting the infection that clearly results in emotional distress. Therefore, although the widely used HIV/AIDS-Targeted Quality of Life Instrument (HAT-QOL) has a dimension for disclosure concerns (W. C. Holmes & Shea, 1997, 1998), the PROQOL–HIV goes a step further and juxtaposes anxiety about transmitting the infection with fear of disclosure.

The survey showed that feelings of stigma were heightened in those more recently diagnosed in contrast with those who had a longer history of HIV infection, including those infected via IDU who might be expected to experience compound or layered
stigma related to their membership of another marginalised group (Goffman, 1963). However, in the interview group those perceptions of stigma appeared to have persisted over time for the majority, and particularly by way of effects on relationships and employment opportunities, as has been found in other studies (Bouhnik, et al., 2008; Logie & Gadalla, 2009; Rongkavilit et al., 2010). Holzemer and colleagues (2009) showed that stigma had a negative impact upon quality of life independently of HIV-related symptoms and severity of illness. More recently Hutton, Misajohn and Collins (2012), using the personal well-being index (PWI-A), reported that stigma impacted on subjective wellbeing in PLWH in Australia and the USA. While disclosure fears have been reported in a number of studies (Anglewicz & Chintsanya, 2011; Bouillon et al., 2007; Hosseinzadeh & Bazargan-Hejazi, 2011; Kalichman et al., 2007; Körner, 2007c; Logie & Gadalla, 2009; Nachega et al., 2012; Rongkavilit et al., 2010; Wolitski, Pals, Kidder, Courtenay-Quirk & Holtgrave, 2008) we could not find evidence in the literature to confirm that transmission anxiety per se is a cofactor in HIV-related depression, or studies of interventions targeted to reduce transmission fears and lower anxiety. However, there have been interventions aimed to increase coping and reduce stress in PLWH, and contagion fears have been addressed in educational interventions with uninfected individuals (Brown, Macintyre & Trujillo, 2003). Courtenay-Quirk, Wolitski, Parsons and Gomez (2006) found that HIV/AIDS stigma in a community of HIV-positive men who have sex with men was associated with increased levels of anxiety, loneliness, depressive symptoms, suicidal ideation and avoidant coping strategies. Winnie Mak (2007) however, in a meta-analysis, explored the relationship between stigma (not specific to any condition) and mental health and found ‘meaningful patterns’ between the constructs but no strong moderators. She acknowledged that this may be due to limitations in her study, and the diversity of

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measurement instruments used in the studies included in the analysis, among other factors.

It is concerning in this sample, that the fear of infecting others, which in some individuals results in irrational behaviour, will likely not be uncovered in the course of most clinical consultations, and may be linked to depression which we note was prominent in our cohort in direct comparison with others in the larger study. Since stigma may be nuanced by its various associations with sex, death and ethnicity (Goffman, 1963), and deeply internalised (Herek, 2002), it could be examined by assessing the limits that people place upon their lives as a result of the anxiety. Furthermore, it was observed that the intensity of disclosure fear is proportional to the fear of infecting others, which, while it seems to be attenuated by duration of infection, persists for a large proportion, although some people perceived stigma but attributed it as a problem of ‘others’.

A number of demographic factors contributed to a diminished perception of HRQL among the respondents to the interviews and the questionnaires. Notably people living alone cited restricted intimate and/or social relationships, although whether this was as a result of self withdrawal or inhibition with regard to disclosing HIV status, or some other reason, is not clear. Older age and longer duration of HIV were associated with an improvement in HRQL, as observed by others (Tsevat et al., 2009). In particular, older Caucasians were less troubled by health concerns related to regular CD4 and viral load monitoring and progression of the disease, perhaps reflecting their adjustment to diagnosis, better knowledge of the disease and/or greater confidence in the treatment, reinforced by successful treatment outcomes. However, unemployment and disability resulted in diminished HRQL regardless of age and the
interviews revealed a picture of social isolation and physical discomfort not necessarily directly attributable to HIV disease.

People on PIs reported more symptoms, especially gastrointestinal, and more tablets overall compared with those on NNRTI regimens. This translated into greater treatment impact, but not into reduced HQRL overall, most likely because of improvements in overall physical health and perhaps psychosocial adjustments associated with the longer average duration of ART and time since diagnosis. The level of adherence in our patients was higher than in the other cohorts in the international study, perhaps reflecting once daily dosing (Juday, Gupta, Grimm, Wagner & Kim, 2011) and our standard of adherence support (Herrmann et al., 2008b) but we did not find a direct relationship between adherence and global HRQL. However, non-adherence to ART remained predictive of lower treatment impact scores over and above treatment choice and viral load but with some abrogation, once account was taken of the number of gastrointestinal symptoms, although this was not statistically significant. This finding suggests that the benefits of treatment were not perceived by non-adherent participants.

This study consolidates the utility of the new PROQOL-HIV instrument which had been powered to show significant site-specific effects of covariates on HRQL domains. The total HRQL scores from the test PROQOL-HIV and the MOS-HIV in the Australian group were similar to France, USA, Thailand and Brazil but higher than in the Chinese cohort in the larger study. Briongos-Figuero and colleagues (2011) demonstrated comparable total MOS-HIV scores in a Spanish cohort which matched the Australian for age, but encompassed more women, IVDU transmission and HCV coinfection. Carrieri and colleagues (2003), proposed that influential dimensions impacting HRQL may be
missing from the MOS-HIV and showed that ART initiation was associated with general improvement in HRQL moderated by immunodeficiency, time since diagnosis, increased age, side effects and choice of regimen. In our study the combined covariate sets explained 75% of the variation in the MOS-HIV PHS and 70% of the MHS but 55% in the PROQOL score variation suggesting this score may incorporate facets additional to just health-related components. This finding concurs with I. B Wilson and Cleary’s (1995) conceptual model suggesting that total HRQL is substantially impacted by some hard-to-measure factors relating to personality, which may contribute to resilience and coping (A. Armstrong, Galligan & Critchley, 2011; Frain, Berven, Chan & Tschopp, 2008). It is likely that MOS-HIV with a greater focus on general physical and mental health correlates better with symptoms and clinical factors emanating from non-HIV comorbidities. In contrast, PROQOL-HIV is measuring concepts of quality of life that are specifically related to HIV and is assessing additional information from a patient perspective that cannot be adequately inferred from the usual sociodemographic or biological variables.

There were limitations to our study. Cross-sectional design is less robust than longitudinal measurement where responses are measured over time; however, the qualitative component strengthens the internal validity of the study. The closed-ended format of the questionnaires did not accommodate explanations, but the questions were derived from the themes gathered in the interviews where respondents qualified their responses to semi-directive questions freely. There are, potentially, factors not accounted for that influence quality of life; some of these may relate to idiosyncrasies in personality. However, the interview data captured aspects of acceptance, adaptation and coping in a number of respondents which reflected their experience of living with HIV.
The development of PROQOL-HIV, has allowed the measurement of dimensions not assessed in the past. Application in this local setting has demonstrated that the instrument will provide a useful tool in cohort analysis to assess health-related quality of life in general, and those that result from treatment interventions in particular. Inclusion of a stigma domain adds further utility since it is evident that stigma is a persistent feature of HIV-infection and may result in emotional harm, especially in those less resilient. The multiple nuances of stigma should be disentangled in future research in order to develop suitable interventions. In conclusion, disease-specific HRQL instruments can bring additional information to the classical criteria for evaluating clinical outcomes and should be part of studies evaluating health policy and treatment strategies (Chassany, Sagnier, Marquis, Fullerton & Aaronson, 2002).
CHAPTER FOUR

PEOPLE IN RURAL AND REMOTE ENVIRONMENTS
CHAPTER FOUR  PEOPLES IN RURAL AND REMOTE ENVIRONMENTS

Background

In the first twenty years of the HIV epidemic in Western Australia (WA) HIV infection was largely confined to high risk groups, namely men who have sex with other men (MSM) and people who inject drugs (IVDU), within a relatively static local population. Since 2002, however, there has been a steady rise of HIV notifications to the WA Department of Health among women and heterosexual men, against the previous trend of risk and transmission in MSM (Combs & Giele, 2009). Geography, population mobility and the idiosyncrasies of health care provision across the state have also served to shape the epidemic and influence health outcomes. The rise in numbers of people living and/or working in remote areas (see Figure 1 in the Introduction) who are both citizens and non-citizens, has added to the complexity of managing HIV; and for the person affected may present numerous personal challenges including living in a small community and distance from specialist HIV care.

Figure 17: Map of designated regions
These changes in the social and ethnic diversity of the current epidemic in this state have not yet been described in peer reviewed publications on the subject of living with HIV in country areas or on rural HIV services in WA, although there have been conference presentations and reports in recent years related to models of care and workforce planning for example (Cain et al., 2008; McLean & Savage, 2009). More recently, a WA Department of Health-initiated evaluation of HIV management in rural and remote areas was carried out in 2010, but is not publically available. Researchers (Bonar et al., 2004; Newman et al., 2007a; Newman et al., 2007b; S. C. Thompson et al., 2009) have published Western Australian studies giving valuable, firsthand accounts of the complex attitudes of Aboriginal people towards HIV and usage of anti-retroviral drugs, however the experience of non-indigenous people living with HIV in rural WA has not been described to my knowledge. Since linkage and engagement with HIV services is a critical factor in determining health outcomes in PLWH, this chapter is divided into two parts focusing on: Part One (a) the perspectives of health care providers on delivering care to people with HIV in the North-West and Goldfields (Kalgoorlie-Boulder) regions; and (b) a brief description of those cohorts. Part Two contains the results of interviews with 19 ‘patient’ participants who either reside or work in rural areas, detailing their experience of living with HIV, and accessing care and treatment. Three of these participants were from the Kalgoorlie-Boulder region, the rest were dispersed across Western Australia. Interview data from nine participants used in Chapter Four will also be accessed in Chapter Five since Chapter Four is concerned with issues of geographical remoteness; and Chapter Five, with visa status. Themes emerging from the participants’ narratives are discussed at the end of the chapter but will be explored further in Chapter Six.
A Tale of Two Cohorts: The North-West and Goldfields HIV-Outbreaks

The introduction of effective combination antiretroviral drugs in the mid-nineties resulted in fewer deaths from AIDS, and a growing but clinically stable population of (N=\~1700) individuals is currently linked with a simple network of state-wide clinical services provided by either RPH, Fremantle or Sir Charles Gairdner Hospitals, their rural outreach services (RR Service) and in cooperation with the WA Country Health Service. There is one small but growing cohort (N=\~32 in mid 2010) of Aboriginal people dispersed over the North-West (NW) of the state and about 15-16 of them are followed up by staff at the Gascoyne Population Health Unit. A second, more epidemiologically diverse cohort of \~30 patients is engaged with the Goldfields Population Health Unit in Kalgoorlie-Boulder (K-B). Both the ‘North West Town’ and Kalgoorlie-Boulder are within the Yamatji region of Aboriginal people. An arrangement with the Rural and Remote Service at Royal Perth Hospital has created the ‘shared care model’ described in Chapter Two. In both of these cohorts, HIV was acquired largely through unprotected sexual contact between men and women, but the K-B cohort is representative of a divergent epidemic reflecting international population movement from high prevalence to low prevalence areas driven by travel and work opportunities.

The Service Model

The current service model seeks to deliver optimal care state-wide. Central to successful management of HIV is the provision of ART. In addition, HIV education, medication adherence counselling and psychological support are hallmarks of effective HIV care, although access to these and in particular to specialist services, is limited in country areas. Since the emergence of HIV in Australia 30 years ago, controlling the epidemic ‘in the bush’ has been an overriding and sometimes very public (Date, 1992),
concern for health care providers because drivers of HIV transmission, such as rates of sexually transmitted infections (STIs) and drug and alcohol use, are higher in rural areas (Wright et al., 2005). However, despite continued high rates of STIs, rates of HIV transmission, particularly among Aboriginal people remain low (National Centre in HIV Epidemiology and Clinical Research, 2011). In the North-West region this is largely attributed to a swift response to the original outbreak and uninterrupted, intensive health care provision to affected individuals now known as the ‘North-West Cohort’. Nonetheless, there are increasing numbers of non-indigenous Australians with HIV infection residing and working in regional areas, together with a growing number of infections in non-citizens or temporary guest workers which have been contracted outside Australia. Some in this group are based in Perth or in Kalgoorlie-Boulder and travel to work on mine sites in remote locations. It is notable that some FIFO workers traverse the country from centres on the east coast of Australia. Table 11 provides a demographic ‘snapshot’ of the Kalgoorlie-Boulder region.

**Attainment of treatment goals are challenged in Aboriginal Communities**

The goal of administering ART is to reduce the level of virus in individuals to a point at which it is considered undetectable using current tests. Reducing the viral ‘load’ stimulates immune recovery and moderates the risk of HIV transmission. However failure of medication usage to treat many acute and chronic conditions in Aboriginal communities has led to poor health outcomes and unnecessary mortality from all causes. While HIV medication adherence rates have improved over the last ten years in the metropolitan area (Herrmann et al., 2008b) likely through improved, more tolerable drug treatments and supportive, educative measures, there is, purportedly a dissonance between Aboriginal cultures and belief systems and Western medical
culture (McConnel, 2003). This has resulted in poor adherence to ART and other medicines in Aboriginal people infected with HIV despite some successes in the North-West Cohort over the years. Health providers’ early concern over adherence issues has been a factor underpinning the provision of funds and the deployment of health workers to rural areas, and has shaped the way that HIV care is delivered.

**Methods Specific to this Chapter**

*Interviews with Health Care Providers (Key Informants)*

Semi-directed interviews lasting between 50-60 minutes were conducted at Royal Perth Hospital with the Rural and Remote Clinical Nurse Specialist and an HIV Physician with a long-term association with the rural outreach service. Much of the information from these interviews provided contextual data for the methods section (Chapter 3) of the thesis. Health providers in Kalgoorlie-Boulder and the ‘North West Town’ were also interviewed in those towns in May and September 2010, respectively. Interviewees (Goldfields) were: the Public Health Physician (PHP) and the Senior Public Health Nurse, Population Health, WA Country Health Service. In the North-West Town: the Public Health Physician of the Gascoyne Population Health Unit, the Public Health Nurse, the Aboriginal Health Worker and the Unit’s Secretary. The NW PHP was interviewed alone and the three other staff members as a group. In Kalgoorlie-Boulder and Perth the interviews were conducted one on one. The interviews began with a request for informants to describe: their roles; background relevant to their cohorts; particular challenges managing and administering HIV clinical care; engagement with patients; ensuring follow-up and achieving good clinical outcomes. Patterns of communications within the RR Service were also explored. Questions were open-ended, conducted in a conversational manner and informants were encouraged to
express professional opinion. The interviews were recorded, transcribed and sent to the interviewees for further feedback.

**Interviews with Participants**

Interviews with 16 patients enrolled in the Rural and Remote Service and those who identified as working in remote areas were conducted at Royal Perth Hospital in Perth. Three more patients were seen in the Population Health Unit in Kalgoorlie-Boulder (total N=19) at an outreach clinic held in August 2010. One of those patients had been interviewed in the RPH clinic prior to the Kalgoorlie outreach clinic and was followed up subsequently, again at RPH. Semi-directed interviews lasted between 40-130 minutes and were recorded and transcribed. Questions were open-ended and based on the broad themes that emerged from the PROQOL-HIV study and gaps in previous research in the same centre. Patients were encouraged to speak freely about issues important to them but questions relating to ART access and experience of taking medication were explicit.
Part One

Clinical Data

The WA HIV Cohort database was accessed to audit clinical data and present group statistics for the cohorts in the North-West Town and the Goldfields in mid 2010. This data can be found in Table 10.

Table 10: Group statistics for cohorts in the North-West Town and the Goldfields (audit data mid-2010)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Kalgoorlie-Boulder n=22 (%)</th>
<th>NW Town n= 12 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years (mean (SD); range)</td>
<td>39.6 (9.1); 28-66</td>
<td>35.8 (4.1); 29-44</td>
</tr>
<tr>
<td>Gender f/m</td>
<td>9f/13m</td>
<td>10f/2m</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African</td>
<td>9 (40.9)</td>
<td>0</td>
</tr>
<tr>
<td>Caucasian</td>
<td>6 (27.3)</td>
<td>0</td>
</tr>
<tr>
<td>Asian</td>
<td>3 (13.6)</td>
<td>0</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>3 (13.6)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (4.54)</td>
<td>0</td>
</tr>
<tr>
<td>Have children</td>
<td>~11 (50.0)</td>
<td>~7 (31.8)</td>
</tr>
<tr>
<td>Visa status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temporary</td>
<td>9 (40.9)</td>
<td>0</td>
</tr>
<tr>
<td>Permanent residents</td>
<td>12 (54.5)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (4.54)</td>
<td>0</td>
</tr>
<tr>
<td>Probable place of infection</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>4 (18.2)</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Overseas</td>
<td>17 (77.2)</td>
<td>0</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (4.54)</td>
<td>0</td>
</tr>
<tr>
<td>Years since diagnosis (mean (SD); median)</td>
<td>6.3(7.0);3</td>
<td>13.4 (2.8);15</td>
</tr>
</tbody>
</table>

*Treatment status

| On ART                                | 15 (68.7)                   | 8 (66.7)          |
| Generic ARVs                          | 5 (33.3)                    | 0                 |
| Viral load detectable/no of treated patients | 6/15 (40.0)                | 7/8(87.5)         |
| CD4 T Cell count mm$^3$ (%)           | 520.7 (230.2); 24.6 (8.1)   | 652.5 (384.2); 22.9 (12.4) |

*Unknown for two patients

Within the Kalgoorlie group it was documented that fifteen patients taking ARVs reported complete adherence in the month before their clinic visit. One patient was receiving directly observed treatment (DOT), and two had assistance filling either calendar boxes or Webster-Pak®. Eleven patients had their treatment scheduled once daily. Two patients had reported interruptions to their treatment, another reported
missing doses. Thirteen patients were married or partnered although there were two patients whose status was unknown, and eleven had children whose HIV status was not available.

For the North-West cohort adherence monitoring data was not available in the database, but six of the eight patients treated with ART had detectable virus. Five were taking their ARVs once daily but had concomitant medications that were scheduled BD. Seven of the patients in the group were known to have children.

Access to Anti-Retroviral Drugs in Regional Areas

For the North-West cohort antiretroviral drugs are prescribed by the RPH-based Immunologist who reviews the patients’ clinical results either during a clinical case review teleconference between the PHP and Population Health Unit team, or directly during the outreach clinic when the hospital-based team travel to the North-West Town to see patients, once or twice a year. These clinics have not always been successful as oftentimes Aboriginal clients have not kept appointments with the hospital specialists (personal communication, Martyn French, 7 June 2011). This potential discontinuity in care between client, the North-West providers and the RPH specialist service is mitigated in part, by the teleconferences and by the quick turnaround time for feedback to questions directed to the RPH service by email or telephone and triaged by the RR Nurse coordinator. It has meant that: “If there’s any queries (sic) in between then we just send an email and then within hours we get a response so it’s extremely responsive support” (Public Health Nurse, North-West Town). This serves to augment local care with specialist input. The Schedule 100 drugs prescribed by HIV specialist physicians are couriered to the Population Health Units in the North-West Town or Kalgoorlie-Boulder and are then taken to a local pharmacy for
individualised calendar (Webster-Pak®) packing with any other prescribed drugs. This practice serves to promote safe and uninterrupted use of medicines but also to disguise ARVs so that clients can avoid family or friends becoming aware of their HIV status.

In the Goldfields nearly half of the cohort is ineligible for Medicare and PBS subsidised, patented antiretroviral drugs. Five patients are importing generic bioequivalent drugs purchased from internet vendors which sent to their homes. Unlike communication practices with the North-West, teleconferencing is less common, clinics are more usual and fewer patients have their medication prepared in calendar or ‘dosette’ packing. **Table 12** contains an extract of my field notes taken during the outreach clinic conducted at Kalgoorlie-Boulder in August 2010.

**Interviews with Key Informants**

**The North-West cohort: ‘containing’ an epidemic**

Incidental testing for blood borne viruses led to the first diagnosis of HIV in an Aboriginal man from the North-West in 1994 when he was being treated for a trauma injury at RPH. After screening approximately 300 people in the NW, some of them four or five times, twenty five were found to be positive for HIV. More females than males were found to have the infection, two were non-indigenous and one was Medicare ineligible. The size of the current cohort engaged with the Gascoyne PHU numbers 15-16 patients.

The view of the PHP as to why there was not more extensive transmission of the virus is that a large proportion of infections were in women and the virus transmits less efficiently from female to male. However, she added that patients also underwent STI
and HIV screening every three months and infections were treated so that conditions that favoured HIV transmission (other STI coinfection, and lack of awareness of HIV serostatus) were reduced. She also noted that there was a reduction in sexual activity although there were “some women who continued to put themselves at risk” and others “who were also putting others at risk on a regular basis” by failing to have protected sex. In addition, two of the four men infected were “extremely sexually active, extremely” and both of them, due to ongoing risky sexual behaviour, were required to go on case management in the local town. This took the form of a curfew preventing them from going out at night and placing them under the supervision of the PHP who visited every day up to three times in 24 hours. The alternative was to exercise the provision under Public Health Act and send one of the men to Perth, to an isolation unit (which to the PHP’s knowledge has never been used). She noted that “that was considered too expensive actually, more than anything else.” Evidence that there was ongoing unprotected sexual intercourse was confirmed by rates of other STI’s and that sixteen babies had been born since the epidemic started in the region. 

The imperative to test, diagnose, treat, assess and monitor people with HIV in the North-West led to the establishment of the Rural and Remote HIV Service at RPH, funded through WA Country Health. However, Federal Government concern over an (long feared) outbreak of HIV in Aboriginal people living in rural areas prompted the funding, independent of the WA Country Health budget, of extra staff, including two dedicated Aboriginal support workers and a non-Aboriginal case manager to assist in containing the epidemic. This funding arrangement represents one of the many points of difference between the NW and Goldfields cohorts.
Kalgoorlie-Boulder: the ‘divergent’ epidemic

The impetus for an outreach clinic in Kalgoorlie-Boulder (K-B) arose in part from the successful shared care model in the North-West. Previously people from the Goldfields diagnosed with HIV would travel to Perth, seven hours by train, although their immediate health needs were met by GPs in liaison with RPH and the Population Health Unit in Kalgoorlie-Boulder. The establishment of an outreach clinic meant that trips to Perth could be avoided, translating into a cost saving for both the health budget (via the Patient Assisted Travel Scheme) and the patient in terms of time away from work, family and child care responsibilities. The funding for the outreach clinic comes from Rural Health West which is the organisation responsible for the recruitment and retention of a rural health workforce. This organisation supports fares and accommodation for the medical specialist but not the RPH nurse who is the primary HIV clinical contact for patients and medical staff across the regions. As well as offering patients support, queries from GPs and other health professionals are triaged by the nurse directing them, expediently, to appropriate specialist advice at RPH.

The Kalgoorlie-Boulder Population Health Unit is directed by a Public Health Physician. Like the Unit in the North-West Town, the core purpose of the organisation is to prevent the spread of infectious diseases in the community. Infections classified as Notifiable under the Health Act of 1911 (WA), for example, sexually transmitted infections, like chlamydia, and blood borne viruses such as HIV or hepatitis C, are recorded in the Western Australian Notifiable Infectious Disease Database (WANIDD). In addition, the organisation is responsible for sexual health promotion and prevention of infectious diseases (by way of, for example, vaccination programmes), and injuries from alcohol and other drugs. There is also liaison with community health, school
nursing and environmental health services, an example of which is the recent lead contamination of water supplies in the Esperance area. Although there are several sexual health nurses, at the time of my visit to the region in 2010, the responsibility for HIV management has fallen upon one Senior Public Health Nurse.

Table 11: Kalgoorlie-Boulder and the surrounding region

| The Goldfields area covers almost a third of WA's total land mass and is the largest region in WA. Its population is around 59,000, with an estimated 8% of the population being of Aboriginal descent, compared to 3% for Western Australia as a whole. There are 17 Aboriginal communities within the region. Although just over half the population in the Goldfields lives in Kalgoorlie-Boulder, the transport hub for the region, a significant number of workers fly in from Perth and the east coast to work on remote mining sites (FIFO). The East-West (Indian Pacific) railway passes through the town and the airport hosts regular flights in and out of Perth, 595 kilometres west south-west, and more recently, Melbourne, to service the demand for FIFO workers. The town supports administrative organisations that underpin the activities of the pastoral and mining industries; and government agencies including health and education; in addition to retail, recreation and tourism businesses. In the south, Esperance is the major population centre of approximately 13,000 people. Its port is one of the busiest in WA since it supports the agricultural, fishing and mining industries of the entire region (City of Kalgoorlie-Boulder, http://www.ckb.wa.gov.au/). |

The Public Health Physician characterises the Goldfields regional HIV epidemic thus:

We’ve got all sorts of people Australian, non-indigenous Australians who contracted it one way or another either through, either they’re men accepting men or they got it abroad or something and they vary from being again you know dream patients to people who I need to put a bit of effort into. There are people on 457 visas who are on the whole, as a group they need more resources because for all various reasons around Medicare access, confidentiality, not wanting anybody to know, they tend to use us a bit more you know particularly a lot of them use me as their GP because I don’t cost anything, they don’t know how little I know but they come to me. And then we do have some indigenous clients and they, I think there will be other places where they have indigenous
clients who do not cause any issues but we, ours, cause issues and cause us to be, to struggle.

With regard to the ‘457’ ‘contingent’ group, the PHP noted that HIV infection was often diagnosed in a temporary visa holder following treatment for a different, major illness. This has resulted in the need to alert the regional medical community to risk factors other than MSM contact, such as travel and place of birth, when patients presented at their practices with constitutional symptoms indicative of HIV infection.

The K-B team also describe challenges with the small number of Aboriginal people with HIV infection in their region that are echoed by the NW staff. In particular, they speak of the social support needs of the patients that are necessary to augment their medication adherence. According to the PHP, the region lacks allied health staff and the one social worker at the local hospital is busy dealing with inpatients. The Aboriginal Health Service, although providing other non-HIV care, does not support HIV medication adherence in clients so the PHN K-B has extended her role as she comments here:

...the team provides a huge social work type role which we shouldn’t be doing. But in order to make sure [the patient] takes medication we have to do that and we’ve been sort of sucked in over the years into providing more and more of that and people are, there’s nobody else would do it.

Although the treatment as prevention approach is now adopted as a strategy to reduce transmission of infection at a population level, clinicians and particularly those working in public health are ‘vocationally’ motivated to support any measure that underpins critical medication adherence behaviour in individuals. Therefore, HIV management has been shaped by this context. The PHN explains:

There are a large number of people who live the same, exactly the same life as [the patient] does who nobody gives a stuff about, the only reason that we care
at all about this [patient] is that she’s/he’s a public health problem you know otherwise no one would care. So it’s not, I mean it’s just an indictment on the system rather than, and it’s just we got, we feel obliged to make sure [the patient] remains as low a public health risk as possible.

This comment underscores the responsibility placed on public health providers to contain infectious disease. The transmission pattern of HIV disease is intrinsically challenging to track since approximately 40% of transmissions occur when people are unaware of their serostatus. Furthermore, the disease can remain asymptomatic for many years before constitutional symptoms of deteriorating immunity occur. The tension for providers responsible for communicable disease management is clear. The K-B physician further explains the importance of drug treatment:

..we’ve got some people that we think are misbehaving from all categories, well I mean every category I’ve talked about. The non-indigenous Australians, the indigenous Australians, the people born overseas...and it scares the hell out of me ‘cause I don’t know what I don’t know and what’s going to pop up. The only saving grace is all the people we know about are, were, maintaining either on therapy or pre-therapy where we’re maintaining low viral loads on pretty much all of them.
On 7 August 2010 I flew into Kalgoorlie on a busy 6am flight from Perth in the wake of the Diggers and Dealers conference held in the town earlier that week; and on the same flight as government ministers in full election ‘mode’. My companions were the Rural and Remote Nurse Coordinator (RRN) and a pharmaceutical company representative who was sponsoring the dinner at the restaurant where an educational talk was to be given that evening to GPs and other health providers. These talks, given after each outreach clinic by the visiting specialist, are a condition of ongoing funding for the service by Rural Health West.

In Perth, the RRN had collated clinical information from the WAHCS on the patients with appointments and assembled equipment such as Dictaphones, stethoscopes, ophthalmoscopes. The Infectious Diseases Physician or ‘Indie Doctor’ had travelled up the day before and spent some hours at the Population Health Unit downloading results of blood tests from a computer linked with the PathWest Laboratory in Perth, so that they would be available for the two clinics. To avoid local gossip when travelling in country areas, the nurse tells me she deals with casual enquiries by curious locals by trying not to look like a medical professional and has in the past said that she is a midwife to deflect interest in the real reason the team is in town – to deliver care to people with HIV infection. We don’t look like a medical team although the nurse is somewhat ‘outed’ at security by the guard who wants to know of what use is the ophthalmoscope.

The ‘Indie Doctor’ had a long day ahead of him when he picked us up at the airport at 7am. Patients were local but some had travelled from other towns in the region, one patient had driven for three hours. The appointments were made by the RRN in person working out of the Perth office, by phone or email. Some of the working people took advantage of the opportunity to attend a clinic on the Saturday morning. The preparation ensured that each patient had a recent blood test (HIV RNA quantitation, CD4 T-Cell count, and any other tests indicated by the patients’ GP or from previous clinical encounters). Pre-populated blood forms were posted to patients who attend the PathWest collection Centre in Kalgoorlie-Boulder for phlebotomy. The blood sample was couriered to the PathWest RPH laboratory in Perth. HIV monitoring in the regions creates tensions for the patients and the staff since the blood does not always arrive at the lab within the four hour window required for a reliable assay. Furthermore, all of the patients are concerned to ensure their HIV serostatus is not known by non-medical staff. Apparently, in the recent past, phlebotomists have inadvertently disclosed clients HIV serostatus causing them to become angry, embarrassed and distressed.

To maintain patients’ privacy during the clinic, appointments in the long sprawling building were staggered and by using one door as a dedicated entry and another as an exit so people were less likely to encounter each other. I was provided with a small private room in which to conduct interviews with patients. The nurse attended each clinical consultation and frequently walked with the patients as they left the building chatting informally. At the end of the clinic a team case meeting took place and each patient’s medical care was reviewed.

At the evening presentation the Indie Doctor—mindful of the demographic of the current epidemic in WA—focused his presentation on communicable diseases commonly presenting in travellers, temporary visa holders and migrants/refugees, which, he noted, could make diagnosis challenging. The talk was well received and the gathering gave an opportunity for local health workers to meet and discuss common professional interests with their colleagues from the city as well as catch up with local news.
Managing HIV in the North-West: Engaging with PLHV

In 1998, a major challenge for the Gascoyne PHU was how to ensure the ongoing engagement with patients necessary to implement successful HIV treatment and prevention strategies and avoid morbidity and deaths from AIDS. The PHP described the public health imperatives of the time:

[What was] really critical in terms of reducing ongoing transmission was two different mechanisms of contact: One which is all supportive which is us [including the Aboriginal health workers], and another which is more of the policeman thing which is, you know, making sure they know their rights and responsibilities.

Separating the two roles prevented confusion in clients. Today the service employs a senior public health nurse and an Aboriginal health worker but the team includes the unit secretary whose continuity of employment over ten years, knowledge of the workings of the local community and pragmatic approach to problem solving has extended her role beyond that of office administration, to offer wide-ranging support for clients and health workers and particularly when there was staff upheaval:

If other people were busy and somebody needed to be brought back (home) I was quite happy to take them back home or on the way home pick up their medication from Amcal [the local chemist] and all those sort of things which today we are still doing. So I wasn’t only just sitting at my desk I became really quite closely involved with our clients.... Many, many times there was just the two of us like ‘the period’ that people had left and weren’t replaced was a very difficult period, but I suppose, for me, I just became more and more involved. I have had long periods when I was just the only one here so I, when I got phone calls or people came, I had to help them to get what they needed and I sort of loved that...

(Secretary)
All the interviewees described their service as having good engagement with the clients and a collegiate relationship with doctors and local hospital staff who are likely to manage the HIV-infected clients’ comorbidities, such as diabetes and renal disease. It was noted that a period of staff stability at the local hospital has underpinned efficient co-management between the PHU and hospital doctors and allowed the hospital doctors time to establish trusting relationships with the clients.

**Adherence to Antiretroviral Drugs**

*Engagement with health care providers: trust and continuity of care*

Central to promoting uptake, adherence to and persistence with treatment is the therapeutic relationship between the patient and the provider. Recurrent themes throughout all of the informants’ interviews were related to the importance of establishing and maintaining relationships in order to ensure engagement and retention in medical care. The Rural Nurse Coordinator puts it this way:

*Engagement, building rapport, building relationships because the most important aspect is when you first —I think— see a new client with HIV, ‘cause if they don’t like you they’re not going to come back.*

Trust was a word that was frequently used by all the informants, particularly in relation to the maintenance of confidentiality within communities. The Aboriginal Health Worker put it this way: “*and it is the trust where you don’t open your mouth.*”

Fear of disclosing HIV status and of family ‘finding out’ is particularly strong within the Aboriginal community. Health care workers go to great lengths to protect against inadvertent disclosure of their clients HIV status to other members of their family and since family (kinship) ties can be complex to non-indigenous outsiders this can be difficult and lead to some complex management practices. Employing Aboriginal
health care workers helps to ensure that kinship issues that might affect HIV management are taken into consideration. Providers have acknowledged that if they are recognised as trustworthy a closer engagement with clients ensues, represented by regular clinical contact and better medication adherence in the clients. Although the benefits of this relationship have been recognised in people of all backgrounds, it is acknowledged to be particularly pertinent in Aboriginal communities. In the past lack of trust in local hospital staff fuelled by a perception of discrimination led to some clients in the North-West Cohort disengaging altogether. The secretary explained: “Some of our girls have discharged themselves because of treatment from nursing staff in hospitals, the sick ones.”

Because of the need for close engagement between provider and patient, continuity of care and stable staffing levels are critical, since it takes time to establish trust between client and health care provider. The Public Health Nurse provides an example:

...there had been a period where over the last sort of two years there was a bit of an instability of staff and we found that some of the clients were disengaged because they didn’t have the same person that they were coming to see...knowing they were seeing the same person made a huge difference to the engagement of the clients and then coming to the clinic. We did have one particular client who hadn’t had any blood tests for two years and then once she knew that I was the nurse here we started to reengage and then she actually came on track with her three monthly bloods and now we have great continuity of care with her.

The NW Public Health Physician states this more bluntly: “We’ve got a hundred percent contact with our clients [now], which had dropped down to about fifteen percent contact when the staffing dropped here.” Threats to continuity of care are likely in the regions where doctors staffing the local hospitals don’t stay long: The PHP explains: “it’s going to be complicated for them, for our lot, to actually re-engage with another
doctor and go through that whole process of basically letting them know about their [HIV] status.”

Therefore, the intensity of the engagement, the number of staff and the extended roles they have had to play are justified according to the PHP:

M’s been here ten years you know. She doesn’t do a normal secretarial job at all, she knows them (the clients) and drops off medicine sometimes, picks them up, all sorts of stuff… And like I say, we’ve been criticised for this level of care but I think we’re showing results because of it. I’m not sure it’s that realistic everywhere and we do have way more staff (than they do in the Goldfields) you know, just to look after the cohort. I mean we had five staff at one point looking after twenty-three people, you know, how fair is that or how equal is that? Well I would argue it’s extremely, exactly the right response and it’s because of that response that we’ve managed to contain the epidemic.

Cultural dissonance: the concept of ‘Health’

In effect the barriers to medication adherence in Aboriginal people described by the staff are classical but also culturally nuanced. The term chaotic lifestyle, commonly used to describe a way of living that lacks a regular pattern of activity known to be conducive to consistent pill taking behaviour, is a somewhat derogatory term since having a chaotic lifestyle, in Western culture, implies a lack of control over one’s life that is negligent and in that way is morally suspect. The following quote provides a stark reminder of the rigour required to adhere to lifelong ART:

The measure of satisfactory adherence is a dosing history that includes timely initiation of dosing plus punctual and persistent execution of the dosing regimen throughout the specified duration of treatment

(Blaschke et al., 2012)
There is also a Western view of health as centrally important, together with longevity, exemplified by the expressions “you can’t buy good health” and “take care of your health”. Aboriginal culture could be said to be dissonant with Western medical culture which embodies the concept of the centrality of health (McConnel, 2003).

The PHP in the Goldfields had this to say about how culture influences medication taking behaviour in Aboriginal people:

...we’re (white Australians) pretty bloody selfish, we want to be well and happy and cheerful and whatever but and if we get a sniffle we go to the doctor. A number of Indigenous people have other priorities, either their own priority, which might be trying to find somewhere to sleep at night or familial or community responsibilities that take precedence over their own health. So they don’t take the (tablets) long term and (say something like) if I don’t take my tablets I’m going to die. It’s like “oh I haven’t got my tablets with me, I can’t, I’ve got other things to do. I can’t go and get anymore. I’ve lost them” whatever, so it’s yeah they have other priorities. Taking their HIV medication may not be very high on the list. Indeed going to see a doctor is not often high on the list ..., which is part of the reason for all the disparities anyway —is that they just have different things to do.

The NW PH nurse comments similarly:

But I still think that it impacts on their lives in relation to their lifestyles and it’s really hard for them to get into lifestyles particularly when they do like to travel and they do like to be transient and their families are very important to them so they do tend to put their families first before themselves which can have an impact on medication compliance.

Talking with Aboriginal people about medication adherence without sounding like ‘the pill police’ (my expression) taps into these cultural nuances: “Well we do it much more in the sense of we care about you and you’re going to get ill and you know if you get ill you’re not going to get the chance to see your kids grow up” (NW PHP).
Motivators to accept antiretroviral treatment

Uptake or acceptance of treatment has been recognised as the first barrier to adherence since treatment cannot be effective if it is refused. Newman and colleagues (2007b) asked Aboriginal people living in the regions what motivated them to accept antiretroviral treatment and found that pregnancy was a major driver. Aboriginal women continue to report excellent medication adherence during pregnancy, and at the time of my visit in September 2010 there had been no HIV positive babies born in WA to Aboriginal women to date who were aware of their HIV status before pregnancy (Gilles et al., 2007; and personal communication with Allison Cain, 2011).

Fear of death is a motivator to begin treatment as well as to improve erratic adherence. The NW staff members have noticed that: “...every time one dies they get more motivated to take their tablets for a while.” The Goldfields’ staff also noticed this motivation in the small number of Aboriginal people they have cared for over the years. But treatment interruptions and erratic dosing are still common. The NW PHP observes:

... despite that we still have deaths because of non-compliance for all sorts of reasons really. Just making a decision they don’t want to take their meds, or not really, so each year we get a couple. We had one this year, we had one last year, and the one before. But the one [person] who died this year, [had] been positive since 1994, so did quite well really.

In some treatment programs in African countries, access to treatment for an individual is contingent upon the nomination of a helpful friend or relative to help support medication adherence, and social support in general has been shown to facilitate medication adherence (Foster et al., 2010; Merten et al., 2010). A major challenge for the Aboriginal health worker and other staff has been how to break down the barriers
preventing Aboriginal people disclosing their HIV serostatus to each other. But disclosure fears remain strong in Aboriginal and rural communities in general across WA, as the patients in the next section will attest.

**Delivering appropriate HIV education**

HIV education to Aboriginal people in this setting is generally given verbally, in part because of disclosure concerns: “They don’t want to take anything home.” The nurse describes taking a visual approach to HIV education to ensure clients understand how drug resistance develops:

> I try and get them to visualize like with the virus that it’s like, I sort of say to them oh look it’s like a brick wall, you know if you take your medications you’re going to have a strong wall to stop that virus getting through but as soon as you don’t take your medications there’s a crack in that wall and then that virus is a very smart virus it can get in the crack and then it can actually develop a resistance.

The fact that the virus can be quantified and ‘counted’ is also helpful and the clients who have regular blood tests are interested in their results and aware of changes that occur as a consequence of poor adherence and/or treatment persistence. The other members of the team say they are careful to reinforce each other’s educative messages.

However, the Goldfields PHP commented that:

> There’s never been very good HIV related information for indigenous people because this hasn’t been, you know it’s not been perceived as a major issue amongst indigenous people.

**‘Supporting them in their everyday lives’**

The service given to Aboriginal clients may seem paternalistic and it is evident that the Public Health personnel do ‘what it takes’ as the NW PHP states frankly:
We definitely put way more energy than would be considered normal it would be perceived by some people as being paternalistic even maybe. But they contact us for all sorts of reasons you know. They ring us because of a funeral they have to go and we’ll help them with their fares, we’ll fly them down.

And the Aboriginal Health Worker offers support, working across team roles to reinforce engagement:

...with our crew I’m just more or less the ‘in between’. I’ll pick them up for their transport or, you know, whatever they’ve got to do around town, if they need help or come in here, just do whatever they need.

Another factor underpinning successful adherence is engagement as incentive, the PHP explains:

We have become...a major incentive for them to take medication. ... you have to actually help them out in other ways which is what you do, you know, with food and transport —[it] is bizarre isn’t it, but that’s one of the motivations.

Travel in general is considered to present an organisational challenge to a person’s ability to adhere to the scheduling of medication, and Aboriginal people frequently travel great distances to see family, attend funerals and cultural ceremonies, at short notice. The NW unit has adapted to accommodate this way of life by introducing a free call number for people who find themselves without their ARVs, use of this initiates a chain of events:

All of a sudden we’ve got to jump to attention, make sure that we have got the medication here, go and get to the chemist, post it out so it could be at least four or five or six days before they then have their medication.

The staff remark, wryly, that by the time the medication has arrived in one rural town the client has moved on to another, hundreds of kilometres away. Yet social and professional networks between health and other services in the bush often help to locate people who are travelling between towns. And the attentive liaison between
the rural services and the service at RPH, where all the medicines are dispensed means that medication can be made available at short notice to avoid treatment interruption.

On the other hand the team was very clear about the principle of autonomy and how their close cooperative team approach strengthened their ability to behave effectively to reinforce this view with clients: the term ‘united’ was frequently used. The nurse unpacked their comments for me:

Yeah, because whilst we are there to support the clients, you can’t like I said you can’t, they do have to maintain their own lives and they’re very, very capable of maintaining their own lives so you do have to be careful not to cross that barrier where you make them totally dependent, I, you know I think it’s very important.

**Barriers to medication adherence: alcohol and other drug use**

In addition to unplanned travel, another classical adherence barrier, and an important risk factor for HIV transmission of infection, is substance abuse. Both the NW and Kalgoorlie-Boulder PHUs freely administer needle and syringe packs (‘fits’) with no questions asked. At the time of my visit in 2010, to both centres, about 900 fits per month were being dispensed at the Unit in NW, although the NW PHP thought it important to stress in a subsequent communication with me, that IVDU drug use was “not an issue for our cohort” (personal communication NW PHP, 16 August 2012). In K-B and in addition to the local Hospital vending machine and chemist, the PHP observed that the unit distributes: “something like between six and eight thousand needles a month through the door here”. This number was confirmed by the PHN the next day. Substance abuse clearly concerned the K-B PHP who had this to say about alcohol consumption in the region:

> Our rates of alcohol consumption are far in excess of state average and that’s not indigenous people, that’s non-indigenous people as well. We’ve got more
pubs than you can shake a stick at. Liquor outlets everywhere people getting, and I enjoy drinks I’m not a, I’m not anti-alcohol but we have shocking rates and this clinic is full of people who come in and say I’ve woke up, been to bed with someone, I’ve been drunk, worried, don’t know who he/she was, don’t know her/his phone number. Come back positive, no idea where to go. So there’s huge amounts of unprotected sex as a result of alcohol which then, as HIV becomes more prevalent, is going to increase our risk here.

Despite evidence of intravenous drug use among the community and transient workers, mainly in the fishing industry, substance abuse in the North-West Cohort is usually in the form of alcohol. Alcohol affects medication adherence directly, by way of intoxication, which leads to missed doses and also by the belief, quite entrenched, that mixing alcohol and prescribed medicines is harmful (Kalichman et al., 2012). But it is possible for health care professionals to assist individuals to overcome the impacts of heavy alcohol consumption and to adhere to treatment, in part by understanding the patient’s pattern of alcohol consumption. The NW PHP talks about some successes: of patients who continue to drink heavily but adhere to ART and maintain blood levels of clinically undetectable virus. She reiterates the value of being non-judgmental and remaining engaged with the clients in the long term:

That’s one thing I feel really strongly about, that is totally unacceptable, because people have preconceived ideas and they sometimes get it absolutely wrong. There was a perception amongst some that it [introducing ART] would be a waste of time, they wouldn’t take it and it’s just not been the case...So I think that assumptions around socioeconomic and other things that they have in their life can be so wrong and we become their colleagues, you know their friends or part of their family ironically ... then that is a major incentive for them to take medication.
Summary of Part One

From the interviews with staff in both regions it is clear that the needs of the clients differ along demographic and cultural lines. Although this finding is not new it highlights that recognising social ecology in health care planning and delivery is important and directly impacts on health outcomes. The care needs of the North-West cohort are echoed in the small numbers of Aboriginal clients in the Goldfields region, and are in contrast with the growing number of Medicare-ineligible clients in K-B. However, the approach to patient care in both regions and overall through the Rural and Remote Service, is focused on remaining engaged with patients/clients to promote their retention in medical care and ensure treatment is delivered in a way that is acceptable to them. This approach is fundamental to adherence theory (M. A. Thompson et al., 2012).

The need to contain the epidemic is a pressing responsibility for public health workers. This is particularly challenging in HIV because of the current (pharmacological) necessity of maintaining continuous treatment. It is evident particularly from the interviews with the health care providers in the NW that disruption to staffing levels and the quality of the interaction between health providers and the clients affects ongoing engagement and continuity of care so that there is a visible waxing and waning of the clients’ health according to the current level of service and the capability of the team. In practice therefore, the primary goal is to maintain engagement with clients: medication adherence is an outcome of that therapeutic engagement.

The clinical management of both cohorts is complicated by the need for stringent vigilance around inadvertent disclosure of HIV status since all patients, regardless of ethnicity, fear stigmatisation and discrimination. This situation has contributed to
patients preferring to limit their care to particular providers, and in the Goldfields region the PHP has become the primary provider for the temporary visa holders or ‘457s’. The increase in temporary visa holders—essentially non-citizens with HIV in Kalgoorlie-Boulder presents further challenges by virtue of ineligibility for Medicare and subsidised medicine, leading to concerns over the implications of HIV for visa status; and the tensions within families and the social issues that arise from these tensions. The staff at RPH has developed a current body of knowledge around visa issues in order to advise the regional providers and provide information for those people willing to access the RR Service. However, there is general concern about the social impacts of HIV for example, within the marriages of the growing numbers of heterosexual couples especially since social services are limited and not evenly spread across the regions and, additionally, may not be suitable for the needs of a culturally diverse group. Finally, it is apparent that the temporary visa holders are limiting their contact to personnel they consider essential to their needs.

Substance abuse, although a pressing health concern on a number of levels is a particularly critical issue in sexually transmissible infections and clearly concerns the providers responsible for public health in both regions. As a factor complicating HIV clinical care, it presents a barrier to successful adherence, and is a risk activity for transmission of HIV. Although heavy alcohol use is common in the two regions, intravenous drug use is clearly prevalent in Kalgoorlie-Boulder and as was described by the K-B PHP, is cause of considerable concern.

Despite the great distances involved, the rural and regional providers are able to access seamless, city-based expertise in HIV medicine via a straightforward and responsive chain of communication. They are also able to facilitate access to
antiretroviral drugs at an individual level by interventions tailored to fit with the lifestyles of patients in those regions, for example those travelling frequently between rural towns. Medical conditions in temporary visa holders and travellers that are not commonly seen in resident Australians, complicate HIV care, as do social issues around visas that limit access to Medicare and patented ARVs. Therefore, the social manifestations of HIV infection clearly complicate the management of the condition at a number of levels: health providers recognise the importance of remaining engaged with patients/clients and that this engagement may need to be on their terms. In Figure 18 I provide a summary of the social and structural elements which promote engagement with care which have been shown to be critical in the successful management of HIV infection (Gardner, McLees, Steiner, del Rio & Burman, 2011; M. A. Thompson, et al., 2012) and which the findings of this study support.

![Figure 18: The social and structural elements that support relationships and engagement with HIV care](image)

**The Role of HIV Support Services**

It was difficult to ascertain the role of HIV support services, specifically the Western Australian AIDS Council, in the regions. The NW PHP said that WAAC had, in the past, provided speakers for them between the years 1999–2002 and funded the purchase of...
some ‘white goods’- a word applying generally to electrical appliances such as refrigerators. In her recent communication with me she said “they aren’t really relevant in our situation though perhaps we need to revisit that” (Personal e-mail communication 16th August 2012). From the perspective of personnel, the Australasian Society for HIV Medicine was very active in supporting staff including those within the rural workforce, to attend conferences and educational meetings.

**Conclusion**

In Part One of this chapter I have given the perspectives of health care providers working across the state of WA to deliver HIV care. Part Two will present the voices of PLWH either living or working in rural and remote areas in the regions of WA or in the case of two participants, offshore.

**Part Two: Participants Living or Working in Regional Western Australia**

**Introduction**

This section focuses on participants who were either living in the country or working in remote locations. The potential mediators of the impact of HIV on the participants were considered in relation to their personal, social and geographical circumstances. Knowledge about HIV was nuanced by life experience, some people especially those from HIV prevalent regions, knew family or friends who had either died or were still living with the infection, while others had no such experience. As well as being ethnically diverse, the group came from a mixed educational background. The recorded interviews began with general questions about the circumstances leading to HIV testing; the immediate aftermath; and a reflection on managing chronic HIV
infection in a regional area or remote workplace. The mostly open-ended questions steered the participants to speak about: access to ARVs and HIV clinical care; managing HIV in the workplace; and issues of concern around confidentiality nuanced by living or working in a rural area. The results are presented as a narrative reflecting the flow of questions, beginning with the experience of receiving a diagnosis of HIV and the circumstances surrounding this event.
### Table 13 (a): Demographic characteristic of the participants either living or working in regions designated as rural and/or remote (N=19)

<table>
<thead>
<tr>
<th>Age (mean ± SD)</th>
<th>Male</th>
<th>Female</th>
<th>Median year of diagnosis</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>41.2±10.0</td>
<td></td>
<td></td>
<td></td>
<td>2006</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Indication for first positive HIV test</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness or concern re symptoms/risk</td>
<td>9 (47.5)</td>
</tr>
<tr>
<td>Health screening</td>
<td>10 (52.6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Self-reported HIV exposure</th>
<th>Self-reported location of HIV exposure</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heterosexual</td>
<td>Country of origin</td>
<td>11 (57.9)</td>
</tr>
<tr>
<td>MSM</td>
<td>Australia</td>
<td>7 (36.8)</td>
</tr>
<tr>
<td>Unknown</td>
<td>Abroad</td>
<td>2 (10.5)</td>
</tr>
<tr>
<td>IVDU</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment</th>
<th>Visa Status</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FIFO worker</td>
<td>457 long stay business visa</td>
<td>4 (21.0)</td>
</tr>
<tr>
<td>Full-time other work</td>
<td>Other</td>
<td>1 (5.5)</td>
</tr>
<tr>
<td>Unemployed or home duties</td>
<td>Permanent resident*</td>
<td>12 (63.1)</td>
</tr>
<tr>
<td></td>
<td>New Zealand citizen</td>
<td>2 (10.5)</td>
</tr>
</tbody>
</table>

**Abbreviations:** FIFO=fly in fly out; * Four ex-visa holders

### Table 13 (b): Clinical and treatment characteristics of the participants either living or working in regions designated as rural and/or remote (N=19)

<table>
<thead>
<tr>
<th>Drug Regimens</th>
<th>Number/schedule</th>
<th>Treatment Status</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FTC/TDF/EFV</td>
<td>5 (OD)</td>
<td>ART naive</td>
<td>1 (5.5)</td>
</tr>
<tr>
<td>FTC/TDF/NVP</td>
<td>1 (BD)</td>
<td>On ART</td>
<td>18 (94.7)</td>
</tr>
<tr>
<td>FTC/TDF/LPV/RTV</td>
<td>3 (BD)</td>
<td>Generic ART</td>
<td>3 (15.8)</td>
</tr>
<tr>
<td>3TC/AZT/RTV/ATV</td>
<td>1 (BD)</td>
<td>On patent ART</td>
<td>14 (73.6)</td>
</tr>
<tr>
<td>3TC/AZT/ABC</td>
<td>1 (BD)</td>
<td>Medicare ineligible</td>
<td>5 (26.3)</td>
</tr>
<tr>
<td>3TC/ABC/NVP</td>
<td>4 (OD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3TC/ABC/RTV/DRV</td>
<td>1 (BD)</td>
<td>Self-reported adherence</td>
<td>18 patients</td>
</tr>
<tr>
<td>TDF/LPV/RTV</td>
<td>1 (BD)</td>
<td>Never missed</td>
<td>4 (22.2)</td>
</tr>
<tr>
<td>FTC/TDF/DRV/RTV</td>
<td>1 (BD)</td>
<td>Missed &gt; 3mths ago</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Missed &lt; 3 mths ago</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>CD4-T cell count cps/ml</td>
<td>542.47±311.72</td>
<td>Last month</td>
<td>4 (22.9)</td>
</tr>
<tr>
<td>CD4-T cell (%)</td>
<td>26.11±10.76</td>
<td>Average no. self-reported side effects</td>
<td>5/30</td>
</tr>
<tr>
<td>Median CD4-T cell count cps/ml</td>
<td>558</td>
<td>Average cost of generic ART (AUD)</td>
<td>177/month</td>
</tr>
</tbody>
</table>

**Abbreviations:** OD=once daily dosing, BD=twice daily; ART=antiretroviral treatment; 3TC=lamivudine, FTC=emtricitabine, TDF=tenofovir, ABC=abacavir, AZT=zidovudine, EFV=efavirenz, NVP=nevirapine, LPV=lopinavir, RTV=ritonavir, ATV=atazanavir. ‡ One patient naive to treatment; two patients recently changed drugs; two patients recently recommenced.
Results

Sociodemographic and Clinical and Treatment Characteristics of the Participants

There were nineteen patients included in the analysis (Tables 13a and 13b). Ten (five women) lived and worked in rural areas and nine (all men) worked in remote regions, typically working for two weeks continuously, with one week off when they returned to their homes in the metropolitan area (FIFO). The sample was ethnically diverse: eight were Caucasian, six were from East Africa, two from South-East Asia, two were from Oceania and one was of mixed Caucasian and Aboriginal and Torres Strait Islander descent.

Rural Participants

Of the ten participants living and working in rural areas: one lived in the Wheatbelt, one in the Mid-West, three in the Goldfields, four in the Peel, South-West or Great Southern Regions. Eight of the 19 participants had Permanent Residency, but three of them had been on temporary visas before that. Two (both women), were on current temporary visas, and were therefore ineligible for Medicare—one of these was a Long Stay Business Visa (457) holder working in the health sector. With regards to employment, two worked in family businesses, one in the mining industry, one in the health sector, one in hospitality, one in education and two in general employment. Two (both women), were supported by their spouses and one had an Australian-born HIV negative baby. Three of the participants had children, and two of those children lived in other countries with family members and were receiving financial support from their parents in Australia. Four of the five women were married to Australians or New Zealanders. Two of the women were not fluent in English. Six of the participants
had been exposed to HIV by having unprotected sex with members of the opposite sex and four infections were in men who had sex with other men. Six of the rural participants were diagnosed during health screening.

**Fly In fly out and offshore workers**

With regard to the nine men working in remote areas, two were classified as working offshore (internationally) and the others worked in WA in the mining and construction industries, as either skilled tradespeople or skilled professionals such as engineers or geologists. Three of the participants were on temporary visas and two were New Zealand residents and therefore eligible for Medicare. Five were either married or partnered, and seven out of the nine had children and six were living with them. One working man on a temporary visa was a sole parent for two children under five years old. Seven of the participants were exposed to HIV by having unprotected sex with members of the opposite sex, and two infections were in men who had sex with other men and injecting drug usage was an additional transmission risk factor. Three of the FIFO workers were diagnosed during health screening for employment or application for residency, two suspected they had HIV infection and sought testing from their GPs and one had been diagnosed in East Africa.

**Interview Data**

**The Impact of HIV Diagnosis**

Most of the nineteen participants had received their results from city-based health personnel in either Australia or New Zealand after pre-test discussions took place, although the quality of these is not known. One patient received the diagnosis in a Middle Eastern country and was given one month to leave voluntarily or be deported. Another woman received results by phone in a rural area of WA; and a WA man
describes being telephoned at work by his city-based GP, who gave him the results of the HIV test, citing “he was about as subtle as a train smash.” Those diagnosed through Health Services Australia, now Medibank Health Solutions, were referred to specialist services at RPH where they received emotional support and HIV-specific education from nursing personnel, sometimes prior to clinical assessment by a medical practitioner.

The immediate reaction of most participants to a diagnosis of HIV was one of shock, even though at least three people suspected that the results of the test would be positive, and some other men had knowingly participated in high risk behaviours. However, one gay man diagnosed interstate and now living in rural WA had this to say:

> I don’t know whether it’s a self denial or whatever, I just didn’t take much notice. I thought oh it probably doesn’t auger well so I wasn’t shocked when I actually got the news from the specialist surgeon that you know I’d had HIV.

This deeply religious man talked of communing with the Holy Spirit before being told of his diagnosis, indicating that he had received the news ‘spiritually’ before hearing the results from his doctor. Another rural gay man infected in 1991 speaks about his low self esteem and depression at the time he was infected saying: “I sort of set out to infect myself as a form of self harm.” Most reactions were primed by what people knew and thought they understood about the condition. People from HIV-prevalent regions had vicarious experience of HIV. However, a small number of people in this group, came from low HIV-prevalent regions, had few risk behaviours and little experience of the disease; for example the person infected while living in the Middle East said:

> I mean I thought I’m going to be dead within two or three years to be honest because prior to this HIV really didn’t, yeah didn’t interest me, wasn’t part of my
life, I didn’t know anybody who had HIV and yeah didn’t think, I wouldn’t even think about that illness.

Some of the participants from regions in Africa, Asia or Oceania had seen people looking sick or even close to death, and assumed that they had HIV/AIDS or lost family members. This led to the belief that they would also die rapidly of the condition. One man in this group had delayed testing:

I was reluctant to go for a test, I didn’t have the courage. But then when I was getting sick and sick then I finally just decided to go for an HIV test.

Concerned about steady weight loss, a second man went to his GP:

...after having seen some members of the family die, with my educational background I just went to the doctor and I said I want to be tested, what for, I said HIV. He said are you prepared, I said yeah then he goes ah yeah it’s alright because now with medication for that we can keep it under control so we will send you for the test.

(African man, FIFO worker)

Yet another African FIFO worker could not understand how he came to be infected and two other men were similarly mystified:

...this came as a shock because I didn’t know where I got it and I tried to find out and I couldn’t think of anything of the way that I knew it was transmitted.

Months after his diagnosis the patient continues to ruminate and perseverate, over what might have been the source of infection. And, possibly because of this confusion, he fears inadvertent, casual (so called) transmission to his family. The Australian-born participants’ basic knowledge of HIV was also rudimentary and often based on advertising campaigns going back many years (‘the Grim Reaper’). And except for one man who had worked for an AIDS Council as a volunteer, there was a general lack of awareness about improvements in drug treatments that have led to increased survival.
There seemed to be no difference between those who identified as gay (all Australians), who might have been expected to have some prior knowledge of HIV because of the country’s swift, high-profile response to the epidemic and ongoing funding for prevention, and those who were not. A gay man living in a rural area talked about “being knocked for six.” Another gay man put it this way:

I was devastated, absolutely devastated. At the time my thinking was that this was a death sentence, that was the state of my knowledge, and yeah, I was devastated.

The women also described their reactions as coloured by their prior knowledge of the condition: one woman living in a rural area said: “my whole life was basically thrown upside down” and another Asian woman travelling around Australia explained: “Just feel want to die or something.” The immediate threat to health was tempered by the quality of the pre and post-test discussion which was variable, as was seen in the case of the first FIFO worker. One of the Asian women’s husbands talked about receiving a diagnosis of HIV while visiting a remote town in WA: they were phoned with the results and he took the call explaining that his wife could not ‘understand’ the message. He talked about his perceptions of the reaction of hospital staff when they went for confirmatory testing:

...then we went had more blood tests in [one country town], both of us, and we had more blood tests in [another country town], and everybody was pointing the bone if you know what I mean, like you know. You’re virtually dead like you know you’ve got HIV, you’re crap you know.

He implies that the health care workers in the country hospitals were just as ignorant of HIV as they were.
The role of socio-cultural norms in mediating the impact of HIV

Half of the participants were diagnosed with HIV before they developed constitutional signs or symptoms of HIV. But the impact of an HIV diagnosis is emotionally ‘disabling’ in the sense that the appraisal of HIV is mediated by deeply held socio-cultural norms reflective of contexts such as country of origin, rural vs city settings, gender and sexuality. For example, in East Africa one of the men observed that in his experience:

So promiscuity level is a bit managed because there is a lot of cultural things involved and procedures given [so] traditionally, [to] approach a girl or a woman for sex is hard.

He went on to explain:

So this stigma is based upon lack of faithfulness; and marriage relations are highly respected; and issues like, because they either say: one, you’ve been promiscuous; number two: you’re a homosexual and the homosexuals are not accepted in the community at all, so it’s across the board that’s why there’s this stigma.

A man from Oceania pointed out that the experience of being HIV-positive in a rural town is isolating whereas in the capital no one knows or cares: “Yes, back in the traditional villages yeah, people talk bad things about you. Like you know don’t want to be near you or talk to you or things like that yeah.” This was also true in Asia where the disapproval extends to the whole family and in small villages an HIV-affected family can stand out: “Oh people very hate that family or something. Them hate all family, not just one people” (woman, traveller).

One new Australian resident who had been on a spousal visa noted that attitudes in the large regional town were ‘backward’ explaining:

Remarks... I mean might have to do with K-B as well, remarks, I mean nobody except [partner] knows what’s going on with me but remarks you hear from
colleagues about, I have a colleague in [the city] who is gay and they just make remarks about him and then relate AIDS and HIV to him even though he probably has nothing. But ahm they’re [the] remarks about Aboriginals which really make my hair stand.

Once the initial personal threat had been processed most people were concerned that they may have infected their spouses, partners and indirectly their children. This can cause considerable anxiety: “I would die if I gave it to someone, not die but you know be horrified if I gave it to someone” (FIFO man). Allied Health Services to support people with HIV are not readily available in the country regions and specialist HIV care is limited. People with HIV living in remote areas commonly travel long distances to the RPH where they have access to a social work and psychology service. Whether people who don’t have family support in the city do this to the same extent is not clear. Although the RRN offers direct telephone and e-mail communication to deliver emotional support to people in distress, which helps to overcome lack of access to supportive services in rural areas, this will not be adequate for people who need a specialised mental health assessment and ongoing treatment for any condition that might be uncovered. However, it was beyond the scope of this study to evaluate this service.

**Access to HIV Medical Care and Treatment: Overcoming Distance**

The FIFO group all attended the RPH Immunology Outpatient Clinic for follow-up HIV care, scheduling their appointments on their work-free week. However, unlike most of the West Australian-based workers, the two offshore workers maintained e-mail contact with the RRN. Another WA-based worker, diagnosed in 2004, remained engaged with the RRN over a seven year period, despite peripatetic living and work arrangements around the state and a long-standing personal need to keep his
diagnosis private. All of the rural dwelling participants used the e-mail link with the RRN, but also telephoned on occasion to request another batch of ARVs, a blood request form or general advice and support. One country participant put it this way:

*It’s just more efficient. I can talk to A [the RRN] via email any time if there’s a problem. You’ve got someone to talk to without necessarily annoying a professor who’s got 500 people underneath him or, has got a heavy workload and so, and someone who knows you and knows that you’re not overreacting, they understand that you wouldn’t be contacting unless it was a valid reason.*

The FIFO workers take advantage of their week free. One participant describes how he accesses the service:

*More often than not I just walk in there and say. ‘Cause I’ll have me break, like say me break started today and goes for a week, well I’ll go in there knowing that if I get blood test done today by the time I see the doctor in four or five days the blood test will be through, you know, so off I go.*

As was described in Part 1 of this chapter, rural participants can attend a regional pathology collection service (PathWest WA) for sample collection and subsequently the specimen is couriered to PathWest in Perth for analysis of CD4 T-cell count and HIV levels. In this study, patients reported reluctance to use the pathology centre in their home towns but travelled to another regional centre to avoid disclosure of their HIV serostatus to people they might be known to in their communities. A man spoke about his own uncomfortable experience in the past:

*...I think if you’d turned up for a leprosy test she probably would have been just as judgemental for want of a better description. I mean a double lot of gloves you know and sort of like taking the samples. Her body language said a lot...*  

He went on to comment that times had changed and pathology staff use what are generally known as ‘universal precautions’ as a matter of protocol for all phlebotomy procedures. Universal precautions in this and many other health settings, assume that
bodily fluids from all persons are potentially infectious and that the same level of protection is required. This protects health workers from infection with blood borne viruses and patients from discrimination.

Three of the ten rural participants attended the outreach clinic in the Goldfields but the rest attended RPH for three-four monthly appointments, some driving for up to six hours from regional centres and returning home the same day. One patient flies down from the North-West. It is a seven hour train journey one way from Kalgoorlie and one hour by plane.

The cost of petrol may be reimbursed or subsidised through the Patient Assisted Travel Scheme, but the temporary visa holders are ineligible to access this. West Australian-born patients often stay with family or friends and make the trip to the city an occasion for visiting or shopping, but the temporary visa holders usually travelled home the same day. One of the rural participants enjoyed seeing the allied health workers, in particular the clinic social worker from whom she received psychological and practical support:

*All the people in hospital, about ten people, right ten people here help me, help me, expect me, push me, hello P how are you, you look beautiful, you look more healthy.*

Although most participants were listed with GP only a few reported visiting them for other illnesses; and disclosure of HIV serostatus was a carefully considered decision in a country town, as this man said:

*Look partly too I think, the GPs would be very confidential and very good but I still feel a slight stigma attached to going to see a GP because they probably hear when I come to see [the medical team from RPH at the outreach clinic] there are no sort of manifestations of any problems or whatever so I figure I only go to a GP when I need to really.*
Another woman in a country town feels similarly, her newborn baby is under the care of a child health nurse with whom she feels very comfortable but she is less so with GPs and travels to another town to ensure privacy and she knows her rights: “…it’s my right I don’t have to say it if I don’t want to say it.”

However, one man (FIFO) said that he would prefer to be under the care of a GP and not attend the hospital-based service at all, since he complained of discontinuity of care by medical registrars and a dislike of the public waiting room:

No I just hate coming here I’d rather just have a GP. I’m worried about people seeing me in there that I know and stuff you know. But I’d just much rather the privacy of a GP, off you go, get your tablets.

Two of the South-West participants, in particular, described ‘good’ relationships with GPs, and in one town, teleconferencing facilities between city and country hospital are used – but not for HIV care. One of these men noted that because he was from a country town, his hospital stay was prolonged: “I mean the only reason why they kept me in for three weeks was because I was country patient and they wanted to get me sorted out.” These men expressed satisfaction with HIV care and their views were representative of nearly all the participants interviewed regardless of ethnicity or gender.

**Antiretroviral Drugs: Access, Adherence and Persistence with Treatment**

Three of rural group attended the outreach clinic in the Goldfields and received ART from the Population Health Unit where it was mailed from the RPH pharmacy. But the rest collected their treatment from the hospital pharmacy, apart from the three interviewees who received a generic supply posted to their homes by internet vendors. Another visa holder required drugs that were not easily accessible in generic form and he was granted compassionate access to patented drugs by the Director of Clinical
Services at RPH. The Medicare ineligible participants were more likely to access nursing services at RPH for assistance in maintaining an uninterrupted supply of ART. The offshore workers sought permission from the RPH Pharmacy to receive a longer supply of ARVs which are regulated to be dispensed on a three-four month script and they took these with them internationally. Three of the participants described treatment interruptions. One participant (FIFO) diagnosed and treated in Africa, came to Australia on a 457 Long Stay Business Visa. His supply of ARVs was interrupted for six weeks until he sought assistance from a GP who referred him to the service at RPH where he was introduced to a generic supply. Subsequent immune monitoring uncovered nevirapine resistance which occurs commonly after continuous treatment with the drug is interrupted.
Table 14: Case study of participant (diagnosed in 2004) living and working in a rural area

September 2004-2006: Thirty-four year old gay-identified man living in rural area & working in family business. Diagnosed interstate & referred to RPH for care. Not ‘out’ to parents & limited friends: “You know? [its] a small country town so everyone talks and gossips and shit like that so it’s a bit harder I think.” So you sort of just keep it to yourself. Received adherence support per 2004 protocol & enrolled in RR Service. Adherence/persistence patchy, developed resistance to NVP, adherence complicated by secrecy of HIV serostatus & taking meds, poor health literacy, mobile lifestyle working in family businesses, side effects of Rx & helicobacter infection. Feels depressed & overwhelmed from time to time & finds number of pills a burden, however he eventually stabilised on ART by the end of December 2005.

December 2006-2010: Moved interstate and slowly disengaged from care “...there’s no like interaction like you and me are talking...I think that’s why I just stopped.” Spent one year in Africa & ceased ARV’s altogether. “I was just over taking tablets all the time and I just thought oh ‘cause I’m feeling so good, I’ve put on a lot of weight and, and just felt really good inside and outside and I just thought maybe I can stop.”

April 2010-2011: Presented at a rural Public Health Unit with Kaposi’s sarcoma. Family supportive & concerned about ‘illness’ still no disclosure of serostatus to family. “She’ll look at me differently or treat me differently or I don’t know. That’s the worst thing I’m worried about”. Motivation to adhere to ART is strong: I suppose if you’re thinking about going off your medication because you feel really good and stuff like that I wouldn’t, I would get that thought right out of your head.” Still has difficulty naming & recognising drugs, currently engaged with service providers.

Abbreviations: Dx=diagnosed, Hx=history, Rx=treatment. 3TC=lamivudine, ABC=abacavir, RTV=ritonavir, ATV=atazanavir, NVP=nevirapine, LPV=ritonavir, DRV=darunavir
Two country participants had at some stage disengaged and re-engaged from the service at RPH. One of those men (diagnosed in 2001) had a comprehensive knowledge of HIV and treatment having worked as a volunteer for WAAC and known, personally, many people with HIV who had died of AIDS. Despite this knowledge, while working for 18 months in South-East Asia he rationed his six months daily supply of ARVs taking them three times a week. During this time he was not engaged with the RR Service and did not realise that he could access medication from Australia. He took this attitude “And so I thought well... I’ll worry about that down the track.” The second man (diagnosed in 2004) who reported interruptions, left the state and enrolled with another service from which he slowly disengaged, he then left the country did not take ARVs for at least a year, when asked what he was thinking when he stopped treatment he said:

*Just didn’t want to [take ART]. I thought I was feeling pretty good and stuff like that and yeah and I thought oh maybe it’s a miracle or something like that yeah. I’m feeling, I don’t know I just think I was just over taking tablets all the time and I just thought oh ‘cause I’m feeling so good, I’ve put on a lot of weight and, and just felt really good inside and outside and I just thought maybe I can stop.*

The man reengaged with the WA health system when he presented with Kaposi’s sarcoma at a regional hospital in 2010. Now he talks of the deterioration in his health as ‘a reality check.’ A case study of this participant, juxtaposing clinical and social aspects of his illness experience, can be found in *Table 14*. Another participant who reported treatment interruptions described taking all his tablets, never missing a scheduled dose, but then waiting for his next supply to arrive. He also believed that the medication would continue to ‘kick in’ and suppress the virus thus demonstrating his lack of understanding concerning the development of drug resistance. The
examples above show the importance of retaining patients in clinical care; and for ongoing monitoring and evaluation of patients' health and treatment literacy and motivation to continue with therapy.

One of the major challenges for clinical service delivery is to support uninterrupted medication access to patients across the state. The coordinating role of the RRN underpins this effort. Despite the challenges of accessing ARVs and supporting their cost—particularly for those importing generic versions—nearly all patients expressed good motivation to take medication continuously although it was evident from the patients with a history of treatment interruptions that that was not always the case. One patient, a temporary visa holder and FIFO worker, had not yet started medication and expressed his reservations about whether the medications would benefit his health. Some others expressed concern about the long-term effects of the medication and a couple of people from HIV-prevalent regions wondered whether it would continue to work after many years:

I’m really happy but the thing that concerns me is I’m not sure if the medicine I’m on might, my body might get used to it that after a while the virus start rejecting it. That’s the only thing that I worry about.

However, of the 18 participants on treatment only four had missed doses in the last month but these were regimen-related interruptions: two of the participants recently changed drugs and two recently commenced. Over half reported last missing medication over three months ago or never. This high level of adherence may be due in part to a relatively low frequency of side effects (an average of five out of a possible 30), the most common concerns being either weight loss, weight gain or in the women vivid dreams.
One rural participant’s comment encapsulated some others’ views:

*But I, I can understand how non-conform, non-compliance can affect people because in some ways if you’re having, if you’re having medication and you’re having no side effects or minimal side effects then you’re fine. It’s a very easy routine to get into and it’s like comfy slippers. But if you’re, every time you take that tablet you can feel your fingers coming dead or there’s another layer of skin coming off you sort of, after a while you think what’s it doing to my organs inside you know...And what is the side effect that’s going to show up in 10 years time even from a 12 week exposure to that medication.*

However, few participants articulated concern for long-term side effects.

Another prerequisite for successful adherence is motivation to maintain the treatment regimen in spite of barriers that must be overcome to achieve this. Sometimes this is underpinned by personal experience (or antecedents) like one of the participants who reported a significant treatment interruption and developed an AIDS complication:

*Well like well now I know how important medication is because I got really sick and stuff like that, I don’t want to go through all that sort of stuff again anyway.*

Or as the Public Health Physician in the previous section noted, every time someone in the North-West Cohort dies, fear of death becomes an incentive for others to increase pill-taking behaviour. This may also be a motivating factor, particularly in the African and Asian groups since they had observed death from HIV/AIDS at close hand.

However, another evident motivating factor is the desire to protect (sexual) partners and also remain well to avoid distressing family members, for example elderly parents. People with children and dependents are also highly motivated to remain well, employed and therefore financially secure. One single father, a FIFO worker said:

*“yeah I got to live, I got children to take care, I can’t like bow down to the sickness or*
what people say to me you know.” Seven out of nine FIFO workers had children to support as opposed to three out of the ten rural patients.

**Adherence: supportive strategies and healthy behaviours**

All of the participants either used alarms, calendar medication boxes or had developed idiosyncratic routines to support continuous dosing. These strategies and the careful consistent ordering of generic supplies in the case of the Medicare ineligible participants; and close communication with the RR Service, demonstrates that patients are highly motivated to take treatment. In addition they show a leaning towards health seeking behaviour in general, particularly with regard to healthy diets and a low rate of tobacco use—only two out of 19 were current smokers. Three of the 19 had a history of intravenous drug use and five had used marijuana but none were currently using recreational drugs. Although only six of the 19 drank alcohol daily or weekly, four of the six drank five or more drinks in a session, which would be considered risky under the National Health and Medical Research Council (NHMRC) Guidelines for alcohol intake (2009), and three more participants, including two women had similar amounts two or three times a month. However, only one of the rural participants reported alcohol interfering with her capacity to adhere to ARVs in the past.

**Work in Remote Areas – Living With HIV ‘On the Job’**

Recent publicity and a government sponsored national review of the health and social impacts of FIFO and DIDO work highlights current concerns about the social effects of living in one place and travelling to distant work places for up to one month at time, but most commonly for two weeks ‘on’ and one week ‘off’. A lot of this concern centres around the effects on the family life and relationships of the workers:
You’re working away from (my) family, you’re working eight hours every day for two weeks straight, it’s kind of stressful and it’s sort of, it’s a routine job whereby it’s wake up, go and eat, go to work, come back, go eat, go into a room for fourteen days it’s all, it’s a bit monotonous (FIFO worker)

This participant was particularly concerned about his children’s education and the need for him to supervise their homework since he said that in his home country in East Africa academic advancement was critical to improving employment prospects because unskilled labour was paid so poorly unlike, he observed, in Australia.

For people with HIV, the FIFO work environment takes on other dimensions, not all of them negative. For example, the same ‘routinisation’ and block of work-free time can support adherence to medication and facilitate engagement with medical care by allowing time to attend hospital appointments. One participant spoke with me while waiting for his clinic appointment. Despite being unhappy about working away from home because he missed his children, he noted that regular time off means he can schedule and attend his hospital appointments. He also finds that the routine of FIFO work facilitates regular dosing, except when he has to share a room. When this happens he conceals his medication and takes them privately. When he returns to Perth on his week free he finds regular dosing more challenging since as a single father he is busy and preoccupied with domestic and child-centred activities in the time he has off work—he is also very tired. Although this participant would prefer to work in the city he expressed concern that return to regular work would make attending medical appointments difficult and this is one of the factors, for him that weighs in favour of the FIFO lifestyle.
Many of the men spoke of the Occupational Health and Safety regulations in the workplace as far as management of accidents and blood spills as being ‘good’ and held the opinion that safety regulations would not be so good in other workplaces: “In fact in the mines you are fairly safe working at the mines than working at a factory in the city there, it’s not safe.”

However most men feared blood spills and all of them used the equipment supplied:

They call it personal protective equipment which is your clothes, your gloves, long sleeves and you’ve got hard hats and you’ve got boots. So and even when you are working, when you are doing some certain hard work you use leather gloves (FIFO, 457 visa holder)

And they follow the protocols for safe practice in the workplace. However, some remain anxious and the following patient, another 457 visa holder, not yet on ART, spoke most expressively on this theme and was representative of others in the FIFO group:

I try by all means to avoid a cut, a simple cut and if I’m cut I don’t want to be helped by anyone, I do it myself. If I can’t help it that’s it and to be honest with you I don’t feel comfortable to even go to anyone in the event that there’s a cut and say I need assistance.

He notes that use of sharp implements is common in mining workplaces:

We’ve got what we call utility knives, those are the dangerous things, avoid things that are sharp. Watch where you’re going, what you’re doing. So every time it’s in there that I don’t have to hurt myself because I was told that if I have any health problem, whoever I go to for treatment I must declare [to them] that this is my condition. So that’s very hard for me to go and tell everyone and in the work environment [and] you don’t go by yourself, the health and safety officer will there for your or maybe your supervisors will be there with you, takes you and the doctor comes in, there you are declaring that.
One FIFO worker, who manages a large, contained offshore workplace, had this to say:

...we protect our people as much as we can and all the work’s done in such a fashion or we try to do it in such a fashion that, well our motto is nobody gets hurt so there isn’t very often there is a blood spill thank God and you do feel safe in your environment. You’re probably safer in what we do than if you’re working in the kitchen here at home where you don’t bother about these safety rules and regulations that we do.

Health care access on the mine sites in general is cited as good: “They’ve got a site nurse over there and yeah if you’ve got any problem call, you can just visit the site nurse and he or she attends to you” said one FIFO worker on a 457 visa.

In the health sector, despite increased safety precautions and new needle and syringe technology to protect staff from needle stick injury, percutaneous injury does occur and these events can provoke high anxiety in someone with HIV:

Yeah sometimes I think like this other day it happened that I was prickled [by the glass ampoule], I was in the middle of giving some morphine but then I was prickled so but then thank God I just told, I just told that the colleague that it wasn’t safe for me to give that medication because I don’t trust myself is what I said and they just put discarded.

(457 visa holder)

A small number of participants showed a less fearful appraisal of risk of transmitting the infection via a blood spill—this man after commenting on the fact that the paramedics in his industry practice adhere to safety standards, commented:

So I don’t worry too much about you know. It’d be different if I wasn’t taking me tablets and me viral load was miles high and all that sort of stuff then I’d sort of worry.

The workers fear transmitting the infection in a work place accident. Some of this anxiety may be related to not wanting others to go through what they have, as
expressed by a number of participants, but it appears that anxiety is associated with
the requirement to disclose HIV serostatus if such a situation was to arise.

I've got four supervisors I'm in good books with them. We chat, we laugh, we do
everything but I don't know when that comes what will happen but because of
the visa issues my HR manager knows and a few managers at work knows...So
how they would respond I'm not sure. So I don't know.

(FIFO worker, 457 visa holder)

Fear of disclosure

Most participants anticipated negative appraisal from others, however, some cite
tables of where they felt they had been exposed to discrimination. One FIFO
worker described, furiously, how his HIV serostatus was disclosed by a hospital-based
health professional to the company doctor. The clinic staff intervened with
communication that supported his overall good health and ability to work, but not
before the participant advocated on his own behalf and pointed out that the hospital
worker had breached confidentiality. This participant had been working ‘up there’ for
over seven years, mostly on contract this meant that he had to undergo regular
medical checks and drug testing prior to their award. Since efavirenz is detected in the
urine as a metabolite of cannabis (tetrahydrocannabinol or THC) erroneously, he had
failed a number of tests. Subsequently he changed his medication to an alternative
drug in the same class. This characteristic of efavirenz, a ‘first-line’ treatment for HIV
and commonly coformulated with emtricitabine and tenofovir to the generic brand
Viraday (Cipla Ltd) and the patented Atripla (Gilead Sciences Ltd), is a common
problem for people working in jobs that require regular and unscheduled drug testing.
Most employment in the mining industry involving manual labour or driving would fit
into this category.
Another rural participant on a 457 work visa works in the health sector and described feeling anxious about disclosing her HIV status to her managers. But support from a family member helped her overcome this:

So yeah it was hard for me to approach them [the management] and let them know but I just thought oh, but my sister was very supportive. She was like oh there’s many people with different diseases here so don’t be afraid just approach them and let them know and usually here there’s private so it’s nothing to worry about.

This same participant is preoccupied with the fear of infecting another person, she volunteered this information: “I’m always living in fright in Australia”. When asked why, she said “Oh I’m just afraid maybe if I accidentally infect someone.”

The concern expressed by the FIFO workers may in part be attributed to the perception that mine sites and oil rigs have a “very masculine type, homophobic type atmosphere”, as one man working on an offshore rig described it. All of the nineteen participants whether FIFO workers or not were reluctant to disclose their HIV status to future employers, their managers or their workmates. One man, who worked offshore, one month ‘on’ one month ‘off’ for an international company, was screened for HIV during routine professional licensing. When the doctor learned that the man would most certainly lose his employment, he reported his HIV status as negative after referring him for treatment with an HIV Physician. In his work environment, on an offshore oil rig there is an on-site medical doctor with whom workers are required to leave a list of their current medications. This participant omits ARVs from his list which includes medication for other chronic medical conditions. When asked what would happen if he included the ARVs, he said “Because I’d probably lose my job.” He clarified this response by saying:
Mmm well if it got out yeah you know, there’d be the questions asked why? Are you HIV positive, are you gay? And if that came out then in my type of job I don’t think management would consider a gay person capable of doing it although I’ve been doing it for 40 years.

This man acknowledges that the rig, owned by a European company is likely is to be bound by anti-discrimination legislation but notes that “I’m an Australian so we’re more dispensable.” In effect the participant felt the need to conceal both the fact that he identifies as gay and that he is HIV-positive.

This view is echoed by the respondent who had worked for a mining company in Africa and then was offered a position with the same company in an Eastern European country:

I obtained a job in [the Eastern European country] and I had to give up on that job and that’s why I’m back here basically without a job because [that country] has a policy of no entry [for people with HIV].

This situation is ironical since the company publicises supportive programs for employees with HIV and encourages regular testing of HIV-negative employees in high prevalent areas. However, it was the case that this patient anticipated being stigmatised by his company to the extent that he refused to access free ARVs available from the company clinic when in Africa citing:

I could have gone there but as I said I didn’t want the things to be on the company records...It’s hard to know, there’s a stated policy, there’s an unstated feeling do you know what I mean? And my feeling was that this was not going to do me any favours.

He chose to access ART in Perth and travel abroad carrying the medication.

Out of the nineteen participants in this group, who feared other people, particularly employers knowing their HIV status, there was one exception. This FIFO worker is now
a permanent resident of New Zealand and is aware of citizens’ rights in that country and that he should be able to access Australian Residency because of the relationship between NZ and this country. In addition to having disclosed his status to his family in East Africa he offers support to male friends in the workplace, sharing his knowledge of HIV, most of which he gets from websites and verifies with the medical staff in the clinic:

What I’ve discovered if you test HIV positive there’s a period where you sort of, you are lost and it’s very important that you have somebody to talk to, to share with.

This man is also unusual in that he has actively engaged with the WA AIDS Council, unlike most of the other people in this group, and reported receiving support from the organisation.

Community Services for People Living with HIV/AIDS in WA

It was not a focus of the interviews to determine if participants had accessed the WA AIDS Council (WAAC) but at least four people out of the nine that knew of the organisation had some contact. One rural participant seemed unclear whether he had received counselling from WAAC or from the Contact Tracing Service after he had received his diagnosis from the Medibank Health Solutions Unit. However, he found the interview frightening and distressing. A FIFO worker felt the service did not cater for heterosexuals and found the interview intrusive:

I think he [she] just... if you weren’t gay didn’t want to know about you basically you know, that was the real impression I got...This is all bullshit aside, walk in there and talking to him and he [she] asked me how I got it. I don’t like telling people how I got it [HIV]. It shouldn’t matter how I got it you know?
Three more people had heard about the organisation but did not want to use it. One Australian-born man feared that his privacy would be compromised:

I think when I was first diagnosed I was told about those but because, a) because I was away and b) you know there’s always the thought in the back of my mind hey if I get in touch with these people then somebody might come back and try and use it against me or something you know.

**Internet access overcomes distance and privacy concerns**

Most of the participants had received standard approved HIV information in hard copy concerning the relevance of ‘CD4 counts’ and ‘viral loads’; how to practice safe sex and the importance of treatment adherence. But it was evident that the internet was used on an ongoing basis to access information and this practice was widespread throughout the group. However, participants did not seem clear about what sites they were visiting. Some accessed information regularly, for example the man who believed it was beneficial to disclose HIV serostatus while others did so less often. Private living facilities at the mine sites and portable ‘laptop’ computer ownership facilitated this. Accessing information in this way was considered an advantage for the privacy it afforded as well as the obvious advantage in overcoming the need to travel and receive information from a health care provider. In this way educated working people could be perceived to be advantaged over those who were not.

**Summary of Part Two**

The interviews reveal that the experience of HIV infection pervades nearly all facets of a person’s life. However, there are common aspects to living in rural communities regardless of the country and ethnicity, that nuance the social experience of HIV and this seems to be related to the number of people that ‘know’ you, ‘know’ your family, and ‘know’ that you have HIV infection. To a lesser extent there is a perception that
people in rural areas are less well informed (‘backward’) and that health care facilities outside of the main regional centres lack requisite knowledge of HIV. So people appear to fear gossip and ‘shunning’ from people and social groups that they know, more so than people that they don’t. There is an apparent desire to control who ‘knows’ and in this there is collusion with health care workers who shape their practices around the construct of confidentiality and the practice of protecting privacy beyond that applied to the management of other diseases.

In a sense, the workplace also represents a small community and thus has some of the same social, ecological attributes of a rural community except that there is an expectation of conformity to certain practices that protect people with HIV and those around them from accidental transmission of infection, for example, the health and safety practices in the mining and health sectors. And there are laws which protect the explicit discrimination of people with HIV and ensure equal opportunity of employment—for Australian citizens. In this study, there were two men working internationally for whom a disclosure of positive HIV serostatus would result in exclusion from employment because of the discriminatory regulations of those international companies. However, for the remaining participants it was apparent that people feared discrimination in their places of employment rather than having experienced it and this is compounded for the people who are not recognised as Australian citizens and feel they have a lot to lose. These issues will be further explored in the next chapter.

It is evident and in agreement with the verbatim of health providers, that considerable efforts go into overcoming structural barriers to accessing medication and this is met by participants’ motivation to accept their treatment. Those who interrupted their
regimens, particularly the man represented in the case study who developed AIDS, found the fear of death a great motivation, in common with other people who had seen members of their communities die.

Overall, and in agreement with the reports of the health care workers, people are selective in their access to care and firmly engaged with the shared care network in the regions coordinated by the RRS in Perth. The service has to date, offered flexibility such that country people can attend the city-based service on an *ad hoc* basis while remaining linked to providers in the regions. This engagement is cemented by their need for immune monitoring and drug treatment (the bare minimum of HIV care) that they would not be able to access otherwise without either indirect or direct linkage to the Rural & Remote Service. Some of the participants appear to see the city-based service as a ‘safe haven’, where they can be themselves. However, it is apparent that services other than medical are in short supply in regional areas and that people with HIV may have a number of unmet social and psychological needs that are not being identified, in part because of their limited exposure and contingency status as ‘hard to reach’ populations. In addition their ability to access HIV education may be impeded by secrecy practices.
CHAPTER FIVE

TEMPORARY VISA HOLDERS
CHAPTER FIVE   TEMPORARY VISA HOLDERS

Introduction

Migrants, guest workers and international students represent a growing, mobile population of ‘modern migrants’ who bring the health impact of their country of origin to one or more destination countries. Additionally, international travel and work opportunities support population exchanges and movement between migrant origins and destination locations. In December 2010, there were just over one million temporary entrants in Australia, excluding the half million or so entrants from New Zealand. Traditionally, public health approaches to managing the health of migrants or ‘mobile’ groups have derived from the paradigm of quarantine; protecting the host population from an external threat by a process of exclusion (D. Armstrong, 2011; Gushulak & MacPherson, 2006). In this century, however, Western Australia increasingly relies on skilled workers to fill positions—particularly in the mining sector—and competition for enrolment of international students in universities is keen. Those seeking positions may come from HIV-prevalent regions in Africa, Asia and Oceania, and diagnosis of HIV is commonly made when people apply for visa extensions or permanent residency in Australia, or when people present with an AIDS-defining illness. Thus a person who may have previously been eligible for permanent residency may find themselves suddenly ineligible by virtue of their inability to meet the Health Requirement which is enshrined in Commonwealth legislation under the Health Act 1958 (Cth). The nature of HIV infection with its long, largely asymptomatic phase and current potent and tolerable treatment, allows for a near normal lifestyle for infected individuals who have access to medical supervision and drugs. However, temporary visa status does not confer Medicare eligibility which would otherwise
cover the cost of antiretroviral treatment through the Pharmaceutical Benefits Scheme; and generic antiretroviral drugs (ARVs) are not available for prescription in Australia because of international trade restrictions (‘t hoen, 2009). Therefore, those in need must import from a limited range of generic formulations, usually first-line treatments from internet suppliers. The impact of an HIV diagnosis during health screening and/or outside one’s country of origin is therefore likely to add an extra dimension to the event of diagnosis; and the potential barrier to accessing ART is evident.

At the time of writing this thesis, there were approximately 83 HIV-infected individuals (about 10% of the WA HIV Cohort) on a range of temporary visas, ineligible to receive Medicare, who were attending the Royal Perth hospital (RPH) Immunology Outpatient Clinic (L. Williams et al., 2011). In order to establish the health care needs of these individuals and the wider implications for health care delivery, I sought to: (1) understand the impact of HIV on visa holders; and the broader implications that temporary resident status has for infected visa holders and their families; (2) describe the experiences and outcomes of ART in those without Medicare access and; (3) identify points of difference between those holding temporary visas and those subsequently granted residency. The methods used in this chapter are detailed in Chapter Two but a summary follows to assist the reader and render the Chapter more complete.

Specific Methods

Patients and setting

The study was conducted at RPH in Western Australia between April 2010 and October 2011. Patients were eligible for the study if they had HIV infection; and were, currently
or previously, ineligible for Medicare. This status was established by accessing the case notes of potential participants during their Outpatient Clinic visits. Patients were introduced to the researcher who explained the study and provided an information sheet. At this stage the researcher endeavoured to establish a rapport with participants to ensure that they understood the role of the researcher and felt confident that their private information would be protected. Written informed consent was obtained at a follow-up appointment. Twenty-two patients took part, three refused to participate.

**Semi-directed interviews with patients**

The interviews were conducted in English, which most patients spoke competently as a requirement attached to 457 and student visa status. Three Thai women had limited English but were able to communicate with the researcher when sufficient time was allotted. Two were accompanied by their English-speaking husbands and one had an interpreter present. Questions were largely open-ended and a schedule was developed based on broad themes which had emerged from our previous study (Chapter Three) and established cross-cultural approaches (Carrillo et al., 1999). Participants were encouraged to speak freely about issues important to them and the interviews were recorded and transcribed.

**Results**

A summary description of the sample can be found in Tables 15a and 15b. Semi-directed interviews were conducted with 22 consecutive participants (10 women) fulfilling the study criteria. Twelve interviewees were of East African ethnicity, from either Zimbabwe or Kenya, seven were of varying Asian ethnicities, two were from Oceania and one was European, ranging in age between 23 and 43 years (mean=30.3
years). Ten lived in the metropolitan area, fourteen were in paid employment, six were fly in fly out workers, four performed home duties and one was supported by another family member, and two were students. Five lived in regional areas and one was a ‘traveller’ with no fixed address. Twelve were currently ineligible for Medicare while two had interim access, three were New Zealand citizens and therefore eligible for Medicare; and five had transitioned to permanent residency. Of the sixteen married people, nine had hopes to increase the size of their families and—amongst the temporary visa holders—seven were in sero-discordant relationships. The median year of HIV diagnosis was 2007 and most had been exposed in their country of origin, except for two men infected by other men (clade B) in Australia. Eight patients infected overseas had clade C virus, one had the recombinant form AE and another clade D; the rest did not have results available.

A common reason for HIV testing was health screening for visa or on application for Permanent Residency. Seven had detectable virus, of these, four were treatment naive, one was not on current treatment, and two had been on ART less than four months and the virus was barely detectable (166-224 copies/mL). Co-morbidities were: tuberculosis (TB), hepatitis B, uterine fibroids, haemolytic anaemia, osteoporosis, and dyslipidaemia (each comorbid condition was found in 1 out of 22 patients). In addition, depression was diagnosed and treated in one patient, and self-reported in another. The patient being treated for TB was naive to ART and reported good adherence to treatment for his tuberculosis.

At the time of the study 19 patients had prior treatment with ART via compassionate access and/or generic formulation, including three women who had pregnancies managed with ART; 17 were on current treatment (range: 3-94 months, median = 19).
The average cost of imported generic ARVs was AUD$180/month. Two patients reported treatment interruptions of more than four days. Two patients with compassionate access to patented drugs experienced side effects in the early stage of treatment necessitating a treatment switch. Of the five patients not on treatment only one was likely to be eligible for interim Medicare cover. All 17 on current ART demonstrated high levels of adherence regardless of whether they were taking generics or not. Five patients reported never missing a dose, 4 people >3 months ago and 1 person <3 months ago). Where there was a threat of treatment interruption, clinic staff sought (successfully) compassionate access to meet the shortfall. Patients reported few side effects (5 out of 17 reported none, 11 out of 17 reported up to five and 1 out of 17 reported 10). The most usual side effects were fatigue, pruritus, dry skin and bad dreams. The most common drug combination was emtricitabine, tenofovir and efavirenz (9 out of 17 co-formulated as the generic Viraday.

All of the participants spoke fluent English, except for the Thai women, two of whom were interviewed in the company of their husbands who they frequently looked to for translation, although their partners could not speak Thai. Half of the sample had university or college education, and the other half had finished secondary school and/or vocational training. Computer access was common, and participants, particularly the men who owned computers, accessed HIV information from the internet. This was independent of hard copy material received from the clinic staff. However, one woman avoided HIV information and thinking about HIV altogether. This woman received support from her husband and his family in Australia. Three of the other women had only disclosed to their husbands, but no other family member. But a fourth received support from her husband’s family and was attending English lessons. Her language skills developed over several meetings she had with the author and
consequently, not all were attended by an interpreter. The women were provided with written information about HIV in Thai and were directed towards internet sites affiliated with recognised HIV/AIDS organisations.

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<th>Table 15 (a): Demographic characteristics of the participants (N=22)</th>
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<td><strong>Age (mean ± SD)</strong></td>
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<td><strong>Number (%)</strong></td>
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<td>Female/male</td>
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<tr>
<td>Living in a couple/family</td>
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<table>
<thead>
<tr>
<th>Self-reported HIV exposure</th>
<th></th>
<th>Self-reported location of HIV exposure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heterosexual</td>
<td>17 (77.2)</td>
<td>Country of origin</td>
</tr>
<tr>
<td>MSM</td>
<td>2 (9.0)</td>
<td>Australia</td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (9.0)</td>
<td>Abroad</td>
</tr>
<tr>
<td>IVDU</td>
<td>1 (4.5)</td>
<td></td>
</tr>
</tbody>
</table>

| Living/working in metro area | 10 | Visa Status | 457 long stay business visa | 7 (31.8) |
| Employment |  |  | Student | 3 (13.6) |
| Student |  |  | Student | 3 (13.6) |
| **FIFO worker** | 6 (27.2) | Spousal | 2 (9.0) |
| Full-time | 14 (63.3) | Other | 2 (9.0) |
| Unemployed or home duties | 4 (18.2) | Permanent resident | 5 (22.7) |
| **New Zealand citizen** | 3 (13.6) | |

*All East African ethnicity; **FIFO= fly in fly out

<table>
<thead>
<tr>
<th>Table 15 (b): Clinical and treatment characteristics of the participants (N=22)</th>
</tr>
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<tbody>
<tr>
<td><strong>Regimens</strong></td>
</tr>
<tr>
<td>FTC/TDF/EFV</td>
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<tr>
<td>FTC/TDF/NVP</td>
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<tr>
<td>FTC/TDF/LPV/RTV</td>
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<tr>
<td>3TC/AZT/RTV/ATV</td>
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<tr>
<td>3TC/AZT/ABC</td>
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<tr>
<td>3TC/AZT/NVP</td>
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<tr>
<td>3TC/ABC/NVP</td>
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<tr>
<td>3TC/ABC/RTV/LPV</td>
</tr>
<tr>
<td><strong>CD4 T cells/mm^3 (mean ± SD)</strong></td>
</tr>
<tr>
<td><strong>CD4 T cell (%)</strong></td>
</tr>
<tr>
<td><strong>Median CD4 T cell/mm^3</strong></td>
</tr>
<tr>
<td><strong>Viral Load‡</strong></td>
</tr>
</tbody>
</table>

Abbreviations: OD= once daily dosing, BD=twice daily; ART=antiretroviral treatment; 3TC=lamivudine, FTC=emtricitabine, TDF=tenofovir, ABC= abacavir, AZT=zidovudine, EFV=efavirenz, NVP=nevirapine, LPV=lopinavir, RTV=ritonavir, ATV =atazanavir; *Includes one patient on a spousal visa with interim access to Medicare: ‡= ≥40 copies/ml.
Results of Interviews

Impact of an HIV Diagnosis

HIV is currently ineradicable but treatable, with potent antiretroviral drugs. The analysis of interview transcripts focuses on the impact of HIV and ART on the physical, social and emotional situations of people who have experienced temporary visa status in Western Australia. Moderating influences perceived to be related to personal, situational and environmental characteristics are also presented. The sample was characterised by diversity driven by sociocultural influences including the social perception of HIV in the country of origin. Therefore, there were differences between the Thai interviewees and the Africans, the men and the women. However, there were also commonalities. Since most of the recorded interviews began with general questions about the circumstances predating HIV testing and the immediate aftermath; together with the participant’s reflection on HIV in their country of origin, the results are presented as a narrative reflecting the dynamic nature of the illness experience:

"It’s like I was prepared for it because I was sort of, ‘cause I’ve seen lots and lots of HIV positive people back home and I was displaying all the classic symptoms of being HIV positive so I was, in a way I was sort of, I had sort of prepared myself for it. But despite that you sort of get a shock out of that. Despite being a hundred percent sure that you are positive, still you get that shock."

(African man, NZ citizen)

HIV testing for married people is necessarily a family affair and the family’s future prospects may hang on the HIV serostatus of one member. Indication for testing was, for most interviewees, prior to applying for permanent residency or for a temporary visa. Four were diagnosed in their countries of origin and one while working in the
Middle East who according to the law of that country, had to leave within a month of the diagnosis or be deported. One patient concerned about chronic weight loss wanted to avoid an HIV test in Australia and returned to Africa for testing, citing his fear of the Australian Government’s 2007 position (Stafford, 2007) that argued for the most stringent possible conditions to prevent people with HIV emigrating to Australia:

...that’s when I said (to my wife) ok ...you know what? Maybe I should go. So we’re trying to think where should I go then? My worst fear was... if I do the test here we’ll be deported.

This interviewee received a diagnosis of AIDS in Africa; commenced ART purchased by a family member there and returned to Australia. Generally, interviewees diagnosed outside Australia received their results by telephone. However those diagnosed in Australia received them in person from medically qualified personnel at Medibank Health Solutions, a hospital-based specialist or a GP. In most cases, pre-and post-test discussion took place, although the quality and effectiveness of this discussion is not known. In the case of a diagnosis made by the doctor at Medibank Health Solutions, new diagnosed people were referred to RPH and seen as soon as possible, usually in less than two weeks but mostly within days after diagnosis —by either experienced nursing staff or the staff immunologist. These staff provided post-test counselling and immediate support to alleviate distress and initiate HIV/AIDS education. One woman was glad she had been tested:

I think so it’s good to be tested. Before I used to think no, getting tested, knowing that you are HIV positive not a good thing. I would rather not know and just die without knowing. But I think knowing is a little bit better, at least the disease you can manage it with the medication.

(African woman, 457 visa)
However, health screening for immigration or temporary visas in the country of origin can result in inadvertent disclosure to families and friends of applicants who fail the assessment. One African woman said of her 457 visa application process:

*That’s a requirement that all these countries want for us before we get visas, that has to be checked and it doesn’t come out clearly that you’ll be allowed to come, you know you’ll be stopped so all the time you always think this is, I’m already being told if you’re HIV you’re not coming to Australia. That’s how it looks... So it’s just a first barrier that you have to protect your [country] but yeah still it pushes you back and you think twice, you feel discriminated at that time, at that level you feel discriminated. But coming in I noticed they really don’t, they’re just trying to do what’s best for their country.*

Fear of imminent death was described by most participants regardless of cultural background: “I didn’t cry I was just so scared, it was just so hot, everything was hot, I was feeling tight, like I’m in this tight place. I’m going to... oh die you know”? (African woman, diagnosed with HIV in Africa). This fearful response was nuanced by the perception of HIV and personal experience of death in the participants’ country of origin:

*...there was a time when you would get into your bus —you can really see that when you actually get into the AIDS thing people start getting slim and their hair, you can really see that someone is sick*

(African man, 457 visa, diagnosed in Africa)

And there are immediate implications for partners:

*...it was mainly the stress that was, I think, the biggest thing when I first found out because I mean we’re discordant my wife and I. I think my first, if anything, my first fear was that oh ...I think my wife, oh damn I think I’ve given her (HIV).*

(African Man, 457 visa, diagnosed in Africa)
Although diagnosis of HIV led to testing of partners and children this was not always the case: “She’s gone through a lot, yeah... she’s lost three members of her family through HIV so she’s not prepared to have a test.” (African Man, NZ residency, diagnosed in NZ). One interviewee whose wife is also positive had not tested their children despite his NZ residency providing him with a degree of security from deportation: ‘...from experience the children would be very sick. [Now] I’ve got to have them tested because I want to apply for Australian residence so it’s part of their application to process.’ Two men delayed testing for fear of a positive result while others, once diagnosed, were keen to avoid treatment until it was absolutely necessary.

**Disclosure of HIV Status: “Is she black?”**

Recruitment for this study was challenging. People on temporary visas wanted to confine the number of people who knew of their HIV serostatus to a minimum of those who needed to know; and the nursing staff were keen to ensure that patients did not doubt the nurses’ commitment to protecting the patients’ privacy. Patients approached by the clinic nurse and offered participation in the study were also concerned about the cultural background of the researcher. “Is she black?” asked one man who was keen to avoid anyone in his East African friendship group from knowing his serostatus. There was also concern about how information gained from the interviews would be used, and whether the researcher was a trustworthy person. Significantly, some interviewees believed that when they engaged with the health system, even to participate in research, it meant that they became a ‘burden’ to the Australian Community and that this could affect the outcome of their visa application: ‘nothing is confidential’ (African Man, 457 visa). One patient used participation in the
research to his advantage and framed it as a ‘contribution’ to the community. A letter was prepared that he could use to advocate this stance to the Department of Immigration and Citizenship. This idea of being ‘a burden’ extended itself to treatment, so that people felt that as long as they did not need ART they were less burdensome, despite the fact that in the eventuality of needing treatment they would need to import generic ART at their own expense. The fear of disclosure of serostatus also stemmed from the perception of being considered contagious:

...they write on the clause of the immigration document to say this person is a potential danger to the Australian community and society ...So when such words are mentioned you get even scared of going to the hospital or to any public centre and it says to go into a public place and it mentions school or college and probably maybe hospitals but those are public places you know so what I just thought is I’m only coming here because they are the ones who referred me to come here otherwise given a chance with the letters which I’ve got from the Department of Immigration and what they say about my condition, going to any public place should be a no go area to me.

(African man 457 visa)

The process of disclosure was, in general, universally stressful, although the patterns varied. Six had disclosed to parents or siblings, fourteen had either not disclosed or only disclosed to their partners; and two of the women married to Australian men received emotional and social support from their husbands’ families while their own were unaware on their infection. One of the gay men had also not told his parents about his sexual orientation. A number chose not to disclose because they did not want to make others sad; this attitude was common among women, particularly the Thai women: “I don’t want to her be worried you know and she, I think she going to get worried and tell me to go back to Thailand” and in reference to one’s child:
I don’t want his to know anything about me but I just let him know a little bit like mummy not healthy, mummy not healthy person, one day I will sick, one day I will gone by then or you have to help yourself and I don’t want to carry, for him to carry me around thing.

(Thai woman, Permanent Resident)

In contrast, the European forced to leave employment in the Middle Eastern country, returned home to receive social support from family and access to ‘first world’ treatment. However, very few participants had disclosed to friends. One man, who often sat with his fellows from ‘Zim’ (an affectionate abbreviation for his country) and discussed all of the issues relating to their life in Australia, will not discuss his serostatus with them despite living with the infection for years in Africa.

However, in contrast with his countrymen, another man explains his view:

What I’ve discovered if you test HIV positive there’s a period where you sort of, you are lost and it’s very important that you have somebody to talk to, to share with. It’s sort of takes the weight off you to the person that you have told.

(African Man NZ citizen)

Inadvertent disclosure by health professionals is a constant and real concern as was described by a FIFO worker in the previous chapter. He described a situation whereby a hospital doctor disclosed to his company’s doctor: “I thought I’m not going to make my job just because someone has divulged that information, I didn’t have any peace of mind.” In general there is respect for the qualifications of health professionals as educated people trained to protect privacy, in comparison with others in official positions. For example:

You firstly are disclosing to the receptionist. And then you go and disclose to the dentist. I feel receptionists are not medical people. They are not trained to keep my information secret.
Most people find the hospital clinic to be a safe haven where a small and trusted number of people know that they are HIV seropositive and are seen to actively protect their privacy. However, fear of disclosure can get in the way of gaining access to information and patients rely heavily on a few hospital staff to guide them to appropriate services and provide information on a wide range of subjects without divulging their HIV serostatus.

Fear of Transmitting HIV

Fear of transmitting the virus was common and most acute around children: “I was afraid to breathe near my children” (African man, 457 visa). One woman began to avoid association with children: “...before I not get sick, I have a lot of kid(s) too, like to come to play with me and then I know I get sick I don’t want to play with them I’m scared them gets HIV from me...”(Thai woman, spousal visa now PR). Some avoided sex altogether at first. One woman working in the health sector put it this way: “I’m always living in fright in Australia...I’m just afraid maybe if I accidentally infect someone.” Others were pragmatic citing that their knowledge of HIV transmission made them aware of what practices to avoid. This appeared to be easier for married men: “You know when you’re married that’s such a relief, you know that your wife knows you know, you know you just have to concentrate on you know using your protection and that’s it.” Cuts and blood spills provoked the most anxiety and this was not moderated in any way by HIV education. It is unclear why the fear and sense of contagion was so strong in some participants but these findings reflect those of the PROQOL-HIV study in Chapter Three.
Physical Impact of HIV

The prevailing attitude concerning the physical impact of HIV could be best expressed by the following statement: “I’m not sick or anything, I’m fit for work that’s all they need” (articulated by one FIFO worker on a temporary visa). Indeed, at the time of interview all participants were physically active and/or employed, including two participants with severe immunodeficiency. Many expressed frustration recalling the situation in their country of origin—most commonly Zimbabwe—that if one was walking about then one was well enough to work: “Back home they say ‘look you’re walking aren’t you, OK so you’ve got the job just do your work OK’” (African man, 457 visa). All of the women in the sample, except one, were either working or caring for children. Some patients had concerns about their weight which they seemed to see as a reflection of their overall health, perhaps influenced by their observation of HIV in others and their understanding of the importance of nutrition in the management of HIV:

    So it’s basically, you have to say if you want to have a strong immune system what do you do. You’ve got to eat a lot of foods with a lot of vitamin C and you’ve got to eat a lot of fruit, a lot of vegetables, green leafy vegetables. You’ve got to eat proteins and stuff like that.

    (African man, 457 visa)

Interviewees tended not to take common supplements like fish oil and appreciated the nutritional value of fresh food, although one man noted that ‘everybody’ in Zimbabwe takes ‘vitamins’.
Complementary Medicine and Use of Substances

None of the patients were currently using herbal or complementary medicine, although most had been exposed to it in their countries of origin. One woman explained the use of herbs to treat conditions in Oceania:

...but I wouldn’t trust it for the HIV thing but apart from that I’ll say I’ll trust it for malaria or typhoid because it’s so normal over there...You know it’s been practiced for generations and people know it but HIV I wouldn’t believe it if they say they have a herbal medicine for that.

The African participants who considered themselves educated, spurned the idea of effective herbal remedies for HIV, which were commonly used in Africa, but thought highly of the supportive capacity of good nutrition. Healthy lifestyles were also esteemed in the sample. There was only one who smoked and no one was currently using recreational drugs. Only one participant from South-East Asia had a history of IDU. Heavy and/or episodic drinking was uncommon but reported by a couple of the men and two Thai women, however abstinence was more usual.

Treatment and Side Effects

Most patients held firm beliefs concerning the efficacy of the treatment and their ability to adhere. “The moment that I knew I was HIV positive it was in my mind that if I get something to help me I would adhere to that, I would stick to that” (African man, student visa). There was no apparent resentment about purchasing generic drugs although financial hardship was evident for those with families in their country of origin:

I have to look after the kids, their school fees and their aunty, it’s a bit of a challenge...for the meantime I’m coping since I’ve got a job here and my wife is always assisting me with looking after the kids.
It is also necessary for all temporary visa holders to take out private health insurance. Most of those taking generic drugs expressed frustration that they could not achieve residency by declaring intent to continue purchasing ART and thereby avoid the perceived cost to the Australian community. Once a decision had been made to begin treatment and a prescription prepared, the patients were instructed on how to purchase generic drugs from internet providers. Access for most patients seemed relatively unfettered and potential shortfalls in treatment due to hold-ups by the Australian Customs and Quarantine Service, which are quite common, and delay in postage are minimised by the comprehensive instruction received from nursing staff prior to starting ART:

*Yeah you can always look around for the prices and they’ve got all the set prices and you look for the cheapest and you just go. Ever since I started here I have been buying from one pharmacy. As soon as you order them they will send them to you and maybe two weeks you’ll get it.*

(African man, 457 visa)

One patient said: “*The concern I got the website who is selling it, it’s been four company or three company been changing around. ‘Cause before it’s cheaper and I order them and all of a sudden it stop.”* The first time this happened it was twelve days before the supply arrived and in this period nursing staff sourced an alternative supply. Another patient on medication since 2006 said that he had accessed three or four different sites which had subsequently closed without notice resulting in treatment interruption. In this instance he sought help from an HIV/AIDS service in Sydney to fill the gap until the generic supply was re-established. In another instance, when he moved to Perth, he ran out of ART and could not get an appointment to see a doctor.
for some weeks. Again the same Sydney-based service sent ARVs to Perth. This participant, whose family member purchases and posts drugs from within Zimbabwe, was constrained by supply but also hyperinflation in the economy of that country:

So because of that you know... the prices go up every day including the meds so everything, literally everything would go up every day. So even the companies like they would tell you this quote is valid for the next seven hours.

(African Man, 457 visa)

For a small number of participants presenting with severe immune deficiency or during pregnancy, a request for compassionate access was sought from the hospital’s clinical director, after which patients moved onto generic supplies. One participant said “I’m really not the sort of person who likes to sort of feed, like leech you know off something like that... like there’s a system, but if you abuse the system then it’s not good” (Asian man, student visa). One patient’s husband purchased medication full price from the hospital pharmacy amounting to $1000 AUD/month rather than have his wife run the risk of treatment interruption which, he understood, was important:

I just didn’t want any hold ups. I wanted to make sure she had them every day. I didn’t want to be sitting on the letterbox waiting for the tablets to arrive and she run out. I didn’t want that to happen. They told me I can buy cheaper but I said as long as I’ve got the money to pay for them I don’t care.

(Husband of temporary visa holder)

There were few reported minor side effects and concern was expressed by those who had experienced severe side effects. One woman was hospitalised following separate hypersensitivities to nevirapine and cotrimoxazole and another experienced rash and abnormal liver function while on nevirapine and subsequently efavirenz. These side effects to the commonly used generic drugs presented obstacles since alternatives (generic) are few and generally more expensive when they are available. The first
woman went onto a compassionate supply and the second stopped treatment altogether and returned to her country of origin. During pregnancy, taking ART is not always straightforward: “I like it much more better (now) because when I was pregnant they put me to another medicine and it was, I was too much vomiting and all this so I switched again so now I’m feeling very happy with this medicine.” (Oceania woman, 461 visa).

A number described having vivid dreams as the only side effect of the three drug combination (lamivudine, tenofovir and efavirenz) known as Viraday or Atripla. One patient describes violent nightmares: “Oh let’s say in a week I’ll say two to three times in a night and just very long ones and very scary ones”, from which she wakes screaming (Oceania woman, 461 visa). Another views them positively: “Sometimes they’re a bit emotional then I find myself that I’ve cried, you wake up and you’ve wet cheeks but it’s nothing negative it’s all like really happy tears...” (European, PR). A third young woman on generic drugs described the dreams and confusion as occurring only during early treatment: “Like I would feel dizzy, oh I would feel dizzy, I couldn’t even eat. Oh the dizziness was so bad and I was nauseous... I mean otherwise bad dreams and confusion it was only when I first started taking the medication.” Dizziness and mood changes were described by the young men also and a common anecdote concerning Atripla vs Viraday emerged during the interview with another young man on generic ART:

Atripla had the side effect of a bit of a weird taste in the mouth, in the back and oh you would just feel so dizzy. I don’t know if dizzy’s the right word, basically your head going round and it would last for probably half an hour to an hour... But Viraday on the other hand which I’ve become a great fan of does not give that side effect at all. There’s not a hint of it.... So there have been no side
effects with Viraday at all which I find weird because this is basically the generic brand of Atripla.

(Assian man, student visa)

Only one of the two patients on a lopinavir/ritonavir combination complained of diarrhoea and problems with night sweats and weight loss – this man was in the early phase of treatment and severely immunosuppressed. Otherwise fatigue and skin problems were the only other complaints. More commonly the patients expressed themselves in terms of feeling fortunate, such as in the following statement:

I’m very blessed and lucky, not lucky blessed because I don’t come up with any issues at all. I’ve got no side effects, no nothing whatsoever and it’s sort of one tablet a day, I’m just doing it perfectly fine

(African man, PR)

However, participants naive to ART were apprehensive, possibly because they have not yet received the medication counselling and education which is commenced closer to starting drug treatment.

Adherence to Antiretroviral Drugs

All of the interviewees on treatment were highly motivated to take ART and this was evidenced by the high affirmative frequency to the questions: (1) How sure are you that that you will be able to take all of your medication as directed?; and (2) How sure are you that your body will become resistant to the medication if not taken as directed?

Self-reported adherence over the last 30 days was excellent across all participants: “I just have to take my tablets to keep me going really. It’s like a fuel, how you never forget to fill up your car with fuel, same as me, something which I know that I have to
do” (African woman, NZ citizen). There was also motivation to adhere to avoid drug resistance:

[If] I have to start using the other medications which going to be even more difficult because the price and also the number of the drugs you need to takes going to be completely different.

(African man, student visa)

Some feel they have to overcome some barriers to get their ART.

I think at the end of the day sometimes I think as a patient you do want your meds, you know you do need them. You know [emphasis] and you have to go through so much red tape just to get them.

(African Man, 457 visa)

One participant had started ARVs (lamivudine, stavudine and nevirapine), in Zimbabwe in 2006. He had taken these continuously for two years until his supply ran out three months after arriving in Australia to work as a FIFO worker for the mining industry. He attended a GP and was referred to the RPH clinic and given compassionate access to one month’s supply of ARVs to cover the period until a generic supply was established. This gap represented a six week treatment interruption. Six months later, testing showed NNRTI resistance and his therapy was subsequently switched to another generic combination. He responded well to this treatment with excellent adherence and no complaints of side effects. This man takes a pragmatic view of his illness and has pride in his ability to manage his medication despite the potential difficulty posed by shift work. He also keeps up to date with HIV information on the internet as do a number of the other participants.

Most participants felt they needed to hide their medication and either rebottled their ART or kept it out of sight. One man, for example, kept his in his car. Motivation to
take treatment and social support overcame some potential threats to medication adherence posed by ‘situation’. For example, one interviewee with a new baby said:

But just when I had bubs I, my whole attention was him and I’d fall asleep tired and I’d think, just three or four times I kind of forgot. But J, before I sleep J always reminds me, have you taken your medicine?

(Oceania woman, 461 visa)

This same woman expressed great confidence in ART: “So it’s only one little bottle and that’s it. It’s pretty good—it’s amazing how this one little tablet can do so much for you.” Three of the ART naive interviewees demonstrated some misgivings about the efficacy of ART. As one man explained:

...because back home in Zimbabwe we’ve had people with HIV, some of them they have even gone to take antiretrovirals’ but what we have noticed across the board of many people who’ve been taking HIV antiretroviral drugs, instead of them getting better they’ve been getting worse. So I don’t know whether it’s because it’s in Zimbabwe or it happens across the board, I really don’t know, it’s not something I’ve experienced so I cannot conclude and say it’s going to help, it’s not going to help, I’m blank with it. So that’s my position with that.

(African man, 457 visa)

A Thai woman contemplating starting ART said: “The scary thing is I think when got somebody got very sick yeah, that scared me. Yeah like I can see when somebody got very sick they very like skinny and weak.” Other women believed the medication would stop working as they thought it inevitable that they would die of AIDS eventually, despite ART. Some patients were concerned about the long term side effects of ART and hoped one day not to continue taking it.
Returning to Country of Origin

Fear of returning to country of origin was expressed by all but two of the participants on temporary visas. After the interviews, two participants returned to their countries because their temporary visas were not renewed. One returned to Africa reluctantly; she had not disclosed her HIV serostatus to her family and had concerns about access to appropriate ART. She had been switched off first-line treatment in Australia due to toxicity and would probably need close supervision and dose/drug adjustments. She said: “So yeah it depends on how react to the medicine but after the two trials here I know I’m very sensitive to the medicine so it’s scary” (African woman, 457 visa). She was not, however, prepared to risk refusal and the waste of the application fee in applying for residency. The main fear of participants’ concerned access to treatment, regardless of their country of origin:

*I will not survive. It’s really hard over there... it’s really complicated I think to get the medicine in, you need a lot of money for that, like way a lot of money. Cause people trying to rip you off and yeah and then it’s, yeah it’s harder, not every city got it and I’m not from a big city as well...that’s why my cousin pass away ’cause he can’t get access to medicine and then the pay we get over there... the wages over there for months is very (low), you know for one month medicine*

(South-East Asian man, bridging visa)

Participants’ awareness of treatment access in their countries of origin varied widely and —at least in Africa—probably reflected the patchy coverage of AIDS treatment programs. A number of interviewees cited corruption and poor standards of confidentiality as threatening uninterrupted access to generic ART: “Yeah it does worry me because if anybody gets that disease in Zimbabwe then the only way for them is to die because there is no medication for that in Zimbabwe” (African man, 457 visa). Two patients were relatively unconcerned about returning to their country of origin but
needed to support their wives who were keen to stay in Australia. One of these had experience of unfettered access to ART in Zimbabwe in the region in which he worked and was sanguine about return stating: “But now with this introduction of ARVs you can really hardly tell now ‘cause everyone is getting normal” (African man, 457 visa). He felt supported by his sense of intrinsic worth with regard to being fit to work and had also improved his work related skills while in Australia. Another interviewee, whose HIV-infected spouse remains in Zimbabwe along with their son, cited that ART was readily available from the local hospital.

**Relationships and Support**

Sero-discordancy was common in this study (13/22 participants) so that the diagnosis had implications for the relationships of the interviewees in a number of ways, and not merely for future intimacy and child bearing. This creates tensions within relationships: ‘[We] both felt like we killed each other and I told him killing each other would not take it away so it, either we continue the relationship or we just break apart’ (African woman, 457 visa). However, supportive partnerships were common, and their reactions also helped to consolidate adjustment to the diagnosis:

I felt like the world was coming down on me and I told her to, I got to a point where I told her to move on with her life, I’m helpless you know and she tell me, no she really give me a lot of support and she told me that’s not the way to go about it and she showed me so many things

(African man, now resident)

Others have not yet adjusted. One man has yet to tell his wife who lives in another country, as do his children. In two other couples, the wives were fearful to be tested. Sero-discordancy also complicates visa applications for couples and families creating ‘visa-discordance’ where ‘ineligibility’ lies with only one member. This in turn appears
to place stresses on the marriage and wider family relationships. Conversely the support received from families in general was a powerful moderator of HIV-related adversity. Two of the young women married to Australian men spoke of the broad range of support received from their husband’s families, including support for their residency and acceptance of their HIV serostatus. A number of interviewees cited a supportive family member in their home countries and many were comforted by their religious beliefs: “Yeah that keeps me going really. Yeah I trust that He will look after me” (African woman, NZ citizen), while recognising the (Christian) Church’s position that promiscuity is immoral. This led one participant to say: “No it’s like in, in religion they tend to sort of associate HIV with being immoral...Yes, yes they are judgmental” (African man, NZ citizen). The role of Buddhism in the lives of the Thai participants was less clear although the Temple seemed to provide a meeting place for some women both in Perth and in Thailand: “…but I still look after young children, the little children at the temple for the old people at the temple but they don’t know what happened to me.” And there is the role of karma and prayer:

Yeah more, more because they can’t afford to buy the medicine [for HIV] but I think now the way they can fix by themselves they just think their luck or their bad luck but we are so pleased like we are Buddhist and we can pray.

An African man stated in the interview:

I don’t know if it’s Christianity or but it carries you to do good things, yeah I would say the right things. It might not be existing or whatever but it somehow carries you to do things that are human and that are right that does not offend the next person...

**People With and/or Wanting to Have Children**

The impact of HIV on people with children and those who would like to have children was considerable: “Concern is always there. Am I going to be able to have a partner or
have kids like normal” (South-East Asian man, bridging visa). In addition to this stress was the fear of passing on the infection, during conception and childbirth and unwittingly by some unknown (as yet) mechanism: “I’m concerned about is that probably the way we are told that it only is transmitted is not the way we get it…” (African man, 457 visa). One interviewee, naive to ART, fervently believed she would die young and just wanted to see her children become independent: “I don’t want to be sick, sick and then they have to get sick and sick to the end I really don’t want that” (African woman, spousal visa). A number were concerned about how they would tell their children and how that would affect their relationship: “…especially when they are young like this and I would want them to find it out from me and they are too young for them to handle something like that” (African woman, NZ citizen). Others were concerned about financial support for their children since their own ability to apply successfully for personal insurance may be affected by their HIV status.

**Outpatient Care: Social Support**

Like many Australian residents living with HIV, people on temporary visas and those that have transitioned to permanent residency are characterised by their wish to minimise the number of people who are aware of their HIV serostatus. Often there is no one outside the hospital system who knows that they are HIV seropositive. This can place enormous stress on people, although others adjust and are comfortable with this ‘duality’. In addition temporary visa holders are sometimes reluctant to access hospital services beyond those absolutely necessary. The two key roles are the clinic nurse and the clinic doctor. Participants in this sample respected and relied on these positions to fulfil a number of ongoing functions, not only to monitoring their HIV and negotiating visa renewals and applications to support Health Waivers. Participants spoke about
being able to ‘be themselves’ and were greatly appreciative of the social support they received and access to the service: “It was wonderful, you can’t ask for anything more than that” (African man, NZ citizen). The stress of visa application described by one African interviewee was moderated by her clinic experience:

Being here, getting my visa made me know that it’s possible to still come in but you still, you have to be strong hearted to keep on fighting but how many is strong hearted to keep on jumping the hurdles? So it’s possible to come in and they treat you right, Australia treated me right and I’m not saying it just because I’m being recorded. I felt easy to talk and even allowing you [the researcher] to come and talk to me it was easy and I’ve talked to [the nurse] about this, I’ve cried in [her] office and we’ve talked you know and laughed a lot and you feel human again.

For those diagnosed during screening for Permanent Residency status in WA by Medibank Health Solutions, the unit responsible for immigration health screening, the experience of diagnosis was tempered by close liaison between clinic staff and the unit. This is because once a diagnosis of HIV is made by the doctor the person is referred promptly to the RPH service. The nurse is therefore able to offer post test discussion and implement HIV support and education before the patient is seen by the hospital doctor. A typical experience is described here:

I think it happened in one day when I phoned the Health Services Australia and the doctor called one of the nurses and then the nurses said to me you can come and see me any time. So I went to see her and then she organised for my blood to be taken again and fresh tests and diagnosis to be done and then they did it and I was still told that I’m HIV positive. So that’s how it went, it wasn’t, it didn’t take long, it was, it happened in a few days.

Others described experiences akin to emotional rescue after receiving their diagnosis.

One African man who now has residency said:
Since I started this medication and I learnt more about it and I know there is more research being done about it I’m quite positive and just the way the first times I came and I saw the doctors and they told me: ‘look you need not to worry about anything. You can live up to 70, 80 using the right medication. That changed my whole, my whole life and the way I looked at it. Since that time I’ve never stopped to wonder will I be here tomorrow or the day after because I know with the right medication I’ll just, I’ll be fine

(African Man, PR)

Employment

A diagnosis of HIV has immediate implications for temporary visa holders since it is not possible for them to meet the Health Requirement necessary for successful application for permanent residency and it complicates renewal of a temporary visa. Seven of the interviewees were on 457 work visas. Once someone on a temporary work visa knows that they are HIV-serostatus positive they must, by law, disclose their serostatus in the event that they apply for a new visa. Should the company go on to sponsor the applicant, a situation leading to the applicant feeling bound to that company can arise: “the truth is at the moment I’m locked with this company almost for life” (African man, 457). This leads to a common perception that either a visa will not be renewed or that employment will not be continued. The same man explains his frustration:

I applied for another job with another company and the Department of Immigration told me to go and have HIV test and they demanded $40,000 from that company for them to grant me the 457 visa, which the company said we can’t do that but that was a better paying job so my source of income is highly, it’s [HIV] holding me up.

A common problem for temporary visa holders with HIV is that they find it difficult to access advice since to do so may require them to disclose their status. This seems to extend itself to the number of people who ‘know’ about them. In Western Australia
people may use migration agents, but may also (or instead) seek pro bono advice from the HIV legal centre in Sydney as there is not an equivalent organisation in WA. They fear and have experienced discrimination, and many feel shame; stigma is a nuanced and multidimensional phenomenon. For those that go onto a bridging visa, the conditions attached to that visa are dependent on the subcategory assigned to it and some may not be allowed to work. One man in this study, a young able-bodied person, had not worked for some years and was being supported by a family member with residency.

Three of the Medicare ineligible interviewees were diagnosed in their country of origin during screening for work visas which, to their surprise, were granted. They were subsequently confused about whether it was necessary to later disclose their HIV serostatus and they said this caused them some anxiety. One interviewee already in Australia suspected that he could be seropositive and flew back to his country of origin for testing because he was fearful of the consequences of testing HIV seropositive in Australia.

**The workplace**

Interviewees commented on the perceived necessity of keeping their HIV status a secret from their colleagues and employers to avoid stigma on a personal level and discrimination on a professional level: “I haven’t talked to anyone in the company about these things. Yeah and I’m, I don’t want to talk to them” (Oceania man, 457 visa). In the health sector, in Australia, it is mandatory to have an HIV test; two of the study participants worked in this area. Their supervisors were aware of their status, and the interviewees were fearful of a break in confidentiality. This was also a problem for an HIV seronegative spouse working in the health sector when a curious workmate
asked uncomfortable questions. Breaches in confidentiality have occurred and although the outcome is not always detrimental, the breach nonetheless results in emotional distress. Workers in the FIFO sector find it stressful when they are subjected to random drug testing. This has led to a change in prescribing practices away from efavirenz so that workers can keep their HIV status confidential. Most of the interviewees are acutely aware of the likelihood of workplace injury and, driven by their common, acute fear of transmitting the infection, welcome the stringent universal Occupational Health and Safety precautions implemented by the mining companies. These precautions serve to moderate anxiety related to transmission fears in the infected person and serve to protect others without the infection:

Yeah but nearly everybody is trained to do with injuries and everybody is following the procedures, even if I get injured and blood comes out of me you’re not supposed to be getting infected from that because there is a medical kit, they have gloves in there, you need to just take your gloves put them on. So even if I’m getting injured, if I see someone treating me without gloves I will soon be telling him to put on his gloves

(African man, NZ resident)

Accommodation on the mine sites assures them of privacy to store their medication, while private accommodation combined with an internet connection, allows them to access information about HIV readily and confidentially: “yeah internet I would say that’s where I get most of the information” (African man, 457 visa). Another advantage of working in this situation is that on their weeks off they need not miss work to attend hospital appointments— a common source of stress for other PLWH.
Culture: Anonymity and Visibility

The African interviewees in particular viewed themselves as protected by a degree of anonymity because they were separated from their extended family networks, however in general they felt that their skin colour made them visible in the small sea of white faces in the clinic waiting room “...definitely it’s a worry that people would be so ignorant to think that everyone from Africa has got HIV or everyone from Africa is poor”, said one man. Another man talked of how his homeland was regularly associated with crime. Although the personal attention received from clinic staff was appreciated, anonymity in the waiting room is desired. For example, one participant prefers to be referred to by number and not name, believing that this better protects his privacy. The Thai women also ‘noticed’ each other in the waiting room through their recognition of shared phenotypic ancestry. The differences in cultural norms between Australia and PNG were articulated by one interviewee who, in response to a question concerning the stigma attached to HIV said: “Yes, back in the traditional villages yeah, people talk bad things about you. Like you know, don’t want to be near you or talk to you or things like that.” In contrast with Australia, which offers anonymity and something more, or less: “Here it’s ok, nobody like really talks about you or cares about each other. Like they don’t talk about people and yeah I think its ok in Australia. It’s different to PNG.” This sentiment was expressed similarly by an African woman:

...I’ll go to the hospital and I’m comfortable just because I know not so many people know me here and yeah will talk open. They’ll ask me a question i can tell even over the counter because I know the next person here doesn’t know me.
Other interviewees prefer to mix outside their ethnic groups, while one man prefers the company of other Africans to his Zimbabwean countrymen, whom he referred to as ‘cliquey’. In Thailand the stigma extends to the attitude of health workers:

... if somebody know I got HIV and they try to like isolate from them. I don’t know even doctor and nurses, I feel like they not, they not really sincere or really happy to deal with them.

In contrast with the non-judgmental care received by this Thai woman in several health facilities in Australia: “I feel like that but in Australia they like, they do (treat) like really normal like other people you know.” The marked difference in the sample was the European living in rural WA who comments:

So that really is one thing that disturbs me and I think in this point Australia is a little bit backwards and I think in [European country] it’s more, yeah it’s more proactive and people are more supportive and open about it [HIV]. Here it’s still very much stigmatised but that’s why I don’t tell anybody.

A difficulty negotiating cultural nuances can arise when couples need marital counselling. One man spoke at length about how, in his opinion, it was not possible to counsel ‘across racial lines.’ He recommended that counselling be provided by professionals of the same culture. He also commented that in Zimbabwe men often married women who are not as well educated as themselves and that this had implications for how they viewed HIV, for example: “…she has that image of people dying in Africa whereas I’d sort of done my homework, I’d done a lot of reading so I was in a better position than her.” Since a diagnosis of HIV infection can place pressure on relationships and complicate family dynamics the observation made by this man is relevant for service providers.

Some interviewees said that, in Africa, polygamy is practiced by some communities. A few participants discussed promiscuity as an ‘immoral’ behaviour which they did not
identify with themselves. One man thought that, in fact, Australian men were the more promiscuous, he made this comment:

*Here I have seen people they come to work, some work mates they tell you ‘I know I used to be in love with so and so, I’ve moved, I’m now with so’ and [so] if you look at them they’ve had maybe four or five partners and you really wonder.*

Promiscuity was frowned upon by both men and women from East Africa. A few participants observed that African society is less forgiving of a promiscuous woman. The opportunity to access casual sex is hindered by personal codes of behaviour and social mores. One man explained how things were in his society:

*Even if you look at the young people they, until probably around the age of about 19 or so your contact with the opposite sex is very minimal and you can only get in contact with the people of the opposite sex probably in your twenties because there is culture issues and stuff like that. So promiscuity level is a bit managed because there is a lot of cultural things involved and procedures given traditionally, [to] approach a girl or a woman for sex is hard. But of course you get like prostitutes in the streets, they are there, but not as much as probably, here you don’t see them in the streets but what you witness what happens across the partners...*

Another man talked of differences in how Africans spend their time socialising and the impact of a fly in fly out employment:

*For starters you don’t have a social life here. It’s like you are sort of living in a society that you cannot sort of fit into. How can I put it? It’s like the way we spend our free time in Africa is very different from the way Australians spend their free time. In Africa we’ve got a set up whereby you tend to visit your relatives most of the time. But here [we] don’t have any relatives and I don’t have anybody to visit except my friends and most of the time maybe they’re at mines or they’re at work so we tend to have different free times.*
Cultural attitudes towards work practices differ between Africa and Australia. This man comments upon the constraints placed upon work opportunities by, arguably, organisations designed to protect workers from harm:

That’s what I like about people back home, as long as you’re working it’s like oh so he can work, you know unlike here it’s like oh no you can’t, ok look you’ve got this condition, ‘oh look I am sorry you can’t get in’. Back home they say ‘look you’re walking aren’t you, ok so you’ve got the job just do your work ok’. Here they start looking at all these complications, [for example] what impact it will have with Work Safe.

Adaptation and the Future

Some interviewees appeared to adjust to HIV emotionally and pragmatically, demonstrating self efficacy which was apparently mediated to an extent by education, support received (primarily from partners and hospital workers) and the passage of time since diagnosis. The European was the only interviewee, besides one of the African men with NZ citizenship, who had disclosed to a friendship group, (albeit outside Australia) and explained in this way:

So I tried to find out as much as possible. Lucky there was, when I then was back home in Europe I had a very good clinic and very good doctors looking after me so I’ve been yeah I’ve read up a lot and talked to quite a few people and yeah learned to, learned to live with it now it’s doesn’t faze me at all to be really honest.

However, this person has indicated that they do not intend to disclose to anyone in their regional community. An African man also referred to the benefits of understanding the disease: “I know how to deal with my family, like my kids, my work mates, my family at home, how to protect them from any exposure which is hardly close to zero exposure... yeah everyone is safe from me.” Satisfaction with care seemed to give people a ‘lift’: 

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I’m getting used to it because I’ve got really good doctors in Perth and nurses and I call them and I have concerns and all that worries and it’s doing pretty good so right now I’m, all my virus level is undetectable so I’m happy.

The power of positive thinking crossed cultures: “I think it sort of as well your body works around it as well and you just tend just to grow stronger and better. So the main thing is acceptance I think and just keeping it very positive.” The word ‘positive’ was also used by the four Thai women, despite their limited English, in expressing how they try and view the future, knowing that they will have to continue with the infection.

However, some use different coping mechanisms. As one young African woman says:

But really I treat myself like I don’t have it. I don’t want to know, I know what I know, I know it’s bad and it’s going to be there like forever and I can’t treat it but really I don’t, I’m just I know I’ve got it but I treat myself like I don’t have it. I treat myself like normal, I don’t think about it, I don’t want to go and look about it yeah. So, even in my house when I got a letter like this I really want to throw it away I don’t keep it, it’s just me. I don’t want to look at those words and just see because it just reminds me about me.

The African man who believes in the value of disclosure now supports other family members adjust to the impact of HIV within the extended family: “It’s sort of takes the weight off you to the person that you have told.” But this ‘unburdening’ from one person to another was precisely what the Thai women were keen to avoid since they wanted to avoid causing others distress.

**Discussion**

This is the first study investigating the impact of HIV infection on people holding temporary visas in Western Australia. The data gathered in this study illustrates that for people seeking to work or reside in Australia, a positive HIV test has wide-ranging implications, including aspects that can dictate the futures of people affected and their
families. For those applying for long stay business visas, once diagnosis is established it must be declared on application for renewal of 457 visa status. Inability to meet the Requirement limits access to permanent residency which might have otherwise been met by other attributes or those of spouses. Furthermore, Medicare ineligibility precludes temporary visa holders from accessing subsidised patented ARVs as would Australian citizens. In this study, diagnosis made during visa screening in countries of origin also had implications for the interviewees since they feared being exposed as infected in their own communities, if the visa application was refused. It was also the case that interviewees thought refusal was automatic and were surprised to find that they were successfully issued with a visa to enter Australia.

Treatment with current antiretroviral drugs can prevent HIV transmission, disease progression and death from AIDS (Cohen et al., 2011; Cohen & Gay, 2010; Hogg et al., 1997; Palella et al., 1998). However, an individual must be highly adherent and ARVs must be taken continuously without interruption to prevent virological failure (Hogg et al., 2002; Parienti et al., 2008). The clinical imperative, therefore, is to ensure access to potent drugs and consistent and effective medical and psychological support. Despite many common findings, a contrast with that of Körner’s studies (2005; 2007a, 2007c) was that the temporary visa holders in this study who were diagnosed in Western Australia, engaged with the WA health system, in spite of their lack of citizens’ rights, via a simple chain of clinical care delivery from screening by Medibank Health Solutions (previously Health Services Australia) to Specialist Tertiary HIV Services. They were also able to negotiate access to patented or, more commonly, generic ARVs. The participants’ strong motivation to take ART and their efficacy in executing the regimen overcame two potential barriers to adherence firstly access to ART; and secondly an uninterrupted supply. Private health cover and Occupational Health and Safety
Regulations in places of employment also ensured access to general medical care. The immediate emotional impact of HIV was also moderated by the context in which the news was received. In contrast with the interviewees diagnosed in Africa and the Middle East, timely post-test discussion attenuated distress with reassurance and education. Eligibility for a Long Stay Business or Student visa means that recipients are—at the very least—educated at a secondary school level and have English language skills, although these skills may only apply to the Primary Visa holder and not to their spouses. Proficiency in English may increase a person’s capacity to act autonomously, access information and manage medication and may be another point of difference between temporary visa holders, asylum seekers and refugees. Drummond and colleagues study (2008) on HIV/AIDS knowledge and attitudes among West African immigrant and Australian-born women in Western Australia, showed that knowledge of HIV and HIV prevention was linked to education. Indeed health literacy and numeracy together with clinical protocols for adherence monitoring and counselling, may be a major factor underpinning the successful medication adherence and persistence seen in this group (Waldrop-Valverde et al., 2009). One participant reflected that in East Africa men often marry women of lower educational levels than their own. This may be an important factor to take into consideration when providing HIV and treatment education and adherence support to couples, particularly since some researchers have found medication management may be nuanced by gender (Waldrop-Valverde et al., 2009).

Interviewees also maintained high levels of medication adherence and virological control underpinned by adept management of potential treatment interruptions posed by the importation of generic ARVs. Successful health outcomes for those who were symptomatic at the time of diagnosis may serve as a motivator towards adherence.
Only one of the participants expressed concern that generic drugs might not be effective since he was not experiencing the same side effects that he had when taking a patented combination. This is in contrast with a recent study by Bulsara, McKenzie, Sanfilippo, Holman and Emory (2010) which found that Western Australians were suspicious of foreign generic manufacturers, and sceptical about generic drug bioequivalence. These views were echoed by the epidemiologist Andrew Grulich in an interview featured in the Weekend Australian in 2011 (Dayton, 2011). However, in this study, it was evident from the interviews and self-report questionnaires that ARVs were thought to be effective. From a clinical perspective, only one participant experienced virological failure on medication, and this was likely related to nevirapine resistance acquired or developed in Africa. Importantly, health screening picked up some infections before AIDS-defining illnesses became apparent and, since an estimated 40% of HIV is transmitted by those who are unaware of their status (Coates, Richter & Caceres, 2008), may have prevented inadvertent transmission. Lemoh and colleagues (2010) reported delayed diagnosis in half of the 20 African Australian participants of their study; and clinical and virological failure in seven and five respectively. Arguably in our setting, health screening identified asymptomatic HIV infection and prevented morbidity from delayed diagnosis seen by Lemoh and others (Burns et al., 2007).

However, unmasking HIV infection in non-Australian residents meant that the patients in this study were burdened with the very real threat to future health and longevity because their HIV serostatus could prejudice their applications for residency and necessitate return to their countries of origin where, despite the global scaling up of treatment availability, especially in Southern Africa, coverage remains patchy. In South East Asia and Africa, corruption, cost of drugs, low wages and local turmoil can result
in interrupted supply of ARVs (Posse et al., 2008). The participants in this study also pointed out that, even if they have access to drugs, these would be first-line treatments effective only for those with susceptible virus. Further, participants noted that should side effects occur then options would become limited. Some of the Africans were concerned about access to nutritional food which several cited as necessary for someone with HIV infection to maintain their good health.

Except for the one European, participants pointed out how important the psychosocial support they had received from clinic staff was for their current acceptance of the disease and noted that this would be lacking in their countries of origin. Indeed the small number of health care workers involved in their care could be said to represent a small island of support as, on arrival at the clinic, interviewees could be relieved of their secrecy. Other studies have highlighted the role of health care workers in highly stigmatized communities with HIV (Ruanjahn, Roberts & Monterosso, 2010). However, some of the participants were unsure about whether they would be viewed so compassionately by ‘ordinary’ Australians, their workmates, or people of similar ethnic backgrounds outside the health system. Given the current laws and public dialogue around visas and immigration their concerns are hard to dismiss (Stafford, 2007). These and other perceptions led them to exercise a high degree of vigilance around their need for confidentiality and made them reluctant to seek health services, such as dentistry, outside the immediate hospital environment from those who were not trained to protect confidentiality, such as receptionists. For those willing to proceed with residency applications there was a necessity to negotiate with the Department of Immigration and Citizenship and migration agents. Some participants also accessed pro bono assistance from the HIV/AIDS Legal Centre (HALC), a community legal centre in Sydney that specialises in HIV related legal matters.
In common with the participants of the studies in Chapters Three and Four, most of the participants in this group expressed a high level of anxiety relating to the fear of unwittingly transmitting HIV. For some this fear was out of proportion to the likelihood of the occurrence and did not seem to diminish over time. Although there are a number of studies that explore aspects of stigma, like non-disclosure, in relation to risky sexual behaviour (Adebowale, 2010; Bouhnik et al., 2008; Logie & Gadalla, 2009; Simbayi et al., 2007) the author could not locate any studies that described fear of transmitting HIV as a cofactor in depression—common in HIV (Bhatia et al., 2011; Valente, 2003) nor any studies of interventions to reduce transmission fears. The deeply rooted fears in some individuals may not be uncovered in the course of most consultations. This evidence suggests that the clinical encounter should include an assessment of ‘stigma-related limitations’ and further research is needed to reveal the nature of the issue and develop suitable interventions. When Goffman (1963), articulated stigma as a social construct, he described three manifestations of stigma assigned to deformity of the body including: (1) physical symptoms of disease; (2) taboo behaviours; and (3) racial and social ‘groups’ or tribes. For non-Australian residents with HIV infection the stigma attached to HIV with its associations of sex, death and country of origin, would likely be heightened, as some participants in this study feared.

The impact of HIV was moderated by other personal and situational characteristics of the participants and mediated in turn by ethnic background. Family ties were strongly evident in all the interviewees as demonstrated by the frequency of contact with families in country of origin. Despite this, most families were not aware of the interviewees’ HIV diagnosis. Five out of twenty-two participants only disclosed to selected members of their immediate families—not including their partners—apart
from the two women who disclosed to their Australian husbands’ families. The reasons for this appear to concur with Körner’s study (2007c) which refers to the collectivist attributes of non-Anglo-Celtic cultures that emphasize the interdependence of families, for example, the desire to avoid causing the family distress from the burden of illness and the association with ‘immoral’ behaviour. The interviewees with children also had to consider discussing their HIV status with the children as they grew older. Körner also speaks of the opportunity for gay men to access an ‘alternative’ community allowing them an identity free of family ties. This was evident in my study where two men, who identified themselves as gay, spoke of their friendship and support from Australian gay men, some of whom were HIV-positive. However, their disclosure issues were complicated by their families’ reactions to their sexuality, and the double stigma of being gay and HIV seropositive. The South-East Asian man infected through intravenous drug use, cited support from one parent and a sibling; and his greatest ‘disclosure concern’ was how to meet someone to marry. Although disclosure was an issue for all but one of the participants there were some differences as to how intensely people internalised their diagnosis and their sense of shame. A pragmatic attitude was evident among some, particularly the men who viewed themselves as fit and strong. They considered that they should be able to be ‘like normal’ as with medication they would remain well. They also derived confidence from a sense of knowing how to protect their wives by practicing safe sex. This may well have something to do personal characteristics associated with recovery from stressful events, resilience and coping which have been reported in survivors of difficult circumstances (Antonovsky, 1991; Bonnano, 2004). However the sample was also characterised by the strong support drawn by many from spiritual sources and life partners. Both of which have been shown to assist people in overcoming psychological
distress and adversity (Kohls, Sauer, Offenbacher & Giordano, 2011; Kremer & Ironson, 2009; Makoae et al., 2008; Tsevat, 2006).

**Limitations and conclusions**

The characteristics of the people in this study reflected the requirement of the visas that they hold. For example, the Business Long Stay and Student Visa holders were English-speaking and educated to at least secondary school level. The eligibility for Spousal Visas differs, and only two women held these. Therefore, the findings cannot be generalised to refugees or asylum seekers none of whom were recruited into this study. However, the interview material and triangulation with clinical outcome data provide sound observations. Furthermore, the sample reflects the expanding Western Australian epidemic in people born overseas and temporary visa holders from high prevalence regions; which represented ten percent of the HIV cohort at Royal Perth Hospital at the end of 2011. This situation has implications for service delivery across the state (The Kirby Institute, 2011). In particular, there has been a shift in the type of services and support that is required as a consequence of this epidemiological pattern, for example, there are increased issues around pregnancy and serodiscordancy. In addition to standard HIV care, temporary visa holders seek support for visa continuations and residency applications from outpatient services. Awareness over the perceived cost to the Australian community, which will have a bearing on their applications, appears to limit how and what health services are accessed. Running through the interviews there is a palpable sense of frustration; some feel that the situation is hopeless and give up trying to stay in Australia, while others persist with determination by accessing migration agents and pro bono legal advice. Access to generic first-line ARVs and specialist HIV clinical care in Western Australia is relatively
unfettered and results in good health outcomes but—coupled with the need to take out private health insurance—is expensive. The threat of treatment interruption and adverse health outcomes when people leave the service to return to countries of origin is a pressing concern for most participants; some patients fear for their lives. However, the challenge of applying for permanent residency may prove too daunting for some people who fear refusal, fiscal disadvantage and a repetition of ‘disclosure anxiety’. People with either Australian or New Zealand residency feel secure in their Medicare and there appears to be some evidence that this moderates disclosure and testing concerns. It also seems apparent that people may actively avoid those from their own ‘cultural’ communities because of confidentiality concerns, regardless of their residency status. Furthermore, high visibility as ‘foreigners’ heightens anxiety about potential discrimination from Australians outside the health system.
CHAPTER SIX

DISCUSSION
CHAPTER SIX       DISCUSSION

‘AIDS occupies such a large part of our awareness because of what it has been taken to represent. It seems the very model of all the catastrophes privileged populations feel await them.’

Susan Sontag (1988, p. 84)

Introduction

This final chapter presents a discussion of the major issues emerging from the preceding results and synthesises the primary observations. The research illustrates that while HIV infection has the potential to be a treatable chronic illness, the stigma attached to the condition is universal and operates within infected and non-infected individuals to shape how care and treatment are apportioned, accessed and delivered. Further, the data give clear evidence that even with universal access to the latest, tolerable and potent drug regimes, HIV-related impacts on individuals cannot be resolved through pharmacological treatments alone. Specifically, the data show that most participants accepted treatment, were motivated to adhere to ART, and overcame obstacles posed by access to achieve favourable physical health outcomes; even the few who, at some stage in the illness continuum, chose to stop or adapt their treatment regimes. Health care professionals working in the WA health system contributed to these outcomes by way of thoughtful and creative engagement with patients. They recognised the imperative to establish and maintain contact with patients; and overcome barriers to treatment, in order to increase the likelihood of continuous treatment with ARVs, which has been shown to be critical at an individual and population level (Cohen & Gay, 2010; Elinav et al., 2012; Gardner et al., 2011;
Giordano et al., 2011; Giordano, et al., 2007; Montaner et al., 2010; Rosenthal et al., 2011; M. A. Thompson, et al., 2012).

Despite these positive health outcomes by way of reduced morbidity, the pattern of stigma characterised by persistent fear of disclosing HIV serostatus and infecting others, was nuanced by the particular circumstances of individuals, in terms of visa status, or living and/or working in regional areas. In particular, HIV-positive serostatus affected, and frequently limited, social relationships, aspects of employment; and the likelihood of successful migration.

**Contribution to the field of HIV/AIDS**

The research offers a rich, contextual description of the current Western Australian HIV epidemic while acknowledging historical antecedents. The data are representative of resident Australians, international visitors and guest workers living in both metropolitan and regional areas. In addition, this project is positioned within the current framework of HIV care in the state of WA. While the PROQOL-HIV research is the largest HRQL study conducted in the state to date, the subsequent narratives of participants who find their circumstances complicated by their visa status and and/or living and working in rural areas, reveal new information and understandings about the current epidemic that is relevant on a number of levels. The inclusion of the perspectives of health care workers gained from wide consultation, give a depth of understanding such that the intersection between health care delivery and the patient/participant experience of that care is explicated. The work presented represents the most comprehensive picture of the impact of HIV in WA and the clinical outcomes of care to date. It builds on early clinical observational research conducted in our cohort (Gillieatt & Mallal, 2000; Gillieatt et al., 1992; Herrmann, et al., 2008,
2012; Mallal, 1998), the work of Newman et al. in Aboriginal PLWH (Bonar et al., 2004; Newman et al., 2007a, 2007b); and the survey work of Peter Drummond and his colleagues (Drummond et al., 2011, 2008); and complements the national findings of successive HIV Futures Surveys. While this study of temporary visa holders shares some common observations with Körner and Lemoh’s research (Körner, 2005, 2007a, 2007b; Lemoh, et al., 2010) in CALD communities and African Australians, respectively, it has a greater focus on Medicare ineligibility and how this affects access, adherence and attitudes to ART. It also highlights the lack of support for people who find themselves in the position of being diagnosed with HIV/AIDS; and how they can be isolated within their communities and feel threatened by their non-citizen status.

Further, as was alluded to in Chapter Two, the system of delivering HIV care in WA differs markedly from the other states and this changes the context of care. Another important contribution of this work is to add an understanding of how PLWH manage HIV in work situations, particularly FIFO occupations. In the light of the current recruitment of overseas workers, and a growing workforce engaged with the FIFO work arrangement, this research is of current relevance.

The study juxtaposes with Drummond and colleagues’ Perth-based survey concerning the knowledge of HIV and attitudes towards condom use in West African refugees; and a larger group of West Australian women matched, where possible, with the West African women for age and education (2008). Their findings suggested that HIV-focused educational programs directed at emerging immigrant communities should be customised to their needs and cultural sensitivities. From information shared with me by the migrant health worker at interview, and Professor Drummond himself (August, 2010), it would appear that this recommendation has been acted upon. They subsequently published details of a study (2011) which used West African peer
educators to conduct a workshop on sexual health with recently settled groups of
West African refugees. The authors found that the sexual health knowledge of
participants increased significantly as a consequence of the intervention. Notably, the
study was conducted in consultation with representatives of the West African
community and was funded through the WA Department of Health Blood Borne Virus
Program and Healthway. Both these studies, and the activities of the WA AIDS Council
in WA (to address issues arising from the emerging heterosexual epidemic in WA); and
AFAO and NAPWA nationally, to advocate for non-citizens, indicate a sector response
to changing conditions (AFAO, May 2011; NAPWA, 2009; Sergeant, 2009). However,
only one of the participants (East African and already eligible for Permanent
Residency) in my study said that he had participated in one of the WA-based education
sessions. Further, the data would suggest that the temporary visa holders are averse
to anyone from their countries of origin knowing their HIV status and they would take
steps to avoid situations that may result in a breach of their confidentiality. It may be
the case however, that temporary visa holders while not eligible to access government
funded services and networks available to migrants and refugees, may be members of
other communities, like churches, which may link them to others with whom they
identify socially or culturally, including education and supportive sources.

The PROQOL-HIV Study: Findings and Concordance with the
Subsequent Research

The PROQOL-HIV study presented in Chapter Three serves to explicate the West
Australian context and embed the subsequent research. In addition to fulfilling the aim
of developing a contemporary health-related quality of life instrument to discriminate
treatment-related impacts on HIV, the wider international study uncovered some
universal themes nuanced by sociocultural factors pertaining to stigma and discrimination. For example, the concept of so called ‘courtesy stigma’ where others associated with the affected person, e.g. family or partner experience discrimination from individuals or communities (Goffman, 1963; Rongkavilit, et al., 2010; Talley & Bettencourt, 2010).

**HIV/AIDS and Employment**

HIV/AIDS impacted on work opportunities for those with ill health and choice of work generally. The legal and moral requirement to disclose to prospective partners and, potentially employers, particularly in the case of the person working in the health sector, weighed heavily. Even minor changes in general health were concerning for participants from all the countries that participated in the development of the PROQOL-HIV instrument, and particularly when they affected the ability to work (Duracinsky et al., 2012a). This became evident in the later interviews where some of the motivation of visa holders to access and adhere to treatment could be attributed to the desire to be ‘normal’, to overcome the physical effects of HIV and ‘get on’ with earning a living. Indeed much of the stress around HIV was associated with aspects of employment, being considered not fit to work or a potential hazard in the workplace. Secrecy about HIV seropositive status was evidently stressful. Some participants were afraid of xenophobia and/or homophobia which, in the case of the former is enacted at a structural level in Australia (Stafford, 2007); and in the case of the latter at an individual level, as evidenced by participants who feared being exposed to their co-workers, erroneously or not, as attracted to other men. Some people in the PROQOL-HIV study perceived their career options to be limited because of their fears of an inadvertent blood spill, for example, the participant who abandoned a profession in
catering because of this concern. In the wider literature on stigma Link & Phelan (2001, p. 363) describe how stigma (not specific to HIV) bears on the “distribution of life chances in such areas as earnings, housing, criminal involvement, health and life itself.”

Stigma and Health Seeking Behaviours

A critically important aspect to HIV/AIDS related stigma observed in this thesis, and as cited in other studies and stigma-related literature (Chesney & Smith, 1999; Fakoya, et al., 2008; Körner, 2007a; Logie & Gadalla, 2009; Link & Phelan, 2001), is how it may interfere with health seeking behaviours, specifically accessing testing and engaging with treatment and services studies which are critical for HIV prevention (Gardner et al., 2011; Giordano et al., 2007). This concern has been raised in Australia and Europe, in a number of articles and reports which explicate why people delay testing for HIV (Körner, 2007b) (Adler et al., 2009; Burns et al., 2007). Notably, there seem to be some differences related to citizen status, and not only because of fear of losing the possibility of citizenship, for example, some people born in HIV high-prevalence areas now residing in low-prevalence areas, perceive their risk of acquiring HIV to be reduced. And interestingly, an Australian report of survey data showed that HIV education did not appear to influence voluntary testing rates (Asante et al., 2009).

At least three of the men in this study delayed testing for HIV, even though they suspected that they had the infection, and two of the men diagnosed in WA presented in an AIDS-defining category. One of the men had not had his children tested and another man’s wife refused to have an HIV test for fear of the result. Fear of social death clearly outweighed physical health considerations. Some studies have shown that women are more likely to perceive HIV/AIDS related stigma (Hosseinzadeh et al., 2011). Jane Bruning’s unpublished thesis (2009), explores the impact of stigma on
women living in New Zealand using the method of cooperative inquiry. This innovative study brought about a set of actions developed and agreed upon by the participants that resulted in personal transformation and community consciousness-raising. A more recent Australian study conducted with 236 Iranian-Australians, used a survey instrument to explore felt or perceived stigma (stigma that is anticipated) (Berger, Estwing Ferrans & Lashley, 2001; Goffman, 1963; Herek, 2002) and its impact on the social risk associated with HIV testing and disclosure and the decision-making around the same (Hosseinzadeh et al., 2011) Approximately one quarter of the variance in those factors could be explained by respondents’ perception of HIV/AIDS related stigma. The result was strongly influenced by how long respondents had lived in Australia (time since migration). They concluded that these findings suggest that there are opportunities to change the social construction of HIV/AIDS associated stigma in that population. In a recent global survey Nachega and colleagues (2012) showed that fears of disclosing HIV serostatus and the perceived outcome by way of losing family or friends, especially in those diagnosed less than five years, was higher in the Asia Pacific and Latin America in comparison with Europe, North America and Africa. However, a limitation of their study was the pooling of data from Australia and South Korea to create a composite Asia-Pacific region. The epidemics in these countries vary considerably according to mode of HIV acquisition, dominant religious background and sociodemographic makeup and this may have confounded their findings. While Korea did not participate in the PROQOL-HIV study, observations from the 152 interviews from all the countries that did, showed family discrimination was of particular concern in Senegal and India, and that broader issues of stigma were raised more commonly by participants living in Senegal, China, Cambodia, and Thailand. For participants of the
high-income countries (Australia, France, and United States) disclosure of HIV status seemed easier and more frequent (Duracinsky et al., 2012a).

It might be considered that the temporary visa holders in this study were discriminated against by the requirement for HIV testing on application for Permanent Residency. However, discovering their HIV serostatus allowed participants to protect others from infection (via inadvertent transmission) and, as well, offered an opportunity to engage with HIV care and treatment, thus avoiding personal morbidity. There was also evidence to suggest that the supportive, non-judgmental environment in the specialist tertiary centre served to overcome stigma fears and that there was, for some participants, a waning of distress as time passed.

**Persistent stigma**

Of concern, the PROQOL-HIV instrument showed a clear and strong correlation, in one third of patients, between persistent self-reported fears of disclosing HIV serostatus and fear of infecting others, which significantly reduced their total HRQL score. While Link and Phelan in their discussion paper (2001) describe stigma as persistent, this is the first time, to my knowledge that this association has been described statistically. Furthermore, the qualitative data which contributed to the development of the pilot instrument revealed the difficulties of living with HIV, which was reinforced by the more recent interviews, in the domains of forming and maintaining intimate relationships, and chronic ill-health. Subsequently, the psychometric analysis discriminated the impact of treatment via symptomatology, pill burden and treatment duration. But it was concluded that emotional distress, largely due to persistent, stigmatising aspects of HIV infection, and poor physical health were major influences on HRQL in the WA HIV Cohort despite advances in tolerable and effective treatments,
and national antidiscrimination laws. This data supports the findings of other recent studies concerning the emotional and social well-being of PLWH (Hasanah et al., 2011; Holzemer, et al., 2009; Hosseinzadeh et al., 2011; Jia et al., 2007; Kalichman et al., 2000; Preau et al., 2007; Rongkavilit et al., 2010) and provide clear evidence that interventions to alleviate emotional stress in PLWH are needed.

Treatment Access, Adherence, Attitudes and Literacy

In the international PROQOL-HIV psychometric analysis (Duracinsky et al., 2012b) and in contrast with other country cohorts, West Australian participants had the highest proportion of participants taking ART in a once daily regimen (71% OD and 29% BD). Complete adherence to treatment in the two weeks preceding the survey was reached by 78% of participants, suggesting a high level of adherence in a population with universal access to the most modern regimens for its citizens. In the subsequent studies in this thesis, adherence was also high, and participants overcame barriers posed by access. A comment made by one African student is memorable: “The moment that I knew I was HIV positive it was in my mind that if I get something to help me I would adhere to that, I would stick to that.” There was also a pragmatic attitude taken by the temporary visa holders, particularly the men, which indicated their capacity to effectively manage their medication if they were adequately resourced, in terms of education about HIV and access to drugs. This apparent confidence is perhaps reflected by their competency in other areas of their lives, for example, as skilled workers.

Social context influences adherence

Nguyen and colleagues (2007) offer some interesting data that shed light on how social context can influence constructs such as adherence. They write that accompanying the
rapid increase in access to ARVs in Africa, has been high levels of adherence which they cite as at least equal or superior to ‘northern contexts’. Using an ethnographic perspective, they examined the context of access to ARVs in three Francophone countries to explicate the reasons for successful adherence in the face of considerable structural barriers, including a cap on the number of people who could be treated. As an outcome of this research they were able to formulate the term: ‘therapeutic citizenship’ which they describe “as a set of rights and responsibilities to negotiate (these at times) conflicting moral economies” (Nguyen 2007, p. S31). In effect communities evolved a form of social triage to decide who should receive the drugs based on an assessment of who would most benefit the community as a whole. These were people who were considered the most valuable to the community and not the most vulnerable. This decision-making approach diverged from the aims of the donor organisations which aimed to give the most vulnerable (to death) and sickest, favoured access. The people chosen to receive ART by their communities went on to develop leadership in treatment literacy which benefited the wider community by way of sustained and robust ART programmes.

**Treatment literacy**

Treatment literacy in relation to HIV, and an associated concept, community preparedness, form part of a broader concept of treatment education and are defined by UNESCO and WHO in this way:

*Treatment education encourages people to know their HIV status, explains how to get access to treatment, offers information on drug regimens, offers support and ideas for adhering to treatment and helping others to do so, emphasises the importance of maintaining protective behaviours and healthy living, and*

In this statement can be found some of the potential barriers to successful treatment, therefore, conversely, a person who is HIV treatment literate will have the information that follows. Practically, at a minimum, people need to know how to access their drugs without fear of being stigmatised or discriminated, be able to identify correctly and unambiguously the medication they have been prescribed, understand the scheduling and side effect profile and know how to manage any adverse effects. While it was notable that the participants in my research achieved good adherence, it was apparent and consistent with earlier studies in our unit (Herrmann et al., 2008b) that many patients could not name all of the drugs correctly, were confused about co-formulation and brand versus generic nomenclature, and only had a superficial understanding of how drug resistance developed, despite a high level of literacy among the group. At least three of the participants had resistance to NNRTIs, which is most concerning since nevirapine and efavirenz are commonly used in frontline combination treatments for HIV. The ignorance of the patients was reinforced by the clinic staff. Quite frequently staff members would use the generic name for one drug in the combination e.g. nevirapine and then use the brand name for the co-formulation of two (or more) e.g. Truvada and this would be documented in the patients notes. It is possible that clinic personnel try and simplify what they think is complicated information for patients, and it is the case that some patients, despite comprehensive treatment information over time (e.g. the rural case study in Chapter Four) do not internalise this knowledge. However, treatment literacy is critical where people live mobile lifestyles and move between services, states or indeed have to exit the country quickly as is the case if a visa is discontinued.
Treatment literacy is related to health literacy which, in turn, is an interrelationship between neurocognitive functioning, reading literacy and numeracy and is affected by gender, language and culture (Kalichman, Benotsch, et al., 2000; J. O. Moore et al., 2011; Waldrop-Valverde, et al., 2009, 2010). Eligibility criteria for a Long Stay Business or Student visa require recipients to be proficient in English, although these skills may only apply to the Primary Visa holder and not to their spouses. Language proficiency may increase a person’s capacity to act autonomously, access information and manage medication, and may be another point of difference between temporary visa holders, asylum seekers and refugees. Drummond and colleagues’ study (2008) on HIV/AIDS knowledge and attitudes among West African immigrant and Australian-born women in Western Australia showed that knowledge of HIV and HIV prevention was linked to education. Indeed health literacy, and particularly numeracy may be a major factor underpinning the successful medication adherence and persistence seen in the group of temporary visa holders; together with clinical protocols for adherence monitoring and counselling, although this finding has not been replicated universally (Paasche-Orlow, et al., 2006). Only one of the participants expressed concern that generic drugs might not be effective since he was not experiencing side effects that he had when taking a patented combination. This is in contrast with a recent study by Bulsara and colleagues (2010) who found that Western Australians were suspicious of foreign generic manufacturers and sceptical about generic drug bioequivalence.

The ethnographic research of Nguyen and colleagues cited earlier, is relevant to this study, first, because it underscores the value of such literacy, which if it increased adherence and persistence with treatment, has the capacity to shrink an epidemic at a population level by reducing population prevalence (Cohen, et al., 2011; Cohen & Gay, 2010); and secondly because Nguyen alludes to evangelical movements in Africa and a
long history of Christian Missionary involvement in the region (Bornstein, 2001) which gives a cultural context to the current HIV epidemic.

**Religion**

There was a notable leaning towards an active expression of Christianity evident in the African participants’ dialogue and also in their positive expressions of coping, it behoves us to consider how the influence of this culture might impact on people with those backgrounds that are now residing in Australia—whether living with HIV infection or without it—since it may have relevance to how, for example, sex education is delivered. A migrant health worker interviewed for background to this study noted that the attitudes of the wider African community towards the delivery of sex education to teenagers was nuanced by religious-cultural attitudes which had shaped her practice within that community. I acknowledge also that the Asian women cited their active association with Buddhism, which they commented offered them emotional support. A young Asian woman commented “I really think I did something really bad in a past life and this life I am paying for it.” One of the men living in a rural area was a practicing Christian and his experience of HIV was deeply connected with his sense of self with regard to his Christianity. Whether in Australia’s secular society we pay sufficient attention to the role religion plays in people’s lives is a subject that should be examined, particularly in the light of Australia’s growing multi-faith community. It is, however, beyond the scope of this thesis to further explore the role of religion and coping.

**Classical barriers to adherence: depression and alcohol use**

The results of the West Australian arm of PROQOL-HIV, presented in Chapter Three, show that the Australian group reported depression and alcohol usage more
commonly than other countries (Duracinsky et al., 2012). This was not altogether surprising since a contemporaneous study in our unit (Herrmann et al., 2012), the manuscript can be found in the appendix, showed a high and sustained use of alcohol (and nicotine) which we noted was in excess of a comparable Swiss cohort (Conen et al., 2009). Among our recommendations were that clinic-based interventions uncover harmful patterns of alcohol use and address their causes. However, interventions need to be resourced and researched as well as accepted by clinic personnel and integrated into care.

Integrating interventions into this setting is important because it is evident that people with HIV in Western Australia are, in general, not accessing primary care through their GPs who might be expected to manage depression and substance use issues, such as heavy drinking and smoking. And it is particularly true of the temporary visa holders who appear to have reasons related to their concerns about visa continuations and applications for residency. These concerns—which are increasing their stress levels—appear to limit their involvement with the Australian health care system to the minimum required. In the studies presented here, past drug use, including intravenous drugs, was queried as well as current alcohol use and smoking status. Data from the recent interviews showed that only one person was a current smoker and, while three reported using intravenous drugs and 10 recreational (mainly marijuana), in the past, none reported current use. However, 38% of men were using alcohol in quantities beyond that recommended by NHMRC guidelines (NHMRC, 2009) (and so were two women), and four of these men were FIFO workers. It is possible that this mode of working increases the likelihood of heavy drinking. A recent study by the WA Department of Health, which surveyed FIFO workers, found a significantly higher rate of smoking, risky drinking and obesity than in other shift workers associated with
sociodemographic status (Joyce, et al., 2012) Intoxication is a risky state in the context of HIV, and appears more common in the phase of early infection. Since people may not be on treatment at this time, there is a heightened risk of HIV transmission (Conen et al., 2009; Herrmann et al., 2012; Koblin et al., 2006; Woolf & Maisto, 2009).

However, for the participants in Chapters Four and Five, neither alcohol nor any of the other classical risk factors, were cited barriers to medication adherence, except by one woman, and one man who said he drank heavily after learning he was HIV positive. In fact, the primary obstacles to medication adherence and persistence were around the complexity of uninterrupted access to antiretroviral drugs for the people who were not eligible for Medicare; and the potentially fragile arrangement (for people in rural areas) around the process of dispatching ARVs to rural centres. This arrangement seems to rely on close communication and requires both motivation and organisation on the part of the patient; and efficiency and good record keeping on the part of the nurse, to ensure that drugs are ordered and delivered without a treatment gap between scripts.

**Acceptance, support and engagement with HIV Care**

Despite limited access to ARVs posed by non-citizen status and/or distance from dispensing pharmacies, participants overcame potential barriers posed by access. This was largely because of motivation to accept treatment and support from key health care professionals, which resulted in high levels of adherence and firm engagement with care underscoring the importance of patient-provider communication. This engagement was reinforced by health care workers who recognised that establishing and maintaining trusting relationships with clients was critical to the long term engagement (Figure 19) necessary to support, in particular, medication persistence;
and monitor immune status and virological control. It is the case that lack of engagement with HIV care is of increasing concern in the US where less than half of persons from 13 sites surveyed had evidence of ongoing HIV care (Hall et al., 2012). Health providers who contributed to data in this study also focused on ensuring access to care was facilitated by devising means to enhance their availability to clients; and by taking steps to reduce organisational impediments to accessing ARVs and support uninterrupted treatment, as recommended in recent published guidelines (Melanie A. Thompson et al., 2012).

Figure 19: Continuum of HIV care, adapted from Eldred and Malitz (2007) and Gardner et al. (2011)

Access to medication and ATRAS (AHOD Temporary Residents Access Study)

However, at the end of 2011, things changed for a number of people on temporary visas—at least for a four year period until the end of 2015. A joint initiative between the National Association of People living with HIV AIDS (NAPWA), The Kirby Institute and seven pharmaceutical companies, began a programme to provide antiretroviral drugs, at no cost, to 180 people who are in Australia, legally, but ineligible for Medicare benefits. The study is expected to run for 48 months. The Kirby Institute manages the Australian HIV Observational Database (AHOD) in which a repository of data from the enrollees is collated, including information such as: reasons for ineligibility (e.g. visa status and type); and the length of time taken for each enrolee to become eligible for Medicare. It is anticipated that other information to assist the ongoing advocacy work conducted by NAPWA and other affiliated organisations, such as AFAO and state-based AIDS councils, will also be collected. This study, while not
providing a long term solution to the issues of ART access, provides a compassionate short term solution that offers significant support to 180 people across Australia. In WA the entire Medicare-ineligible cohort followed up at RPH no longer have to purchase generic ARVs from internet providers and the study is now fully enrolled. Although the impacts of this study on the participants and the health setting will not be further discussed in this thesis, it is relevant to note that community advocacy consistent with the activism throughout the HIV/AIDS epidemic was largely responsible for this initiative (http://napwa.org.au/trials/atras, website accessed August 2012).

**Changing conditions in WA affecting access to treatment**

A further change which is expected to reduce obstacles to accessing ARVs for people in WA not eligible for Medicare came in March 2012 when the Health Department issued an Operational Directive (OD 0364/12) to address the provision of treatment of Medicare ineligible patients in WA public hospitals. The Directive recognises that it may not be ‘reasonable’ for long term visitors to return to their home countries to access non-urgent treatment and therefore the Health Department “seeks to assist health services in having proper processes in place to identify and support such patients and to recover associated treatment costs” (2012). In effect the Health Department cites the Health Act of 1911 (WA) to indicate that hospitals in WA should provide assessment and treatment free for all notifiable sexually transmitted infections, including HIV, regardless of Medicare eligibility. However, where treatment is expected to be required longer than two months and annual costs exceed $10,000 per annum, final authorisation must be sought from the Director General of Health. In addition “Health Services must have in place, processes for appeal should HIV treatment be refused on compassionate grounds” (Operational Directive OD 0364/12, March 2012, p.3).
addition to these opportunities, people applying for Permanent Residency are now eligible for interim Medicare access, and therefore access to medicines subsidised on the PBS, including ARVs.

**Methodological considerations in the assessment of health-related quality of life**

The analysis of the Australian PROQOL-HIV data presented in Chapter Three, revealed that just over half of the variation in quality of life was explained by the new instrument. This begs the question: what about the other 45% of the variance? In the subsequent discussion I observed that the finding concurred with Wilson’s conceptual model (I. B. Wilson & Cleary, 1995), perhaps suggesting that total HRQL is substantially impacted by some hard-to-measure factors relating to personality, which may contribute to resilience and coping in difficult circumstances. But other researchers (Cummins et al., 2004) have argued that Health-Related Quality of Life Measurement is a confounded construct, limited in its capability and potentially insensitive to change. They argue for the ‘operationalising’ of the subjective component of quality of life—subjective well-being—which rests in the idea of the Theory of Subjective Wellbeing Homeostasis. Cummins cites his own work and that of others to describe the theory which asserts that “...subjective QOL is actively controlled and maintained by a set of psychological devices that function under the influence of personality.” (2003, p. 414). Later, Hutton and colleagues used the Personal Wellbeing Index (PWI-A), an instrument based on the ‘Theory of Subjective Wellbeing Homeostasis; and the HIV version of the unsupportive social interactions inventory (USII) to study perceptions of ‘felt’ stigma, in 128 PLWH in Australia and 146 in the US (Hutton, et al., 2012). Unsupportive social interactions were those that participants found unhelpful or
upsetting, for example, coldness of manner. The results showed that participants scored below the normative range of subjective wellbeing seen in Western populations. This score was negatively correlated with unsupportive social interactions which outweighed any supportive interactions in their net effect on subjective wellbeing. It is possible the findings of this contemporaneous study conducted in an Australian population, have the capacity to amplify the observations made in PROQOL-HIV. Future studies might co-administer the two instruments since while the PROQOL-HIV has been shown to be sensitive to the impact of specific treatment as well as aspects of stigma; the PWI-A appears to accommodate aspects of personality important in the assessment of subjective well-being, such as resilience.

The pattern that has emerged from these studies is one of lives both *shaped and limited* by HIV/AIDS through, not only adverse physical impacts, but primarily through the psychosocial effects of HIV. How people cope with the emotional impairment that HIV stigma provokes through its various manifestations may depend, not only on factors such as social support but internal resources such as psychological resilience. I suggest it would be of particular value to consider the aspects of clinical care that are most important in providing support, particularly around the time of diagnosis since this event provokes a vivid and formative memory as was seen in the participants of this study.

**Summary**

The primary objective of this work was to understand the experience of HIV in the West Australian context and how it came to determine health outcomes; framed by issues such as access, adherence and citizen status; and referenced to health-related quality of life. In the first part of this chapter, I have discussed the issues within that
framework. However, over the period of my candidature, as the work progressed and the data was analysed I discovered that I had become, within the interviews, as Ezzy suggests, “a facilitator who enables the interviewee to re-experience and reflect on events” (Brown et al., 2003; Ezzy, 2010). This was particularly true, for example, with regard to the diagnosis event. As I describe in the methods, I usually began the recorded part of interview with a question about the participants’ responses when informed of their HIV diagnosis of HIV. It was clear that this event was a formative memory for participants. Formative memories have a particular impact on identity and adaptation and three types have been described by Cohen-Mansfield and colleagues (2010) as: first memories, pivotal memories and traumatic memories. The enormity that the diagnosis event posed for almost all participants led me to question the very nature of the threat posed by HIV. What follows is an exploration of the stigma construct in an effort to understand how the participants are confined within it.

The Construction of Stigma

The seminal contributor to the topic of stigma was Irving Goffmann (1963, p.9) and he remains widely cited. He conceptualised the stigma construct as: “the situation of the individual who is disqualified from full social acceptance”, by embodying a significantly discrediting attribute. Historically, this attribute has been represented by a physical manifestation, known as stigmata and disqualification arose from a violation or perceived violation of socio-cultural norms and, in particular, was associated with sex, death and race. Figure 20 illustrates that stigma is constructed within individuals; and collectively within society by way of sociocultural norms. As such, the person applying the behaviour and the person receiving the behaviour can be one and the same. This theory accounts for how people internalise stigma and why educational interventions
to reduce stigma in ‘stigmatisers’, by increasing their knowledge and understanding of the ‘condition’, have purportedly limited effectiveness (Brown, Macintyre & Trujillo, 2003; Parker & Aggleton, 2003; Weiss, et al., 2006). Societal, including governmental structures, that operate to exclude individuals also operate on this level but justify actions against individuals based on the need to protect those that ‘belong’ e.g. citizens against those who do not, non-citizens.

**The Construction of Stigma in HIV/AIDS**

HIV infection is subject to the public health strategy of *cordon sanitaire* or quarantine. David Armstrong (2011) asserts that this practice, adopted before the mid-nineteenth century is one of a number of distinct periods of public health practice which began by marking areas of prohibition between geographical spaces (an early example might be the plague villages in England in the 14th and 17th Centuries) but progressed to drawing lines of exclusion around the human body (Douglas, 1984). These lines of exclusion are enshrined in the legislation of many countries. Humans greatly fear exclusion and rejection, especially from their social groups, and Baumeister and Tice (1990) suggest that this fear is innate. Leclerc-Madala (2011) comments that there are contexts where fear of social death by HIV, is greater than physical death. People with HIV adjust their lives in order to protect themselves and others from real or imagined emotional, social or physical injury. Although scientists have developed potent treatments for HIV, and work is progressing towards a cure, interventions to treat the social manifestations of HIV; subtle, insidious and often invisible, yet so powerful in their effects on peoples’ lives, are lagging behind.
The third epidemic – understanding stigma in HIV

Early concerns about AIDS-related stigma were raised somewhat prophetically, by the Founding Director of the World Health Organisations former Global Programme on AIDS, Jonathan Mann, when he addressed the United Nations General Assembly in 1987. He described three phases of the AIDS epidemic. In phase one, he asserted, the epidemic of HIV would spread silently and to an extent imperceptibly; subsequently the natural course of the untreated infection would lead to an epidemic of AIDS which would represent phase two; and phase three would culminate in a social, political, economic and cultural epidemic characterised by stigma, discrimination and denial (Parker & Aggleton, 2003). Since then there has been a sharp increase in stigma related research (Weiss, et al., 2006); and increased effort to reconceptualise and reframe historical constructs in a way that will lead to greater understanding of the modes of stigma and how they can be alleviated.
Societies are alert to a violation of acceptable socio-cultural norms deeply internalised by individuals

MANIFESTATIONS

Perceived/Anticipated
Actual/Enacted
Internalised

ATTRIBUTES

STIGMA

Reinforced by social structural & institutional factors

- National & International legal and regulatory sanctions
- Emphasis on contagion/criminality
- Emphasis on economic detriments
- Public health campaigns
- Actions of HCP’s (may be well intentioned)

Feelings of

- Sadness,
- Anxiety, depression
- Low self esteem, decreased self worth

Fear consequences of disclosure for self and/or family

- Being publicly shamed within community
- Being ostracized (shunned, banned), personally and/or family
- Experiencing discrimination/workplace

Fear consequences of transmitting infection

- Causing harm to another, or loved ones (partner/children)
- Punitive actions of society

Social and health impacts

- Influences decision-making processes around health seeking and risk behaviours e.g. disclosure and adherence to medication
- Influences interaction with health services with regard to testing and engagement with care
- Limits personal/intimate relationships
- Complicates decisions around pregnancy
- Complicates parenting
- Limits employment, economic, travel, migration opportunities

Figure 20: Model of HIV-related stigma, theory, manifestations and
**Stigma and discrimination**

In the field of HIV/AIDS, Parker and Aggleton (2003) asserted that there was a collective inability to confront Mann’s *third epidemic* because of the limited theoretical and methodological tools. They argued that current research emphasis is centred on the individual, that is, the view that stigma occurs as a consequence of mistaken beliefs about the condition or the race of the person affected, rather than the social and economic exclusion that results from social structural conditions, and is perpetuated by policy. This first view tends to lead to educative interventions operating on the ‘stigmatisers’ that will result in more ‘tolerance’ of the ‘stigmatisee’.

However, informed by Michel Foucault, a contemporary of Goffman’s, Parker and Aggleton (2003, p.17) assert that: “*Stigma arises and stigmatisation takes shape in specific contexts of culture and power*”, and that “*Stigma always has a history which influences when it appears and the form it takes.*” In effect it is Foucault’s powerful ‘regimes of knowledge’ that asserts social control by defining normal and deviant properties. Once defined, these properties can then be applied to categories of people in order to place them within systems or structures of power. By reframing stigma in this way, the authors assert that the theory then leads to the possibility of understanding stigma and stigmatisation as central to the constitution of social order. This is, in effect, how stigma functions as a social construct within wider societies which are based on fundamental structures of hierarchy and inequality. Link and Phelan (2001), in particular, offer insights that speak to the multidimensionality of the construct. Most importantly in the study of HIV disease, this interpretation may help us to understand why people with HIV are stigmatised across cultures, and how this impacts on their well-being to a greater or lesser extent. The contextualised
characteristics of stigma and how they are made manifest were vividly described in vignettes presented at the recent World AIDS Conference held in Washington in July 2012.

Attributes of HIV/AIDS stigma

*The treatment or the symptoms—no problem, medications—take care of all that, but I think it’s the psychological factor that’s the toughest.*

(Man with HIV living in a rural area of WA).

Stigma can be experienced through a perception of others’ views based on an assumption of shared sociocultural norms; this is stigma as it is perceived, anticipated or ‘felt’. Stigma is also experienced as enacted in that social exclusion occurs as the consequence of action taken against an individual or group by an individual/s or group. This is commonly known as discrimination. Perceived and enacted stigma has interpersonal and intrapersonal dimensions. However, and particularly in the context of infectious disease, there is also an intrapersonal dimension when acceptance (internalisation) of society’s views leads to a form of ‘self’ discrimination where one feels deserving of society’s disapprobation. Herek (2002) and Deacon (2006) respectively, give rich insights into the psychological and social dimensions of stigma. Earnshaw and Chaudoir (2009) argue that the three stigma attributes should be assessed separately since they may be related to psychological, behavioural and health outcomes in different ways. These authors also point out that internalised stigma appears predictive of significant outcomes for PLWH. Kalichman and colleagues (2009) found that internalised stigma was associated with depression in populations in South Africa and the USA and inversely associated with social support. Furthermore, Deacon (2006) argues for a model of health-related stigma not wholly defined in terms of discrimination.
Stigma: telling people and ‘giving it to someone else’

The new PROQOL-HIV instrument demonstrated that the intensity of disclosure fear was proportional to the fear of infecting others. This phenomenon may reflect a personal sense of contagion as one participant commented: “Worst fear I have is giving it to someone else and the second most fear I have is people finding out.” This participant had unknowingly infected a partner; and had been in a situation where a health care worker had a percutaneous exposure to her blood during a routine medical procedure. The resultant distress fuelled the sense of being contagious although the incident did not result in transmission of HIV to the health worker. The participant explained to me:

The thought of it terrifies me....and I don’t know why because if someone got infected they could live 20 or 30 years like me, relatively fine, but again it’s the stigma you know yeah I, it would be the worst thing in the world to do to someone.

The participant had a history of depression and identified herself as socially isolated. This example and others presented in the results, illustrate the exaggerated perception of risk around the fear of ‘catching’ HIV and transmitting it once one is infected. But it also demonstrates how people fear harming others, a sentiment that crosses cultures. For example, the Asian and African women did not want to disclose their status to their families for fear of distressing them and this was true of the men as well wanting protect their parents, especially, from the pain of worrying. Nonetheless, it is also possible that people, especially in collective cultures, fear that potentially punitive consequences for themselves and their families might ensue as a result of transmitting the infection.
In my research, the women’s concerns about casual transmission to their own or others children were evident, for example: “I try my best to keep everything nice and clean and disinfected, but I still have this feeling that I will give it to [the child] somehow. That is my biggest scare.”

This sentiment was expressed by women across cultures. Furthermore, HIV complicates plans for having children and not just because of the fear of transmission, which in a successfully managed pregnancy in a developed country is quite unlikely. For example, one of the young women in the PROQOL study who had chosen a partner on the basis of believing her choices would be limited by her HIV status, observed this about the prospect of having children: “What if I did have a baby and it was perfectly healthy, then the poor little kid’s got to face all the like the stigma attached to it, of having a mum that’s positive.”

These examples from my research exemplify Goffmann’s (1963) seminal descriptions of stigma as associated with sex, death and race. More contemporaneously, O’Connor and Earnest (2011) provide a rich description of women’s experiences of stigma and marginalisation living with HIV in India, as does Jane Bruning in her Master’s thesis as mentioned previously in this work. A more thorough examination of the stigma construct, including the position of gender, is warranted.

The role of health care workers in perpetuating stigma

Public health sector communication campaigns can have unintended consequences and convey messages of culpability and responsibility (Guttman & Salmon, 2004); and within the health system the fear of casual transmission can be reinforced by well meaning health care workers. For example, the rigorous efforts of health care workers to prevent inadvertent disclosure of a patient’s HIV serostatus and advise the patient
to consider carefully, to whom they disclose, may send a message which implies that people have something of which they should be ashamed. One family man was advised to rent a house with two bathrooms so that there was no danger of him infecting his children by sharing a single facility. Education about HIV transmission can result in a person with HIV feeling that they should isolate themselves. A man described his post-test discussion experience:

_I think what she did most was just scare and scare, sort of scare me and scare me even more and it was, we were really scared and we didn’t know where to go or what to do._

An extensive review of the literature pertaining to stigma and discrimination around HIV and HCV in health care settings was commissioned by the New South Wales (NSW) Ministry of Health and produced by ASHM in partnership with the National Centre in HIV Social Research (NCHSR) (2012). Interviews were conducted with people who were identified as stakeholders: healthcare workers, academics and service providers working in the area of HIV and/or hepatitis C (HCV), some of whom identified as infected with blood borne viruses. This report identified a number of ways in which the providers perceived that people with blood borne viruses (BBVs) were discriminated that would resonate with the participants of this research; including those related to body language, modifying duties or procedures e.g. double gloving; and lack of understanding of legislative and requirements when providing services to people with BBVs. Interestingly, many of those interviewed had observed that stigma was more likely to be enacted in a primary health care setting rather than a tertiary setting, and that finding non-judgemental care was difficult in rural areas and led to doctor ‘shopping’. This echoes the observation of the ‘patient’ participants in my studies. However, one participant interviewed in the ‘stigma report’ observed that for
Aboriginal people the reverse appeared to be true. Therefore, the treatment ‘appropriateness’ may vary according to the care required and the cultural group that requires it. However, the study was confined to NSW and may therefore be less relevant for the WA context. One interviewee in the NCHSR report made the following observation about structural stigma, that which restricts the opportunities of stigmatised groups (Corrigan et al., 2004) by way of laws and policies, saying that the community is ‘hardly aware’ of this form of stigma. It is notable that the participants of my studies largely cited supportive health care workers in the tertiary setting. Therefore, focusing scarce resources beyond ensuring an understanding of current legislation on reducing stigma in health care settings may be less appropriate in the current Western Australia context.

**National and international legislation, and human rights: structural stigma**

In Chapter Two I outlined the national and international restrictions faced by people with PLWH. By limiting the movement of people across borders on the basis of HIV serostatus, the laws serve to reinforce stigma and discrimination against people with HIV which, in my research, was clearly exemplified by the participants on temporary visas. It is not too strong a word to say that a couple of participants were terrified and most remained anxious. Furthermore, the Health Requirement (Department of Immigration and Citizenship, 2010a) (Walensky et al., 2012) is contributing, at a societal level, to discrimination against people with HIV, and is obfuscated by issues of access to antiretroviral drugs further complicated by TRIPS agreements. There are a number of issues that arise. First, people are afraid of being deported or discriminated against, which prevents them from accessing testing, secondly it appears that there may be some self imposed delay (with some tacit physician involvement) in beginning
ART since people think as long as they do not need medication they are less of a burden on the Australian community. Thirdly, there is not the opportunity for people to ‘level the playing field’ by declaring their intention to continue access and import generic drugs after successful PR application to remove the barrier (to successful PR) proposed by the Health Requirement. There are no generic antiretroviral drugs in Australia available for prescription for citizens or non-citizens. A recent, sophisticated presentation at the World AIDS Conference in Washington showed data demonstrating that switching to generic-based regimens could result in annual cost savings of $1.01B (USD) (Walensky et al., 2012). Removing barriers to accessing ARVs may result in a significant diminution of institutional sources of stigma and flow on ‘test and treat’ benefits.

**Stigma, work and rural environments**

The interviews revealed the extra challenges of living in rural areas and working in small groups as the fly in fly out workers do. I found that there was perception of increased stigma in rural areas and small communities, so that the fear of people finding out was heightened because the odds of inadvertent disclosure were perceived to be higher and the consequences more severe. This was true in Australia and other countries, for example, this man in reference to his country in Oceania “back in the traditional villages, people talk bad things about you.” Researchers have sought to understand the social structures that may lead to increased stigma or perception of it, (Yebei et al., 2008) and the size of the community may matter. An example is the ‘off shore’ worker in a male dominated environment, who kept his same sex orientation and HIV serostatus a secret from his employers and his workmates. But people living with HIV may live also live with family members who care for them, (Knodel et al.,
2011) and this may increase their resilience if family members are emotionally supportive (Frain, et al., 2008). The health care workers in the North West and Kalgoorlie-Boulder regions commented on this in relation to their Aboriginal clients who were fearful of family gossip and disapprobation. This observation was supported by an Aboriginal man in the larger study. My field diary noted his comment that, being in an Aboriginal family everybody talks to everyone else and knows each others’ business, his fear also extended to being afraid of being labelled a ‘faggot’. This man could be said to be part of two small communities: the FIFO community and the Aboriginal community which for many families is dispersed across the state. My research showed that the participants perceived less tolerance in their communities both in the regions, and within the male dominated fly in fly out community of workers.

Heightened concern about confidentiality in small (geographic) communities resulted in many people avoiding health care providers in the town in which they lived and many travelled to Perth to access care where they were less likely to run into people they knew. But they also cited access to a greater variety of services than is available in the country areas. There was one exception to this rule, and this man trusted the goodwill of rural residents:

So I like to think that even in a small town ... they’re not going to go up to the quilters club and [say] you know, Jack he’s got AIDS you know?

However, Preston et al. (2004) reported higher rates of unprotected sex in gay men living in rural areas of the US and attributed this to the influence of stigma on sexual risk in regions where homosexuality and HIV/AIDS were disapproved, noting that people in rural areas were more likely to be conservative. Significantly, they were able
to point towards low self esteem and self worth mediated by stigma as being associated with unprotected sex.

All of the health care workers interviewed reported the high level of stigma in Aboriginal communities leading to considerable efforts by them to maintain confidentiality, and this is supported by the literature (Newman et al., 2007b). This Western Australian Curtin University study by Newman and colleagues used qualitative methods to look at barriers to the uptake of and adherence to antiretroviral therapy in Western Australian Aboriginal people and found that fear of discrimination was a major impediment while pregnancy was a primary motivator for acceptance and adherence. This data and related research (Bonar et al., 2004; Newman et al., 2007a; Newman et al., 2007b; S. C. Thompson et al., 2009) gathered nearly ten years ago in 2003, evokes the broad-based interdisciplinary service that exists in the North-West today. The study identified that participants prioritised families and community over individual health and recommended that:

*Treatment regimens must be tailored to fit the logistical, social and cultural context of everyday life, and be delivered within the context of broad-based health services, in order to be feasible and sustainable.*

The interviews with the health care providers, presented in Chapter Four illustrate their efforts to offer the type of service that meets their clients’ needs with regard to support for HIV treatment, even if that includes social welfare support. According to the North West Public Health Physician this has largely been successful. However, the impact of stigma continues to complicate clinical management and distress their clients as evidenced by the difficulties of establishing trusting relationships when there are staff disruptions as well as with local hospital staff. In this instance clients can disengage from services altogether.
Recommendations

There are a number of recommendations that can be made on the basis of the findings in these studies. I have categorised these as: clinical practice and policy direction, and areas for future research. The recommendations are summarised below:

Clinical practice

- Uncover emotional impacts of HIV and intervene to treat underlying stressors; including those related to stigma and consider the role of the wider multidisciplinary team in improving psychosocial outcomes for patients.
- Ensure staff members are adequately trained in issues that are relevant to the current population of people living with HIV/AIDS presenting for treatment in the hospital outpatient clinic
- Improve treatment literacy and include key information in adherence support protocols that will promote autonomy and independence; and embed evaluation of patient education into these protocols
- Utilise internet and web-based educational resources according to patient preference
- Ensure a focused, educative approach to mobile individuals that will enable and empower them to seek treatment continuation across national and international health care settings
- Ensure staff are resourced and educated to provide and evaluate this education
- Ensure staff familiarisation with protocols, including short term clinical staff and evaluate compliance with protocols
- Ensure staff familiarity with their legal responsibilities around discrimination
Policy Direction

- Efforts could be made to encourage the import of generic ARVs to Australia in order to reduce overall costs and make more funds available for prevention, identification and treatment of infections.
- All people working in Australia regardless of residency or visa status should have unfettered access to life-saving antiretroviral drugs.
- Continue to advocate for changes in laws that discriminate against people with HIV at a national and international level with regard to free movement between countries.
- Governments and HIV representative groups could work with employers to facilitate confidential screening for HIV after ensuring that workers will have free access to treatment and that they will be protected from discriminatory action by their employers or co-workers.
- Develop international networks that support programs that facilitate access to HIV care and treatment for all categories of mobile populations, including guest workers and visiting workers like sailors.

Areas for Future Research

Medication adherence

- Explore the impact and relevance of the emergent FIFO lifestyle on medication adherence and clinic attendance
- Explore the impact of mobility on medication persistence and linkage with care.
- Explore how families manage and what would help them to manage medication issues, especially those with children who or may not have the infection and develop interventions to support good treatment outcomes.
**Stigma-related**

- Further reveal how stigma operates as a construct within society and make it visible so as to design effective interventions.

- The questions are: (1) *Who is being affected by HIV/AIDS stigma?* (2) *How does HIV impact on individuals?* (3) *What are the outcomes of HIV/AIDS stigma?*  
  (Earnshaw & Chaudoir, 2009)

More specifically the following research questions could be asked:

- What is the relationship between fear of disclosing HIV serostatus and the fear of transmitting the infection?

- What interventions will be effective to reduce perceived stigma, anxiety and self imposed limitations in affected individuals and their families?

- What would help individuals & families manage disclosure issues, particularly those with children who may or may not have the infection?

- What issues, nuanced by gender or other potentially devalued identities, need addressing?

- How does HIV serostatus discordancy impact on relationships and within the broader family structure and what can be done about it?

**Health and treatment literacy**

- Research is needed into health literacy and treatment literacy, in particular, taking into consideration knowledge from other disciplines, e.g. education and anthropology. The research should include aspects of gender and culture that may interact to influence what education will be accepted and how it should delivered, and by whom, to the people who will benefit. This also has a broader relevance than HIV, especially for mobile and vulnerable populations.
Rural populations

- More research is needed to understand and meet the needs of people with HIV who are designated ‘hard to reach’; and the issue of why they are ‘hard to reach’ needs to be explicated.

Health sector

- Research into the health of non-citizens such as temporary visa holders, refugees and migrants is required to ensure their human rights needs are met and they can continue to make a contribution to Australian society.
- Research into models of care that will support the populations above will be required in the near future particularly since the numbers of temporary visas is set to increase and swell the numbers of mining and construction, and health sector workers.
- Support and recognition for research is needed from clinicians, particularly in circumstances where patients limit their contact with the health system thus making conventional methods of offering participation in research studies less effective.
- Researchers could be better integrated into clinical practice settings in order to be aligned with immediate and pressing clinical questions, including evaluating systems of care that may be under threat.

Policy

- Potential barriers around the manufacture and importation of generic drugs in Australia, including those concerns related to quality of medicines and drug bioequivalence need to be identified.
A local bureau where visa holders with HIV/AIDS can access free and confidential legal advice around visa and immigration issues could be established. This might be largely *pro bono* like the model for Legal Aid or perhaps funded from philanthropic sources.

**Limitations**

This study has a number of limitations, the first and primary limitation was the lack of representation of women in the study. Further, I sensed that while the women in the study had some things in common, for example, around concerns of how their HIV serostatus would impact on childbearing and rearing, there were other issues that were not explored, although they may have been beyond the scope of this study. For example, the Thai women who presented with their Australian-born husbands potentially lacked an independent voice, and their lack of proficiency in English may have made it more difficult for them to express themselves as fluently as they might in their first language. The interpersonal issues that arise from living in an HIV serostatus discordant relationship were not explored nor were the influences of culture within that dynamic. However, these and other unexplored aspects of the studies leave some area for future research. Further, the PROQOL-HIV studies revealed limitations with regard to intimate relationships which I discuss. But in the latter interviews I did not seek to ‘probe’ issues of sexuality because I believed this would be disrespectful, intrusive and, potentially, culturally inappropriate with the populations that would be included in this part of the work. It was also the case, outlined in the methods, that I used an interviewing technique which allowed participants to lead the conversation towards the subjects most relevant for them and those that they felt most comfortable talking about. This approach led to diversity and heterogeneity of content and is more
consistent with the view of Howard Becker (1998) with regard to understanding the range of certain phenomenon. Ezzy (2010) argues that a good interview is a merging of the agendas of the interviewer and interviewee resulting in ‘communion’ of understanding. This may lead to some items on the interviewer’s agenda being unaddressed. I also tried to ensure that by the end of the interview the participants were not left with feelings of sadness, and given the limited time available, this may have led to some themes left only superficially addressed or unexplored.

With regard to the rural arm of the study, I was able to recruit three participants only who attended the Public Health Physician in Kalgoorlie-Boulder, and they were all permanent residents. Given the social diversity within that cohort I sense that I have not tapped into the experience of living with HIV in that context, and further themes may have emerged had I been able to do so. All of the other patients in the rural group travelled from country regions to the city and were seen by the Tertiary Hospital Team. That I was not able to recruit patients at Fremantle Hospital also impacted on the usefulness of the study in that the opportunity to capture some diversity may have been lost.

**Conclusion**

The research presented in this thesis exposes the paradox of HIV/AIDS showing that, given favourable conditions outlined by Friedland et al. (2006) (Figure 7), one can survive HIV/AIDS but die a ‘social death’ because of lack of intervention into the social effects of the infection. These interventions are lacking, despite best efforts, either because of the technical focus of science, or because as a society we have not fully exposed discrimination nor understood the complex stigma construct, or a combination of these factors. The late Jonathan Mann spoke in 1987, of the AIDS
epidemic culminating in a social, political and cultural phase characterised by stigma and discrimination. This has come to pass. Since the AIDS epidemic has been characterised by the intense involvement of activists partnering with scientists, policy makers and legislators, the work is not yet done — and the invisible must be made visible.

*I suppose for two thirds of my life, because ... I have been living with HIV for a third of my life, I lived a quality of life where I didn’t have to think about everything, I just did what I wanted to do basically within ones responsibilities and obligations. Now, through HIV, my quality of life has changed in that now everything I do has to be considered.*

Man (45 years) living with HIV
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