

Poverty and HIV in South African urban informal settlements: exploring the obstacles residents face in accessing basic services and health care services.



The Johannesburg Skyline

(www.garado.co.za/deena3.jpg)

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Research Elective Report

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Title page

Study Title:

To investigate the difficulties in accessing health and social services for people living in informal settlements in South Africa in a context of HIV, using Sol Plaatjies as a case study ¹

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¹ This is the official study title as approved by the Faculty of Medicine of the Radboud University Nijmegen. The supervisors suggested using the term 'basic services' instead of 'social services'. Therefore the remainder of this report refers to 'basic services'

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Abstract

Title:

Poverty and HIV in South African urban informal settlements: exploring the obstacles residents face in accessing basic services and health care services.

Background:

Urban informal settlements in South Africa are places characterized by poverty and high HIV prevalence. People living with HIV in these settlements face specific challenges in accessing basic services and health care. These challenges need to be better understood and effectively addressed. Using Thiede's 'A-framework' on access to health care and an equity lens, the context of HIV and poverty in urban informal settlements is reviewed.

Aim:

To explore the difficulties people living with HIV in urban informal settlements in Johannesburg, South Africa, face in accessing basic services and health care services, with a particular focus on antiretroviral treatment.

Method:

Ten qualitative semi-structured interviews with key respondents residing in an urban informal settlement and openly living with HIV were conducted. Sol Plaatjies was used as a case study of an urban informal settlement in Johannesburg.

Results:

Respondents struggled with inadequate water supply, no access to electricity and poor sanitation. They reported that inadequate access to basic services had a negative impact on the health of people living with HIV. The majority of respondents eligible for antiretroviral treatment at the time of the study were receiving it and reported taking the treatment as prescribed. Most of the respondents were unemployed and dependent on social grants.

The majority of the respondents at some stage had to borrow money to pay for health care and the cost of transport was identified as the major obstacle faced in accessing health care. The respondents indicated that local health care facilities were understaffed. These staff shortages led to overcrowding and long waiting times when accessing these facilities. Stigma remained a barrier in accessing testing and treatment facilities for HIV.

Food security was a major challenge. This challenge became even more pronounced when respondents had to take antiretroviral treatment.

Conclusions and recommendations:

Respondents were aware of the impact of social determinants on their health. In general, relevant role players- including the Department of Social Development and local government authorities- need to address these, especially in informal settlements. This should include making food security an urgent priority. Regarding Thiede's 'A-framework' on access to health care, transport costs and a review of the eligibility criteria for the HIV disability grant ('Affordability'), human resources within the public health system ('Availability') and the stigma that surrounds testing for and treatment of HIV ('Acceptability') need to be addressed.

Keywords:

Poverty, people living with HIV, informal settlements, Johannesburg, South Africa, access to basic services and health care services, antiretroviral treatment, social determinants of health, equity

Foreword

This report serves as the end product of the study conducted as part of my research elective. This research elective forms part of the undergraduate medical curriculum at the Radboud University Nijmegen, the Netherlands.

There have been numerous calls on health professionals and medical students to become sensitized to and address the issues of social and economic equity, rather than simply limiting their work to the health sector (Gwatkin, 2000; Editorial *Lancet*, 2007). I participated in two courses; 'Poor Global Health' and 'Health and Environment in an Urbanizing World', as part of the Honours Programme² at the Radboud University Nijmegen. In these courses it was stressed that a multisectoral approach is needed to address the world's health problems. These courses made me realize that in addressing the world's health problems, health professionals need to increasingly look beyond the narrow scope of pure biomedical science.

In light of this, I specifically chose not to do clinical research for my elective, but opted for an issue that lies at the interface of medicine, politics and the social sciences. The issue of vulnerable people's access to basic services and health care was well suited for this purpose.

Given the fact that I am a South African citizen and that the South African society is characterized by marked social and economic inequities that impact on people's health, the decision to conduct my research elective in South Africa was made quite easily.

My research elective was conducted in the period between September 2008 and January 2009, with a total duration of fourteen weeks. Twelve of these were spent on-site; the remaining two weeks were used for the write-up of the final report. For the duration of my research elective, I was based at the Centre for Health Policy (CHP) at the University of the Witwatersrand which is situated in Johannesburg, South Africa. This centre forms part of the School of Public Health at the University of the Witwatersrand.

Dr. L. Thomas who holds positions at both the Centre for Health Policy (CHP) and the Medical Research Council of South Africa (MRC) was my immediate, on-site supervisor. Dr. Thomas and I collaborated closely with Dr. F. Barten who acted as my advisory supervisor. Dr. Barten is a staff member of the Department of Public Health at the Radboud University Nijmegen, the Netherlands.

Through the facilitation of Dr. Thomas and J. Vearey of the Forced Migration Studies Programme (FMSP)³ at the University of the Witwatersrand, I was granted the opportunity for certain of my study findings to be incorporated into an overarching project called RENEWAL. (Regional Network on AIDS, Livelihoods and Food Security)⁴ The RENEWAL project explores issues of migration, AIDS, food security and urban livelihoods in an African context. It is facilitated by the International Food Policy Research Institute (IFPRI) and the study within which I incorporated my results has taken place in three countries: South Africa, Namibia and Ethiopia. Johannesburg served as the case study for the South African part of the project where Sol Plaatjies informal settlement was one of the research sites. Sol Plaatjies informal settlement also served as the research site for my study; therefore certain findings from my study were relevant for the RENEWAL project as well.

² For more information on the Honours Programme see www.ru.nl/honoursacademy

³ For more information on the FMSP see <http://migration.org.za>

⁴ For more information on RENEWAL see www.ifpri.org/renewal

Chapter 1: Introduction

A. Literature review and reason for conducting the study

1.1 Equity: Definition and conceptual framework of the study

I decided to use the concept of *equity* as a conceptual framework when considering the challenges that people living with HIV in urban informal settlements in South Africa face in accessing basic services and health care services. Equity is defined as: “the state, ideal or quality of being just, impartial and fair” (Random House Unabridged Dictionary, 2006). It is closely linked to John Rawls’s ‘maxi-min’ principle of distributive justice. This principle calls for resources to be distributed in a way that the worst off people in society get the maximum possible amount of gain (Gwatkin, 2000).

There are two principal reasons for my decision to use equity as a conceptual framework in my study:

- i. The right to equity and health is enshrined in the South African Constitution (Heywood, 2007); and
- ii. From literature (Whitehead, 1990; Gwatkin, 2000) it is clear that access (whether to basic services or health care) is intricately linked to the concept of equity.

Both access and equity, in turn, are very relevant to the situation people living in informal settlements in South Africa, find themselves in. This is particularly true for people living with HIV. Literature regarding equity and health, access to basic services and health care, people living with HIV, urban informal settlements; and the interaction between these entities was reviewed. Where appropriate the literature review first considered the global context and was subsequently narrowed down to the South African and Johannesburg contexts.

This literature review was needed in order to formulate a problem statement and to identify subsequent research questions.

1.2 Equity and health

‘Inequity in health’ as used by the World Health Organization (WHO), refers to differences in health which are not only unnecessary and avoidable, but, in addition, are considered unfair and unjust (Whitehead, 1990). As part of a conceptual framework for equity and health, Whitehead specified seven determinants of health differentials:

1. Natural, biological variation
2. Health damaging behaviour that is freely chosen, such as participation in certain pastimes
3. The transient health advantage of one group over another when that group is first to adopt a health-promoting behaviour (as long as other groups have the means to catch up fairly soon)
4. Health damaging behaviour in which the choice of lifestyles is severely restricted
5. Exposure to unhealthy, stressful living and working conditions
6. Inadequate access to essential health and other basic services
7. Natural selection or health-related social mobility involving the tendency for sick people to move down the social scale.

Of the above mentioned determinants of health differentials, exposure to unhealthy, stressful living and working conditions; and inadequate access to essential health and other basic services are determinants that are particularly relevant to this study. Health differences resulting from these determinants would be considered by many to be both avoidable and unjust (Whitehead, 1990).

1.2.1 History of equity in health

Fifty years ago the Universal Declaration of Human Rights established a benchmark of standards against which to assess equity in health. Article 25 states that:

“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.” (United Nations (UN), 1948)

From around the mid -1970s to mid-1980s there was a worldwide emphasis on basic human needs (Gwatkin, 2000). In the health field this orientation led to the “Health for All” movement that called for equity and social justice and free health care services to cover entire populations (Gwatkin, 2000). The associated 1978 Declaration of Alma-Ata advocated primary health care because of its potential to close the gap between the ‘haves’ and the ‘have-nots’ (Gwatkin, 2000). The 1986 Ottawa Charter on Health Promotion set out some fundamental conditions and resources for health and built on the progress made through the Declaration of Alma-Ata (WHO, 1986). Again, social justice and equity were included in these prerequisites for health (WHO, 1986).

However, this climate with a focus on basic human needs did not last. By the mid-1980s many poor countries experienced severe economic difficulties and the attention of the major policy makers began to shift away from “Health for All” towards health sector reform. These reforms required health care to be sustainable and cost-effective (Gwatkin, 2000). These reforms were furthermore linked to the Structural Adjustment Policies (SAP) pursued by the World Bank and the International Monetary Fund (IMF) during the 1980s and 1990s (Ohkubo, 1997). The SAPs served as prerequisites that the World Bank and the IMF attached to their loans. SAPs emphasized maintaining a balanced budget which forced developing countries to cut spending. The casualties of balancing a budget were often social programs, including education and public health (Ohkubo, 1997). In general, health inequities, even in developed countries, sat uncomfortably with health and social policy at the time (Editorial, *Public Health*, 2006).

Since 2000 there has been renewed concern for poverty and equity in health. In my mind, the two most important developments were the setting up of the Millennium Development Goals (MDGs) in 2000 and the report released by the WHO Commission on the Social Determinants of Health in 2008. I will go onto explain these in detail below.

1.2.2 The Millennium Development Goals (MDGs)

The MDGs form a universal framework for development and were adopted by all United Nations (UN) Member States in 2000. Their coverage is quite wide and includes halving world poverty and hunger by 2015, halving the number of people without access to safe drinking water, and to combat diseases like HIV/AIDS and malaria (UN, 2008).

Progress has been made in some areas and mid-point analyses show that, for example, the overarching goal of reducing absolute poverty⁵ by half is within reach for the world as a whole (UN, 2008). However, global inequities remain and the target of reducing absolute poverty by half is unlikely to be reached in sub-Saharan Africa (UN, 2008). Furthermore, 50% of the developing world's population live without improved sanitation and more than one-third of the developing world's growing urban population live in slum conditions (UN, 2008).

Despite these figures, the Secretary General of the United Nations (Ban Ki-Moon) is convinced that "success is feasible with sound strategies and the political will" (UN, 2008). This political will refers specifically to developed countries honouring their commitments to Official Development Assistance (ODA) expenditure despite the current less favourable economic conditions (UN, 2008). ODA expenditure declined for the second consecutive year in 2007 (UN, 2008) and risks falling short of the commitments made at the 2005 Paris Declaration⁶. At the Paris Declaration over 100 developed and developing countries resolved to reform aid to make it more effective at combating global poverty, but the declining ODA expenditure makes it difficult, even for well-governed developing countries to reach their MDGs (UN, 2008).

1.2.3 Social Determinants of Health and Global Health Inequities

Health care is not the only health determinant and one must not assume that more and better health care is all that is needed to improve health (Ruger, 2004). Social determinants of health are considered to be the underlying conditions that result in a range of health outcomes (WHO CSDH, 2008). This can be illustrated by the fact that despite decades of scientific progress that has expanded health professionals' ability to improve human health, extreme deprivation in health and health outcomes is still widespread. For example, a girl in Lesotho is likely to live 42 years less than a girl in Japan (WHO CSDH, 2008).

Therefore the report released by the WHO Commission on the Social Determinants of Health in 2008, called on policy makers on "closing the gap in health equity within a generation, through action on the social determinants of health" (WHO CSDH report, 2008). This again highlights the importance of equity in health.

I have thus far looked at the definition of equity in health, the history of equity in health and major global initiatives to combat these inequities. For the purpose of my study it is necessary to consider equity in the South African context specifically.

1.3 Equity in the South African context

1.3.1 Indicators of equity and historical context

Although South Africa is regarded as a middle-income country in terms of macroeconomic indicators⁷ (World Bank, 2006), it remains one of the most unequal societies in the world (World Bank Country Report, 2006). Thirteen percent of the population live in "first world" conditions, while nearly 50% live in developing country conditions. In this latter group, only one-quarter of households have access to electricity and running water and over a third of the children suffer from chronic malnutrition (World Bank, 2006).

⁵ Absolute poverty was defined as living on less than US \$1 per day

⁶ For the Paris Declaration, see www.oecd.org/dataoecd/11/41/34428351.pdf

⁷ South Africa's Gross Domestic Product per capita was US \$5400 in 2006; according to World Bank Statistics

Although there has been a decline in the headcount poverty rate⁸ from 51% in 2001 to 43% in 2006, it still remains extremely high (SA Presidency, 2006). Inequity can be expressed in terms of the Gini coefficient⁹. A study by the Human Sciences Research Council of South Africa (HSRC) found that South Africa's Gini coefficient rose from 0.69 in 1996 to 0.77 in 2001 (HSRC, 2004). Official government statistics show an increase in the Gini coefficient from 0.67 in 1993 to 0.69 in 2006 (SA Presidency, 2006). Despite these conflicting figures, the trend appears towards increasing inequity and the fact remains that South Africa is one of the most unequal societies in the world (World Bank, 2006).

1.3.2 History of equity in the South African context

When considering inequities in South African society, it is important to take into account the critical role that Apartheid policies played in creating these inequities. These policies were implemented from 1948 to 1994 and promoted differential access to economic and social resources by 'race' group. It thereby created marked differences in socio-economic status by race (McIntyre, Gilson, 2002). The Infant Mortality Rate (IMR) in the early 1990s was, for example, nearly 11.5 times higher for black South Africans than for white South Africans. Furthermore, in the period between 1980 and 2002 the disparity in IMR between these groups increased by 40% whilst the national average declined (McIntyre, Gilson, 2002).

The democratically elected government, which came into power in 1994, committed itself to implementing measures to reduce poverty and to redress the disparities in the distribution of income and social services. In South Africa the poor, particularly the rural poor, black people, women, children and the disabled have been identified as the most disadvantaged groups whose needs should be prioritized (McIntyre, Gilson, 2000). Their plight has received priority in a number of important policies since 1994: the Reconstruction and Development Programme (1994), the Employment Equity Act (1998), the White Paper for the Transformation of the Health System (1997) and the National Strategic Plan for HIV/AIDS and STI (2007-2011).

Despite these developments various key equity challenges in access to basic services as well as health service delivery remain (McIntyre, 2002).

1.3.3 The right to equity and health and the South African Constitution

Given the historical context and the disparities that still characterize the South African society, the right to equity and health is enshrined in Clause 27(1) of the South African Constitution (Heywood, 2007):

“Everyone has the right to have access to: health care services, including reproductive health care; sufficient food and water; and social security, including appropriate social assistance if they are unable to support themselves and their dependants.”

From its wording it is clear that the Constitution does not view health care in a narrow way as just medicines or clinics. Instead it links health to access to food, water and social security (Heywood, 2007). In this regard the Constitution explicitly acknowledges the importance of the social determinants of health that I have mentioned in an earlier section of this literature review.

⁸ In South Africa the poverty line is defined as an annual income per capita <R3000 (The exchange rate on 2009/01/06 was R9, 35 to the US dollar; www.x-rates.com/d/ZAR/table.html).

⁹ The Gini coefficient has a value between 0 and 1, the higher the value, the more unequal the income distribution

I have explored equity and health in the South African context. As mentioned earlier, the concept of equity in health is intricately linked to that of access. The next step is to consider access to health care services.

1.4 Access to health care services

Equity in health care is often defined in terms of access to health care services (Thiede *et al*, 2007). Access is a multidimensional concept and has been described as “the opportunity to use health services” (Thiede *et.al*, 2007). Beyond this objective opportunity, individuals and communities need to be in a position to choose when to use which health service in a given context. For that reason, access can be defined as the freedom to use health services (Thiede *et.al*, 2007).

1.4.1 An ‘Access framework’

Given the multidimensional concept of access, a framework has been developed to address the concept of access. The framework consists of three dimensions which are interrelated, yet deal with distinct issues and together constitute access (Thiede *et.al*, 2007). The three dimensions are: availability, affordability and acceptability. These three dimensions of access are schematically presented in figure 1.

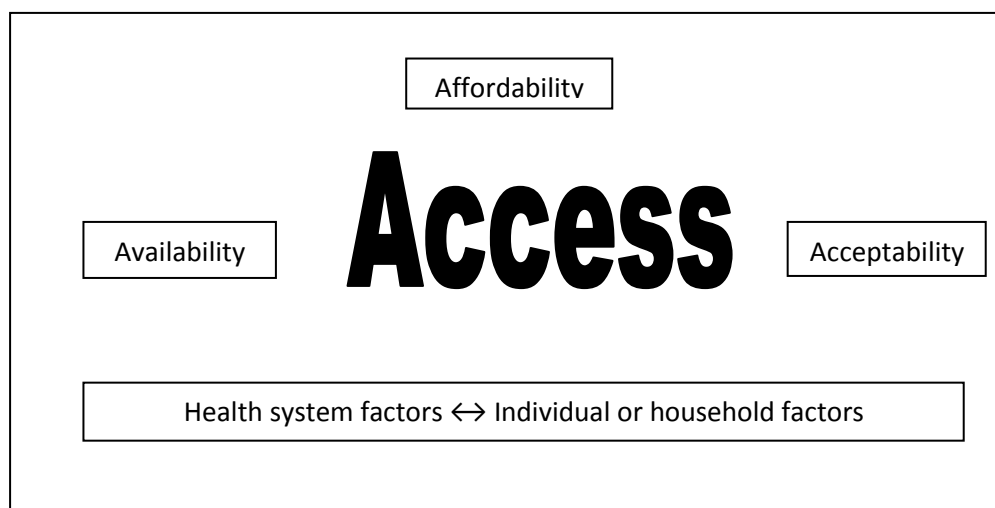


Figure 1: ‘Access framework’ (Thiede *et.al*, 2007)

1.4.1.1 Availability (Physical access)

This access dimension deals with the question of whether or not the appropriate health services are available in the right place and at the time that they are needed (Thiede *et.al*, 2007).

1.4.1.2 Affordability (Financial access)

It concerns the 'degree of fit' between the cost of utilizing health care services and individuals' ability to pay. This dimension is linked to discussions around financial risk of ill health and health service use and the role of the health system in protecting households and communities from this risk (Thiede *et.al*, 2007).

1.4.1.3 Acceptability (Cultural access)

This refers to the nature of service provision and how this is perceived by individuals and communities. The way in which health services are delivered and the way in which patients are attended to may accommodate patients' beliefs and sensitivities or it may deter them from using services to the desirable extent. It is important to emphasize the cultural dimension and the idea that equity and access should not be defined the same everywhere (Thiede *et.al*, 2007).

1.4.2 Access to health care services in the South African context

In South Africa efforts have been made to reduce financial barriers to access and to promote geographical accessibility and service quality (McIntyre, Gilson, 2002). Two phases of free care policy resulted in the introduction of free primary care services for all South Africans in 1996 (McIntyre, Gilson, 2002). The first was the introduction of free care for pregnant women and children under the age of 6 years in 1994. The second phase was the introduction of free primary care services for all South Africans in 1996 (McIntyre, Gilson, 2002). However, health care personnel suggested that the free care policy worsened poor working conditions, particularly overcrowding and staff shortages (McIntyre, Gilson, 2002). These poor staff attitudes subsequently had a negative impact on poor people's utilization of health care services (McIntyre, Gilson, 2002). Some academics have argued that this negative impact might have been so large as to offset the equity gains promoted by the health services most relevant to the needs of the most poor (McIntyre, Gilson, 2002).

When considering access to health care services in the South African context, it is imperative to take the provision and financing of these services into account as these occur within two distinctly different systems. I will describe these systems below.

1.4.3 The public/private mix of health care delivery in South Africa

The provision and financing of health care in South Africa occurs within two distinctly different 'systems': the public health system and the private health system. The socio-economic status of an individual in South Africa is the primary determinant of the system through which the individual will receive access to health care (Harrison, Bhana, Ntuli, 2007). It is very often also a determinant of the level and quality of healthcare that a person is able to access (Harrison, Bhana, Ntuli, 2007).

1.4.3.1 The public/private mix of health care financing

Wide inequities exist between the public and private health systems. The private health system is primarily funded through contributions to mutual insurers called medical schemes (Shisana, 2006). Although only 14% of the total population of 47 million are beneficiaries of private health insurance coverage, 60% of total health care funds were spent in the private sector in 2006 (McIntyre, Thiede, 2007). Furthermore, per capita expenditure in the private sector was five times greater than in the

public sector in 1998, and this ratio had increased to 6.6 times greater in 2005 (McIntyre, Thiede, 2007).

The inequities that exist between the public and private health systems are also evident when looking at South Africa's spending on health care compared to its health status indicators. South Africa's level of spending on health care is relatively high by international standards, it exceeds that in the majority of countries of a similar level of economic development and is similar to that in some high income countries. (McIntyre, Thiede, 2007). However, health status indicators such as infant mortality are far worse than that in other upper middle income countries (McIntyre, Thiede, 2007). These disparities are presented in Table 1. There is, therefore, a strong basis for arguing that the key challenge facing the South African health sector is not one of a lack of resources, but rather a need to use existing resources in a more equitable way (McIntyre, Thiede, 2007; Shisana, 2006).

Country	Health care expenditure as % of GDP ¹⁰ , 2002	Life expectancy at birth, 2003	Infant Mortality rate/1000 live births, 2003
South Africa	8.3	48	53
High income countries			
United Kingdom	7.7	78	5
Australia	9.5	80	6
Middle income countries			
Brazil	7.9	71	33
Malaysia	3.8	73	7

Table 1: Comparison of health care expenditure and health status indicators for selected high and middle income countries (UNDP, 2005)

1.4.3.2 Human resources within the public and private health systems

Wide inequities also exist between the two systems regarding the distribution of human resources.

Since the early 1980s there has been a continued exodus of health care workers from the public to the private health systems (McIntyre, Thiede, 2007). By the end of 2007 the private health sector employed 75% of generalist doctors and 84% of pharmacists (McIntyre, Thiede, 2007). The skewed distribution of health care professionals between the public and private health systems is summarized in Table 2.

	Ratio medical practitioner to population	Medical practitioner per 100 000 population
Public system dependents	1 per 4 219	23.7
Private system dependents	1 per 601	166.3

Table 2: Distribution of medical practitioners by public system dependents and by private system dependents, 2007 (Wadee, Khan, 2007)

¹⁰ GDP: Gross Domestic Product

These inequities between the public and private health systems, both in financial and human resources, are important as evidence indicates that strong and accessible public health service provision is essential within an equitable health system (McIntyre, Thiede, 2007).

My study focuses on people living with HIV and I will now give a brief overview of issues relating to HIV/AIDS in South Africa and how these are linked to the concept of equity.

1.5 HIV/AIDS in the South African context

HIV/AIDS is one of the major challenges faced by South Africa (NSP, 2007). Indicators show that by mid-2006, 5.3 million people in South Africa were living with HIV/AIDS. This amounts to a total population prevalence of 11.2% (NSP, 2007). Furthermore, it is estimated that 326 000 South Africans died of AIDS in 2005 and that this annual toll will exceed 400 000 by 2012 (Marais, 2007).

It is important to consider the HIV/AIDS epidemic in South Africa in the context of the epidemic in Sub-Saharan Africa. South Africa forms part of Sub-Saharan Africa- a region that continues to carry the biggest burden of the HIV/AIDS epidemic-which in 2007 accounted for 67% of the 33 million people living with HIV worldwide (UNAIDS, 2008).

1.5.1 HIV/AIDS and its links to inequities in the South African society

As mentioned previously, South Africa is a society marked by deep inequities. The majority of South Africans living with HIV are poor and are black Africans. In 2005 the HIV prevalence was 19.9% among black African adults, compared to 0, 5% among whites (Marais, 2007). Urban informal areas in South Africa are areas characterized by high levels of poverty and with a HIV prevalence rate of 25.8% these areas have some of the highest HIV prevalence rates in the country (Marais, 2007).

The linkage between inequity and HIV/AIDS can further be illustrated by the fact that studies have found a clear pattern of association between income inequity, as measured by the Gini coefficient, and HIV prevalence across countries in sub-Saharan Africa (Piot, 2008). As mentioned earlier, South Africa has one of the highest Gini coefficients and is therefore rated as one of the most unequal societies in the world. Many researchers point not to poverty itself, but rather to economic and gender inequities and weakened 'social cohesion' as factors influencing sexual behaviour and hence the potential for HIV transmission (Piot, 2008; Krishnan, 2008).

1.5.2 The impact of HIV/AIDS on human and economic development in South Africa

AIDS has rolled back the gains of decades of development in South Africa (Seekings, 2007). This is clear from statistics on the country's Human Development Index (HDI): its HDI peaked at 0.72 in 1995 and then declined steadily to 0.65 in 2003, which is the most recent year for which data are available (Seekings, 2007). This decline is entirely due to South Africa's rapid decline in life expectancy as a result of AIDS. Life expectancy at birth for males now stands at 48 years (McIntyre, Thiede, 2007).

Furthermore, AIDS is expected to have major impacts on the South African economy (Marais, 2007). On a macro-economic level HIV-related labour costs now amount to 2.4% of aggregate annual labour costs in the South African mining sector (Piot, 2008).

Therefore mining companies are investing more in machinery and equipment, in order to reduce their labour dependency (Marais, 2007). This adds to the already high unemployment levels, which stood at 37.3% in 2006 (SA Presidency, 2006).

On a micro-economic level, because the epidemic shrinks household incomes, small businesses are likely to be badly affected. The burden will be especially heavy on the micro enterprises of the 'informal sector'. To further exacerbate the situation, these are typically operated by vulnerable households themselves (Marais, 2007).

1.5.3 Access to antiretroviral treatment (ART)

A systematic review of literature by Posse *et.al* (2008) found that the following were the most frequently cited barriers to ART in developing countries:

- A lack of information about ART
- Perceived high costs of ART
- Stigma
- Long distance from home to the health facility
- Lack of co-ordination across services
- Limited involvement of the community in the programme planning process

The provision of ART to those who need it is imperative as it improves people's health, quality of life and economic position (Schneider et al, 2007). After years of political inertia the South African government was in 2003 compelled by social and political activism to introduce a national ART programme (Marais, 2007). The National Strategic Plan on HIV and STI that was released in 2007 has universal access to ART as one of its main goals (NSP, 2007), but universal access to ART is still far from being achieved. In 2007, a mere quarter of persons in need of ART were actually receiving it (Schneider et al, 2007). Therefore it is important to establish who is gaining access to services and who is not and to ascertain whether these are leading to or exacerbating systematic inequities along geographical, socioeconomic, age or gender lines (Schneider et.al, 2007). From the abovementioned facts, it is clear that in South Africa the provision of antiretroviral treatment to people living with HIV is intricately linked to the concepts of equity and access.

The shortfall of ART provision is especially acute in poorly resourced provinces (Marais, 2007) .In these provinces health systems are malfunctioning as a result of human resource and infrastructure shortages, and inadequate management capacity (Marais, 2007). In one province, for example, 49% of the doctor posts for the ART programme were vacant (Schneider et al. 2007). These facts further highlight the fact that equity, access to health care and access to ART are interwoven entities in the contemporary South African society.

As mentioned in a previous section of this literature review, urban informal settlements in South Africa are places characterized by high levels of poverty, a lack of basic services and a high HIV prevalence rate. I will conclude this literature review by exploring informal settlements in the global context of increased urban migration and in the South African context specifically.

1.6 Informal settlements

1.6.1 Informal settlements in the context of increased urban migration¹¹

Increased migration to urban areas is a worldwide challenge; in 2008 over half of the world's population was estimated to be urban (Vearey 2008, MRC, 2008). This increased urban migration is placing increasing pressure on local governments' ability to respond to the public health and social service needs of urban populations (Vearey 2008, MRC, 2008). This increased urban migration is furthermore leading to an ever larger proportion of urban residents having to live in slum conditions. It is estimated that in 2005 more than 60% of sub-Saharan Africa's urban population lived in slum conditions (UN, 2008). Urban slums are characterized by a lack of safe water and sanitation and a lack of durable housing and a sufficient living area (UN, 2008). Therefore, one of the targets of the earlier mentioned MDGs is to achieve a significant improvement in the lives of at least 100 million slum dwellers by 2020 (UN, 2008).

1.6.2 Informal settlements in South Africa: Characteristics and statistics

Informal settlements in South Africa constitute both rural and urban informal settlements. These settlements must be seen as a manifestation of broader social, economic and political processes that are beyond the control and choice of the individual households (Huchzermeyer et.al, 2004). The number of informal settlement dwellings in South Africa have reached 1.4 million in 2004 and this number is projected to increase to some 2.4 million dwellings by the end of 2008 (Richards, 2007).

Informal settlements in South Africa lack sufficient basic services, including water, electricity, sanitation and food preparation and storage. It is well documented that such conditions are associated with a range of health risks, including diarrhoeal and respiratory diseases (Richards, 2007). Inhabitants of these settlements perceive their quality of life as low, with inadequate housing, low service levels and low levels of access to and satisfaction with healthcare identified as key problems (Richards, 2007). In addition, as mentioned before, urban informal settlements have some of the highest HIV prevalence rates in South Africa (Marais, 2007).

In light of the challenges posed by informal settlements, the South African National Department of Housing committed itself in their 'Breaking New Ground' strategy to the development of 'Sustainable Human Settlements', which will include an upgrading instrument to support the focused eradication of informal settlements (SA National Department of Housing, 2004). Given the equity lens used in this study, it is important to note that equity is included in the department's definition of a sustainable human settlement.

¹¹ This section is adapted from J.Vearey's *Revised PhD Protocol submitted to the University of the Witwatersrand's Faculty of Health Sciences Postgraduate Committee* in May 2008 and a process evaluation report of Joburg Connections (an integrated community approach to addressing HIV/AIDS) by the Medical Research Council of South Africa (MRC) (2008)

1.7 Summary of literature review

From the literature it is evident that the concepts of equity and access are intricately linked to each other. Therefore I have used the concept of equity as a conceptual framework when considering the difficulties that people in urban informal settlements in South Africa face in accessing basic services and health care services.

The South African Constitution grants citizens the right to equity and health. The Constitution further explicitly recognises the importance of the social determinants of health. This is important given the historical context of the South African society and the marked inequities that still characterize it. Urban informal settlements in South Africa are places characterized by high levels of poverty, poor access to basic services and health care services. In addition these settlements have some of the highest HIV prevalence rates. The consequence is that people living with HIV in urban informal settlements are particularly vulnerable to the inequities that prevail in society

B. Background to the study site

Sol Plaatjies informal settlement is an example of an urban informal settlement in South Africa. I chose this settlement as the research site for my study, because my supervisor could provide me with contacts in this settlement that could be used as entry points for my study. This was relevant given the short time span of this research elective

Sol Plaatjies informal settlement is located within the city of Johannesburg in South Africa. In order to understand the context of Sol Plaatjies, I will first explore literature relating to South African cities and city of Johannesburg in general. I will then look at informal settlements in Johannesburg and Sol Plaatjies specifically. The focus will be on issues relating to poverty, access to basic services and HIV/AIDS.

2.1 South African cities

South Africa's nine biggest cities together represent the greatest relative concentration of poverty in the country (Boraine *et.al*, 2004). As mentioned earlier, increasing numbers of residents are settling in informal settlements on the margins of these cities.

The South African Constitution requires local governments (including city councils) to perform a developmental role (Thomas, 2003). In terms of the Municipal Systems Act they are expected to work with communities in bettering living conditions, through the provision of water, electricity, sanitation and waste collection (The Presidency Republic of South Africa, 2000). This developmental approach also has particular relevance for people living with HIV. The rising incidence of HIV/AIDS has led local authorities to experience increasing demand for health and welfare services and has led to local authorities struggling to keep up with this demand (Thomas, 2003). These challenges are important as the ability of households to cope with the care of people with HIV/AIDS is strongly dependent on the quality of housing, sanitation and water supplies. (Thomas, 2003) This reiterates the importance of the social determinants of health.

2.2 The City of Johannesburg

The City of Johannesburg is situated within the Gauteng province of South Africa. With some 3.8 million residents (Johannesburg City Council, 2008) it is the most populous city in South Africa and one of the largest urban conurbations on the African continent (Czegledy, 2003). It was declared a permanent settlement in 1896 on the back of the discovery of gold in 1886 and was declared a city in 1928 (Johannesburg City Council, 2008). Today Johannesburg is the country's premier industrial city and centre of finance. Its diversified economy generates 16% of the Gross Domestic Product (GDP) and employs 12% of the national workforce (Johannesburg City Council, 2008).



Figure 2: Map of South Africa, showing the different provinces and the location of the City of Johannesburg

2.2.1 The City of Johannesburg: Spatial arrangements

Spatially, Johannesburg is also illustrative of the inequities that prevail in the South African society. The city can be divided into 3 distinct areas: the southern townships, inner city and northern suburbs (Tomlinson et.al, 2003)

2.2.1.1 The southern townships

The apartheid strategy of 'separate development' led to the development of sprawling suburbs for people of colour south of the city centre. These townships had an extraordinarily inefficient layout and no sustainable commercial or industrial base (Tomlinson et.al, 2003). Almost 60% of Johannesburg's citizens already reside in these townships and most new informal settlements and low-income housing projects are located south of the inner city (Tomlinson et.al, 2003). Soweto is probably the best known of the southern townships.

2.2.1.2 The inner city

Since the early 1990s, urban decline led to the majority of formal businesses re-establishing in the northern commercial nodes (Tomlinson, 2003). During the second half of the 1990s increasing numbers of migrants from African countries were settling in the inner city. Increasing xenophobia, assaults and conflicts over space and access have led to the inner city to become a defensive,

ethnically defined area (Tomlinson, 2003). Since 2000 the Johannesburg City Council has, however, implemented a number successful inner-city improvement districts that have created dynamic commercial and cultural nodes (Brodie et.al, 2008).

2.2.1.3 The northern suburbs

These suburbs are characterized by tree lined avenues, gated communities and shopping malls. Together these suburbs constitute the wealthiest administrative area in the Gauteng province (Czegledy, 2003). Some have described the northern suburbs as “a national metaphor representing white wealth, Eurocentricism and capitalist materialism” (Czegledy, 2003).

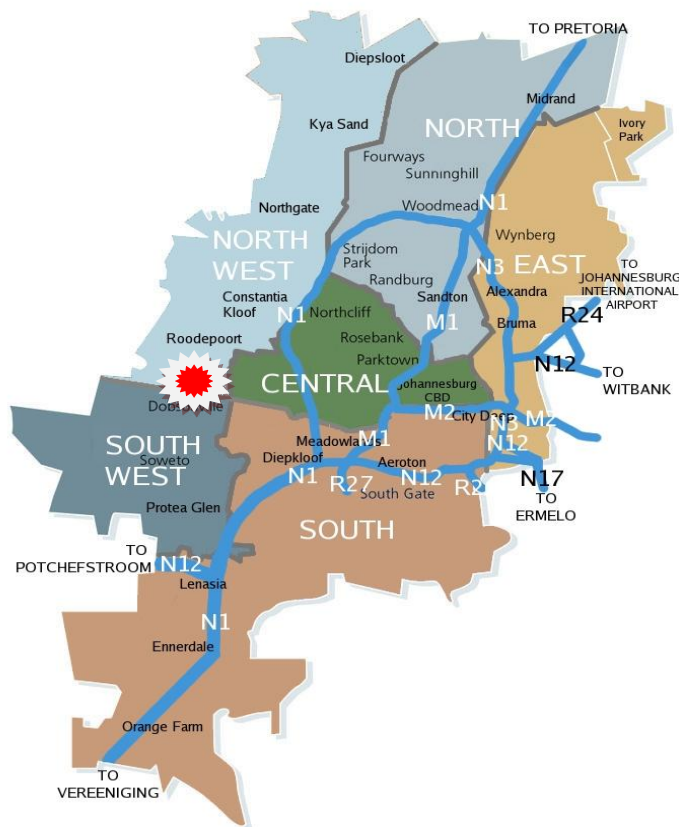


Figure 3: Map of the City of Johannesburg. The red star indicates the location of the Sol Plaatjies informal settlement (research site of this study)

2.2.2 The City of Johannesburg: Selected development and health indicators

With a quarter of the city’s population living in poverty, a third of the city’s population unemployed, a quarter of the population residing in informal settlements and an HIV prevalence at antenatal care clinics of 31%, there is a great need to address development issues and inequities within the city. Table 2 shows some selected development and health indicators for the City of Johannesburg.

Indicator	Percentage
Unemployment (2004) ¹²	32
People living in poverty ¹³ (2006)	24
People residing in informal settlements	25
HIV prevalence at antenatal care clinics (2006)	31

Table 3: Selected Development and Health Indicators for the City of Johannesburg (Johannesburg City Council, 2008)

2.3 Informal settlements in Johannesburg

The Johannesburg City Council regards an informal settlement as an “illegal area of habitation where there is no plan of how streets will run, no electricity, sewage or water services, and the area hasn't been registered formally” (Davie, 2007).

A fair estimate would be to say that there are between 120 and 200 informal settlements in Johannesburg, housing around 750 000 people (Brodie et.al, 2008). These settlements house the most vulnerable and marginal members of society, of which the majority are extremely poor (Brodie et.al, 2008). Informal settlements often adjoin existing townships or formal settlements so that some areas have both a formal and informal component (Brodie et.al, 2008).

There has been a great deal of policy debate on informal settlements in the city, with initial commitments to their eradication in Johannesburg by 2007 and then, when (in 2006) almost 200 informal settlements were counted in the city, a new commitment to rid the city of informal settlements by 2014 (Brodie et.al, 2008, Davie, 2007). The city's Integrated Development Plan (IDP) is one of the policies that in addition to aiming to provide improved housing for the poor also want to create ‘Sustainable Human Settlements’. The ‘Sustainable Human Settlement’ approach is intended to provide economic, social and political opportunities for poor households as well as appropriate housing (Brodie et.al, 2008). This policy is in line with the National Department of Housing's ‘Breaking New Ground’ strategy that was discussed earlier in this report.

2.4 Sol Plaatjies informal settlement

2.4.1 Location and establishment

The settlement is situated on the site of the abandoned Durban Roodepoort Deep mining compound. It is situated about 30km west of the Johannesburg inner city and is a few kilometres south of the Roodepoort Central Business District, which forms part of the greater City of Johannesburg (Van der Post, 2007, Donnelly, 2007). It was established in 1999 when hundreds of people from informal settlements around the Roodepoort area were relocated to the mining compound. Residents were unable to be accommodated in the blocks of mining hostels and started to erect hundreds of tin, wood and plastic shacks.

¹² 2004 was the most recent year for which data on unemployment levels in Johannesburg were available (www.joburg.org.za/content/view/92/58/)

¹³ For more information on the definition of poverty that the Johannesburg City Council uses, see the City's 2005 Human Development Strategy (www.joburg-archive.co.za/city_vision/hr_strategy-05.pdf)

To make things worse, Donnelly explained that “the City of Johannesburg in 2002 crammed another 2000 families from another informal settlement of Mandelaville into the already overcrowded mining compound ” (Donnelly, 2007). No official data are available on the population size of the settlement, but it is estimated to be around 10 000 inhabitants (this emerged from discussions I had with my supervisor and field workers who performed work in Sol Plaatjies for the RENEWAL project).

2.4.2 Developments and upgrading

After a number of years with very little service provision, during 2007, the Johannesburg Social Housing Company (Joshco) started to convert the settlement into a formal township, building new roads, providing street lighting and connections to electricity and water grids. The existing mine housing units were being converted into duplex cluster housing units. This is an example of an in-situ upgrading which allows for informal settlement households to get a formal house and basic services in the same area (Brodie et.al, 2008).

Despite these developments a lot of obstacles still remain. There is only one primary school, secondary school pupils need to commute to surrounding townships and there is only one clinic that is operational (Donnelly, 2007).



Photo 1: The local clinic in Sol Plaatjies.
(Photo taken by author)

2.4.3 Spatial arrangements

Due to the developments that were taking place in the settlement at the time of my study, the settlement consisted of both formal and informal components. These distinctions are based on my own observations during the field work part of this study:

- Formal component: This component consists of Reconstruction and Development Programme (RDP) houses and the converted mine housing units
- Informal component: This consists of a shack settlement
- ‘Silvertown’: This component consists of tin shacks and serves as a sort of ‘transit camp’ where residents are being accommodated whilst their formal housing units are being built or renovated.



Photo 2: In Sol Plaatjies former mine housing units were being converted into duplex semi detached houses (Photo taken by author)



Photo 3: 'Silvertown- transit camp'
(Photo taken by author)

2.4.4 Level of basic service delivery

This is also based on my own observations. A proportion of the housing units were equipped with running water and flush toilets, but there were numerous communal toilets and water taps still present. Rubbish was piled up in certain parts of the settlement. Furthermore, the settlement as a whole was not connected to the electricity grid.

In summary, although developments were taking place within the settlement, the level of basic service delivery was still very low. From observations of the presence of communal toilets, communal taps, rubbish dumps and the fact that there was only one health clinic, it could be expected that residents would face obstacles in accessing basic services and health care. From the abovementioned facts the problem statement of this study was formulated.

C. Problem statement

Sol Plaatjies informal settlement is an example of an urban informal settlement in South Africa. As mentioned before, these settlements are characterized by poverty, HIV/AIDS and residents face numerous barriers in accessing basic services and health care services.

However, there are limited studies that investigate HIV in informal settlements. The aim of this study was to provide insight into the barriers people living with HIV in Sol Plaatjies face in accessing basic services and health care services and that these findings might be used to influence the Johannesburg City Council's response towards them.

Chapter 2: Research questions

In this study, basic services included housing, electricity, water, sanitation and waste removal. The key research questions that the study aimed to answer were:

1. What are the difficulties faced by people living with HIV in Sol Plaatjies in accessing basic services?

- Housing
- Electricity
- Water
- Sanitation
- Waste removal

2. What are the difficulties faced by people living with HIV in Sol Plaatjies in accessing health care services?

3. What are the difficulties faced by people living with HIV in Sol Plaatjies in accessing antiretroviral treatment?

Table 3 summarizes the objectives and methods used to address the research questions.

Objectives	Methods
1. To explore the difficulties faced by people living with HIV in Sol Plaatjies in accessing basic service	Literature review, semi structured interviews with respondents living with HIV in Sol Plaatjies, data analysis
2. To explore the difficulties faced by people living with HIV in Sol Plaatjies in accessing health care services	Literature review, semi structured interviews with respondents living with HIV in Sol Plaatjies, data analysis, access conceptual framework (Thiede et.al, 2007)
3. To explore the difficulties faced by people living with HIV in Sol Plaatjies in accessing antiretroviral treatment	Literature review, semi structured interviews with respondents living with HIV in Sol Plaatjies, data analysis, access conceptual framework (Thiede et.al, 2007)

Table 4: Objectives and methods used to address the research questions of this study

Chapter 3: Research methodology

1. Conceptual framework

The concept of equity and the right to equity in health, that is enshrined in the South African Constitution, formed the conceptual framework on which this study was based.

Within this study access to basic services was analyzed descriptively only, whilst the 'Access framework' (Thiede et.al, 2007) was used to analyze access to health care services (also see the 'Access to health care' section of the literature review chapter of this report). As mentioned in the introduction to this report, some of this study's findings fed into the overarching RENEWAL project. Therefore some of the results from this study were compared to relevant findings from the RENEWAL study.

2. Method of data collection

A qualitative case- study approach was used. The study was exploratory.

3. Techniques for field work data collection

In-depth, semi structured interviews were used. Research show that individual interviews tend to be more useful for evoking personal experiences and perspectives on sensitive topics, whereas the public forum of a focus group can inhibit candid disclosure (Giacomini, Cook, 2000). Because a lot of stigma still surrounds HIV/AIDS in South Africa an approach using individual interviews was selected as more appropriate to the use of focus group discussions.

To increase the validity of the research tool, and because findings from this study fed into the overarching RENEWAL project, the interview schedule was compiled from questions already validated in major studies.

These studies included:

- The RENEWAL project¹⁴,
- The 'Non-citizen access to antiretroviral therapy' study¹⁵, and
- The REACH (Research into Equity in access to health care)¹⁶

The interview schedule with and outline of which questions were taken from which study is attached as an appendix to this research report.

Interviews were conducted in English, but a staff member from the Centre for Health Policy (S. Mporetji), who was able to communicate in a number of African languages which are spoken in Sol Plaatjies, accompanied me during the interviews and provided translation and/or clarification where it was needed.

¹⁴ For more information on RENEWAL see www.ifpri.org/renewal

¹⁵ This research was conducted in the inner-city of Johannesburg – a migrant dense area – to better understand non-citizen access to ART, see <http://migration.org.za/research/#pubs>

¹⁶ For more information on REACH see <http://web.wits.ac.za/Academic/Centres/CHP/Research/AccessHealthCare.htm>

4. Target population/criteria for selecting respondents

Respondents needed to be people living with HIV who were willing to discuss their HIV status and issues surrounding it openly with the researcher. Respondents needed to be older than 18 years.

5. Sampling strategy and size

Ten interviews were conducted over a period of two weeks, with a minimum duration of 30 minutes each. This sample size was chosen because of the exploratory nature of the study, the limited research and interviewing experience of the researcher, the objectives of the study (as part of an undergraduate research elective) and the time constraints.

The staff member of the Centre for Health Policy (S. Mporetji) who accompanied me during the interviews, established contact with a female resident of Sol Plaatjies who was living with HIV. He explained the scope of this study to her and she agreed (albeit orally) to be interviewed. She was used as an entry point for the study. The sampling strategy was purposive with a snowballing effect. The person used as entry point, was asked to introduce the researcher to some of her acquaintances in Sol Plaatjies who were living with HIV and who would be willing to participate in this study. I was aware of the fact that this sampling strategy lent itself to bias, but given the exploratory nature of this study a certain amount of bias could be allowed.

6. Data analysis method:

Interviews were taped and transcribed. Interviews not in English were transcribed and translated by experienced researchers from the CHP, P. Mahlangu and S. Mporetji. A thematic analysis was performed: the interview transcripts were read and analyzed and overarching themes were extracted. To increase the validity of the findings, a group discussion with the abovementioned researchers was held to discuss the extracted themes.

7. Ethical considerations:

The study was conceived as part of the overarching RENEWAL project and the ethical approval given to the RENEWAL project was sufficient to cover the scope of this study.

The Ethics Committee on Research on Human Subjects of the University of the Witwatersrand, Johannesburg, South Africa, granted ethics approval to the RENEWAL study under the study number MO71125 and the study title 'Migration, AIDS and Food Security in Johannesburg, South Africa.'

As required by the Ethics Committee, written, informed consent was obtained from each participant. I was assisted by J.Vearey from the RENEWAL project in compiling the information sheet and informed consent form needed for this study (These documents are attached as appendices to this report).

8. Limitations of the study

The study was the first study in which I have used qualitative research methods. I wasn't able to speak any of the African languages which were spoken in Sol Plaatjies. Although the interviews were conducted in English and the CHP staff member provided translation and/or clarification where it was needed, this language barrier was a limitation of the study.

Another limitation was that the sample size used in the study was small (ten respondents) and data from this study could therefore not be extrapolated to the general population living in Sol Plaatjies. Furthermore, as mentioned before, the purposive sampling strategy with a snowballing effect used in this study, lent itself to a certain amount of bias.

9. Significance of the study

First and foremost this study gave the respondents the opportunity to let their voices be heard regarding the obstacles that they face in accessing basic services and health care whilst living with HIV in Sol Plaatjies. Their voices, in the form of quotes and the findings of this study, will form part of the RENEWAL project's final report. It is hoped that the findings from the RENEWAL report will impact on the South African government's response towards people living with HIV in urban informal settlements.

Chapter 4: Results and Discussion

The section begins with a general description of the demographic, socioeconomic and migration profiles of the respondents. Subsequently, the three objectives of this study are addressed and where relevant, illustrated by quotes from the interviews. The three research objectives of this study were:

1. What are the difficulties faced by people living with HIV in Sol Plaatjies in accessing basic services?

- Housing
- Electricity
- Water
- Sanitation
- Waste removal

2. What are the difficulties faced by people living with HIV in Sol Plaatjies in accessing health care services?

3. What are the difficulties faced by people living with HIV in Sol Plaatjies in accessing antiretroviral treatment?

As mentioned earlier, the study was exploratory (sample size 10) and needs to be followed up with more detailed research where necessary.

A. Demographic, socioeconomic and migration profiles of the respondents

1. Demographic profile of the respondents

Of the ten respondents, seven were female and three were male. Their ages ranged from 22 to 43 years.

2. Socioeconomic background of the respondents

2.1 Size of the household

In the study the size of the respondents' households¹⁷ was used to give a rough indication of their socioeconomic status. The largest household consisted of 5 adult members (older than 18 years) whilst one of the households consisted of a single adult. The number of children (younger than 18 years) within the households ranged from none to four.

The size of the respondents' households was mostly in line with the household size from the RENEWAL project. In the RENEWAL project, the household size in Sol Plaatjies was bigger than in the formal urban settlements and mostly consisted of three or more members (Vearey, Nunez, Palmary, 2008).

¹⁷ In the study a 'household' was defined as all the people who shared the same house and the same food with the respondent

The household size from this study and the RENEWAL project are in line with trends observed in urban areas in South Africa, where households tend to be smaller (De Wet et.al, 2008). The Gauteng province has the smallest household size in the country with an average of 3.3 people per household (De Wet et.al, 2008).

2.2 Employment and livelihoods

The majority of the respondents and/or their head of household¹⁸ were unemployed; some were working part-time whilst only two respondents or their head of household were employed full-time.

Eight of the ten households received money in the form of social grants¹⁹ whilst three households received goods during the last 12 months. These goods included a once-off food parcel from a clinic. The social grants consisted of six Child Support Grants and two Disability Grants. These grants were used to pay for housing, food and school fees in the households in which none of the members were employed or earning any money. It is of interest to note that in this study none of the respondents received assistance from a Non-Governmental Organization (NGO).

In the RENEWAL project 23% of households reported that a member of the household was receiving assistance from social grants and/or NGOs. The majority of these grants were Child Support Grants (Vearey, Nunez, Palmary, 2008). The proportion of households that were in receipt of grants in the RENEWAL project (23%) was lower than the 39% of households that were in receipt of social grants in study on poverty and urban livelihoods in Johannesburg (De Wet et.al, 2008).

2.3 Household assets (in a good, working order)

Eight of the households owned a radio, six of the households owned a cell phone and five of the households owned a television set²⁰. None of the households had access to a landline phone and only two of the households owned a fridge (paraffin powered). These figures are relevantly in line with findings from a major study on poverty and livelihoods in Johannesburg in which 80% of households owned a cell phone and 66% a radio, but only 11 % had access to a landline phone (De Wet et.al, 2008). Figure 4 summarizes the household assets of the interviewed respondents.

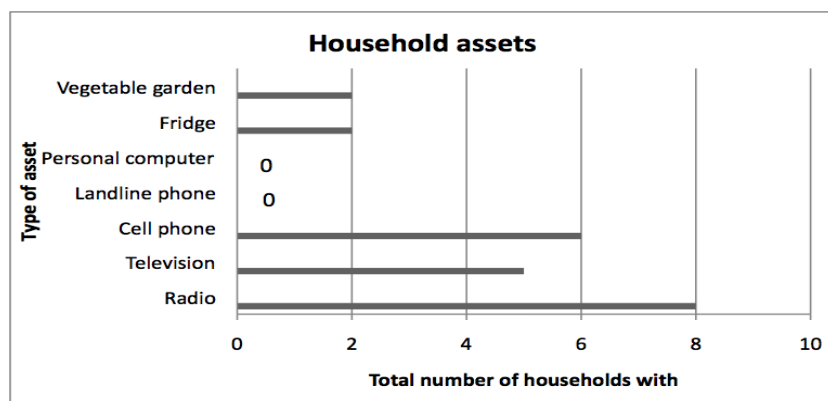


Figure 4: Household assets of interviewed respondents

¹⁸ In the study the 'head of household' was defined as the person that made the important decisions in the household

¹⁹ Social grants in South Africa play a critical role in reducing poverty and promoting social development, they are provided in the form of money or goods for the subsistence of certain population groups defined on the base of their vulnerability. Seven types of grants are accessible to the South African population; these include State Old Age Pensions (SOAP), Disability Grants (DG) and Child Support Grants (CSG). (www.southafrica.info/about/social/social_grants.htm)

²⁰ Although there is no access to electricity in Sol Plaatjies, households use car batteries to power television sets.

2.4 Summary of the socioeconomic background of the respondents and/or their households

The majority of the households were very poor and unemployed, in receipt of social grants and were dependent on the money from these grants to cover their daily living expenses. This is similar to the findings from the household survey conducted in the RENEWAL project (Vearey, Nunez, Palmary, 2008).

3. Migration history of the respondents

All of the respondents were born in South Africa. Four of the respondents were born in Johannesburg; the remainder of the respondents was internal migrants that moved to Johannesburg. Of the internal migrants, three were born in the Eastern Cape Province, whilst three were born in the KwaZulu Natal Province. This is in line with data from the RENEWAL project that found that internal migrants were most likely to originate from the KwaZulu Natal and Eastern Cape Provinces (Vearey, Nunez, Palmary, 2008).

Three of the four respondents who were born in Johannesburg, were born in Diepkloof²¹ and indicated that they were relocated by local government authorities to Sol Plaatjies in 2002. As mentioned in the background section of this report, the Sol Plaatjies informal settlement was established when families from other informal settlements around Johannesburg were relocated to the site of the old Durban Deep mining compound (Donnelly, 2007). The year in which the other respondents came to Sol Plaatjies ranged from 2002 to 2008.

B. Objective 1: Access to basic services

In this section the results pertaining to respondents' access to basic services are discussed. As discussed earlier, 'access to basic services' formed the first objective of the study's research question. As mentioned in the research methodology of this study, this objective is discussed descriptively only. Selected findings from this study are compared to findings from the RENEWAL household survey.

When considering access to basic services in Sol Plaatjies, one has to keep in mind how the settlement came into existence (relocations), that it is spatially fragmented and that major upgrading and development was taking place within the settlement at the time of the study.

1. Housing

As mentioned earlier, Sol Plaatjies spatially consisted of three distinct sections: a formal section, an informal shack section and 'Silvertown'. Furthermore, major upgrading and development was taking place in the settlement at the time of the study. These spatial arrangements and developments are reflected in the study results. Five of the respondents lived in duplex semi detached housing units²² in the formal section of Sol Plaatjies; two of the respondents lived in shacks in the informal section whilst one of the respondents lived in 'Silvertown'. These findings are in contrast to findings from the RENEWAL survey. In the RENEWAL household survey, the majority of respondents were living in shacks in the informal section of Sol Plaatjies (Vearey, Nunez, Palmary, 2008). Figure 5 summarizes the observation of the type of housing that the households lived in.

²¹ Diepkloof is an informal settlement situated in south western Johannesburg

²² The former mine housing units were being converted into duplex semi detached houses.

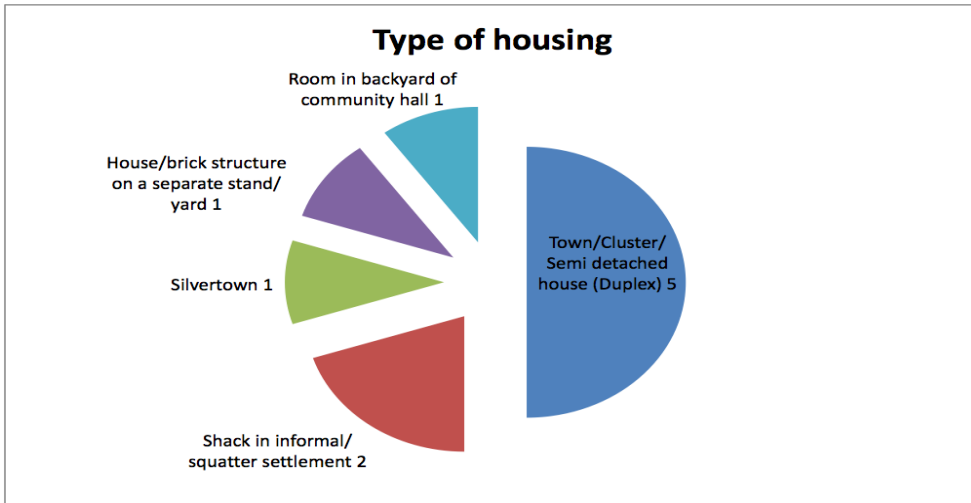


Figure 5: Observation of the type of housing that the household lived in.

2. Electricity

None of the households had access to electricity. Paraffin and gas were the main types of fuel that the households used for cooking whilst candles were used for lighting. The same findings were found in the RENEWAL survey (Vearey, Nunez, Palmary, 2008).

3. Water

Five of the households had running water inside the household whilst the other five households made use of communal taps to obtain water. None of the households paid for water. The RENEWAL survey found that most households in Sol Plaatjies were still using communal taps, despite the recent upgrades (Vearey, Nunez, Palmary, 2008).



Photo 4: A lot of residents of Sol Plaatjies have to use communal taps for accessing water. The areas surrounding these taps are often very dirty and conducive to the spread of diseases such as diarrhoea. (Photo taken by author)

4. Sanitation

Six of the households had a flush toilet connected to the main sewer inside their dwellings; 3 households had no toilet facility and had to use the open field. One household made use of an outside communal chemical toilet. Data from the RENEWAL survey showed that only 35% of households had access to a flush toilet connected to the main sewer inside the household (Vearey, Nunez, Palmary, 2008).



Photo 5: A lot of residents of Sol Plaatjies have to use communal toilets. (Photo taken by author)

The households' access to sanitation is summarized in figure 6.

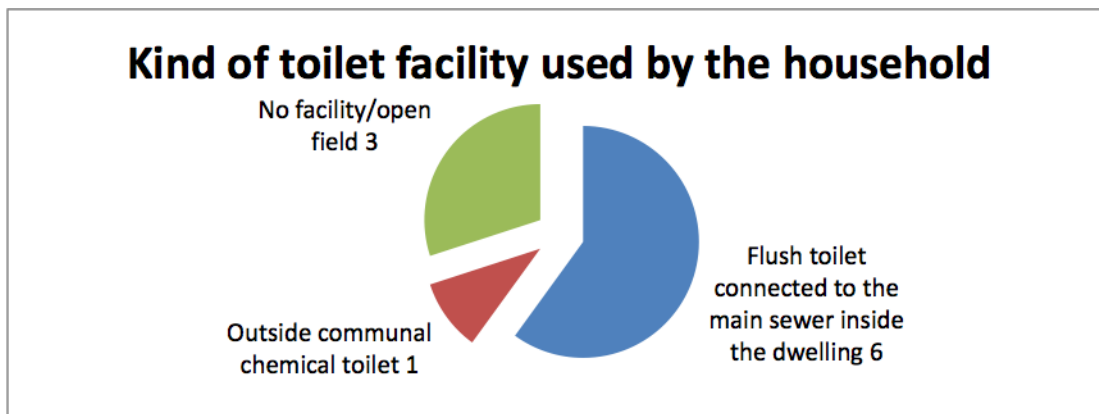


Figure 6: Kind of toilet facility used by the household

5. Waste removal

Half of the households' rubbish got collected weekly; three of the households put their rubbish on a nearby rubbish dump; one of the households dumped their rubbish outside their yard and one of the households burned their rubbish. Data from the RENEWAL survey showed that a quarter of household's rubbish got collected weekly and that 20% of the households dumped their rubbish outside their yards (Vearey, Nunez, Palmary, 2008). The households' access to waste removal is shown in figure 7.

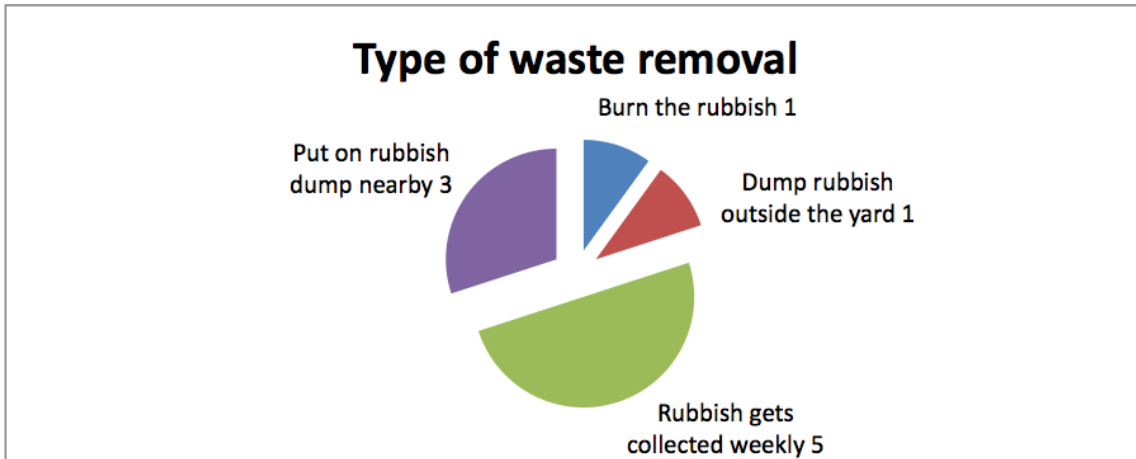


Figure 7: Type of waste removal accessed by households

6. Summary of access to basic services:

Although half of the respondents' households lived in duplex semi detached houses in the formal section of Sol Plaatjies, three of the households still lived in shacks in the informal section. Half of the households had access to running water inside their households whilst half of the households had to make use of communal taps to access water. None of the households had access to electricity. The majority of the households had access to a flush toilet connected to the main sewer inside their households, but three of the households had no toilet facility and had to use the open field- this occurred in spite of the fact that communal chemical toilets were available.

Half of the households had access to weekly rubbish removal and only one household had to make use of burning rubbish as a method of waste removal.

The discrepancies found between some of the results of this study and data from the RENEWAL household survey mentioned in the above sections, are most likely due to the purposive snowball sampling strategy used in this study. As mentioned in the methodology section of this report, the sampling strategy lent itself towards a certain amount of bias.

7. Discussion

The upgrading and development that was taking place within Sol Plaatjies at the time of this study and the difficulties faced by the respondents in accessing basic services and the impact of these difficulties on their health will be discussed.

7.1 Upgrading and development within Sol Plaatjies

As mentioned in the background section of this report, the upgrading that was taking place in Sol Plaatjies is an example of an in-situ upgrading. This upgrading is in line with the earlier mentioned National Department of Housing's 'Breaking New Ground' strategy (SA Department of Housing, 2004) as well as the Johannesburg City Council's Integrated Development Plan (IDP) (Brodie *et.al*, 2008). Through the upgrading, both of these strategies aim to create a 'Sustainable Human Settlement'.

Although the upgrading is a major step in the direction of creating a ‘Sustainable Human Settlement’, numerous obstacles still remain and the upgrading itself led to residents experiencing difficulties in accessing basic services.

Relevant findings from this study illustrate this:

- Although half of the households ‘officially’ had running water inside their households, they were still making use of communal taps, because the water supply was either cut off during the upgrading or the water pipes had not been connected yet.
- Furthermore, three of the six households who ‘officially’ had a flush toilet connected to the main sewer inside their households, were using alternative toilet facilities whilst they were waiting for the water pipes to be connected.

Most of the respondents indicated that the (then) current services were interim services and that certain difficulties in accessing basic services were to be expected during the upgrading. They did, however, express concern that they weren’t informed about the duration of the water cuts. This highlights the importance of the developers (local government) keeping the community informed about the upgrading and also actively involving the community in this upgrading.

7.2 Difficulties faced by respondents in accessing basic services and the impact of these difficulties on their health

As mentioned earlier in this report, the importance of the social determinants of health is explicitly acknowledged by the South African Constitution (Heywood, 2007). In this study all ten respondents acknowledged the negative impact of the problems they experienced in accessing basic services on their health.

These negative impacts on their health that the respondents attributed to the poor environmental conditions are expressed in the selected quotes that have been included in this section of the report. Respondents indicated the following as the main obstacles in accessing basic services.

a. No access to electricity

“Because we have no fridge we must use the vegetables we buy very quickly. Otherwise it is rotten by tomorrow, because it is hot. We can’t have leftover food, when we have food we need to use it quickly. That means that on some days we have nothing to eat.”
(Female respondent)

b. Inadequate waste removal

“There is too much waste. The rubbish truck does come to Sol Plaatje, but sometimes they (the people collecting the rubbish) just sit there and eat and then leave again without collecting any rubbish.” (Female respondent)

c. A lack of running water

d. Stairs inside the duplex semi detached housing units

“I hate the fact that I always have to go upstairs. I am old and when I am sick and weak it is even worse. I don’t like the structure of this house.” (Female respondent)

e. Inadequate sanitation

*“We live next to the toilets and cooking outside and there are flies and rubbish is lying everywhere. It makes the sickness worse. It is not healthy to stay in such conditions”.
(Female respondent)*

“We use the open space as a toilet and also to throw rubbish. It is a problem for HIV diseases as our immune system is weak...” (Female respondent)

C. Objective 2: Access to health care services in general and Objective 3: Access to antiretroviral treatment (ART)

From the interviews it emerged that respondents' access to health care services in general was mostly interrelated with their access to ART. Therefore these are discussed in the same section.

As an introduction to the respondents' health, this section begins with a description of the respondents' self-rated state of health. This will be compared to results from the RENEWAL survey. Subsequently this study's second and third objectives are analyzed using the 'Access framework' (Thiede *et.al*, 2007).

1. Self-rated state of health of the respondents

Half of the respondents rated their health as 'poor'; four of the respondents rated their health as 'good' and one of the respondents rated his health as 'fair'. This is in contrast to the 14% of respondents that rated their health as 'poor' in the RENEWAL household survey (Vearey, Nunez, Palmay, 2008). The higher proportion of respondents who rated their health as 'poor' in this study, might be due to the fact that this study focused on a specific group of people who have disclosed their HIV status, whilst the RENEWAL household survey focused on the general population. The high proportion of respondents, who rated their health as 'poor' in this study, indicates that people living with HIV in Sol Plaatjies are struggling with their health.

2. The 'Availability' dimension of access

This access dimension deals with the question of whether or not the appropriate health services are available in the right place and at the time that they are needed. (Thiede *et.al*, 2007). This section begins with a summary of the respondents' care seeking behaviour, then explores barriers respondents faced when accessing care at the local clinic in Sol Plaatjies and concludes with a description of respondents' physical access to ART.

2.1 Care seeking behaviour of the respondents

The nearest primary health care facility that residents from Sol Plaatjies could access when seeking health care was the government clinic in Sol Plaatjies. During the last 12 months, eight of the respondents felt sick enough to seek care for a particular episode of illness. These eight respondents all sought care at a government health care facility in first instance.

The majority of these respondents sought care at Hamberg Clinic²³ and Leratong Hospital²⁴. Only one of these eight respondents first sought care at the government clinic in Sol Plaatjies.

2.2 The local clinic in Sol Plaatjies

As mentioned in the previous section, the majority of the respondents who sought care at a government health care facility, preferred to not visit the local clinic. This section will explore some of the reasons for this and relevant quotes from the interviews will be used.

It is evident from photo 1 of this report that the local clinic is very small. The majority of the respondents remarked that the local clinic was too small and overcrowded. Furthermore, respondents remarked that the clinic didn't have all the necessary medication available and did not supply antiretroviral treatment. If respondents did attend the local clinic they were mostly referred to Hamberg Clinic and Leratong Hospital, therefore respondents indicated that they preferred to go directly to these health care facilities in the first instance.

Respondents remarked that there was a shortage of health care personnel at the local clinic and this led to long waiting times. It is important to note that the most of the respondents remarked that the shortage of staff was not only a barrier in accessing health care services at the local clinic, but also in the public health system as a whole. This is important in light of the equity framework used in this study. As mentioned earlier, the shortage of health care personnel within the public health system in South Africa is a major obstacle in obtaining equity in health.

The small size and overcrowding of the clinic, the clinic's lack of medication and its shortage of health personnel, that respondents indicated as the main barriers in accessing health care from the local clinic, are illustrated by the following quotes from the interviews:

“There is a nearest mobile clinic, but I don't like using it because it does not have all the medication one might need. It is too small and their service is not good because you can stay there the whole day before they help you. It is difficult especially when you are too weak to wait and sit in that queue the whole day”. (Male respondent)

“Some clinics are ok, some are not. I think they need to employ more staff. The demands exceed supply, e.g. in this clinic in Sol Plaatjies you will also see people sitting outside as the clinics are very small. So there is a need for expanding the clinics”. (Female respondent)

2.3 The 'Availability' dimension of access in regard to ART

It is important to note that, in this study, all data relating to ART are based on self-reports by the respondents. The researcher did not have access to their medical records and could not verify the self-reports.

In total seven of the ten respondents reported that they were eligible for receiving ART from government facilities²⁵. Of these seven respondents, one respondent preferred not to take ART,

²³ Hamberg Clinic is a government clinic situated about 10 km northeast of Sol Plaatjies and when using public transport one has to use both a taxi and a train to get to the clinic.

²⁴ Leratong Hospital is a government hospital situated about 5 km west of Sol Plaatjies.

whilst the other six respondents were receiving ART. These six respondents reported that they were all taking the ART as prescribed and all of them reported they attend six-monthly tests of their CD4 count and viral load. None of these six respondents reported any side-effects of the ART. As mentioned before, the local clinic does not provide ART. The majority of the respondents, who reported receiving ART, accessed it from Hamberg Clinic.

As mentioned earlier in this report the National Strategic Plan on HIV and STI (NSP) has universal access to ART as one of its main goals (NSP, 2007). The results from this study show that for those interviewed, access to ART was not a problem. However, this cannot be extrapolated to the entire population of people living with HIV who are in need of ART.

As mentioned before, evidence shows that universal access to ART is still far from being achieved: a mere quarter of persons in need of ART in 2007, were actually receiving it (Schneider et al, 2007).

3. The 'Affordability' dimension of access

This access dimension concerns the 'degree of fit' between the cost of utilizing health care services and individuals' ability to pay (Thiede *et.al*, 2007). The cost of care in general is described. Furthermore, the cost of transport and the issue of food security when taking ART are discussed. This section is concluded by discussing the HIV Disability Grant in regard to the 'affordability' dimension of access.

3.1 The cost of care

This included all costs associated with the care process and not only costs directly linked to health care such as clinic fees or medication. Six of the respondents at some stage had to borrow money or sell personal/household items to pay for health care. Furthermore, six of the respondents found it difficult to incur expenses for health care

None of the respondents had to pay consultation fees at the clinics or pay for medication. This is in line with the government's free primary care policy that was outlined earlier in this report. Respondents who reported receiving ART, didn't have to pay for it either. It is therefore clear that the costs that respondents needed to incur, didn't relate to health care costs, but rather to other costs involved in accessing health care services. In this study the cost of transport and the cost of food (food security) emerged as the main barriers faced by respondents in regard to the 'affordability' dimension of access to health care services and antiretroviral treatment.

3.2 The cost of transport

As mentioned earlier, the majority of the respondents decided to not seek care at the local clinic, but decided to seek care at government health care facilities further away. Their facilities of preference were Hamberg Clinic and Leratong Hospital. Furthermore, the majority of respondents who reported receiving ART were accessing it from Hamberg Clinic, because the local clinic does not provide ART.

²⁵ The South African Department of Health Guidelines defined the eligibility criteria for receiving ART as a CD 4 count below 200/mL

These facilities (Hamberg Clinic and Leratong Hospital) are respectively 10km and 5km away from Sol Plaatjies and respondents were required to spend money on transport in order to get to these facilities. The majority of the respondents found it difficult to incur these transport costs.

3.3 The cost of food (food security)

The majority of the respondents remarked that food security was a major issue, which became especially acute if they had to take ART. All of the respondents stressed the importance of a healthy, balanced diet for people living with HIV, although the majority of the respondents reported that they did not have the money to buy healthy food such as fruit and vegetables. The issue of food security and antiretroviral treatment is evident from the following quote:

“My health is poor because I am HIV positive, I have lost weight, my CD4 count has dropped to 273 and I get sick often. I am scared that if I get sick they will prescribe ARVs and I don’t have food to take it with.” (Female respondent)

The issue of food security is echoed in data from the RENEWAL household survey. This survey found that of 192 households, the majority reported being food insecure in the last 12 months. In almost 50% of cases an unreliable income was the reason for food insecurity (Vearey, Nunez, Palmary, 2008).

In light of compelling evidence that supports the importance of food security when taking ART (Paton *et.al*, 2006), it is important to note that none of the respondents reported receiving any support in the form of food and that only two of the ten households reported having their own vegetable garden.

3.4 The HIV Disability Grant in regard to the ‘Affordability’ dimension of access

As mentioned earlier, the majority of respondents were dependent on social grants to cover their daily living expenses. Some of the respondents remarked that the cost of living was higher for people living with HIV. However, only two of the respondents reported that they were eligible for and receiving an HIV Disability Grant ²⁶. In light of this some of the respondents remarked that the eligibility criteria for the HIV disability grant should be reviewed.

“My CD4 count does not allow me to be on ARVs. I was told that my CD4 count was still ok and I should only take care of myself. How do I take care of myself when I don’t have the means to? I stress that we should be given the grant simply because we are infected”.
(Male respondent)

4. The ‘Acceptability’ dimension of access

Acceptability refers to the nature of service provision and how this is perceived by individuals and communities. The way in which health services are delivered may deter them from using services to the desirable extent (Thiede *et.al*, 2007). In this section, quality of care, testing for HIV and knowledge about ART and stigma surrounding HIV/AIDS are discussed.

²⁶ In South Africa people living with HIV are eligible for an HIV Disability Grant when their CD4 count drops below 200/mL. Also see, www.southafrica.info/about/social/social_grants.htm

4.1 Quality of care

All the respondents reported that they were treated in a friendly and helpful manner by the health care provider of their choice. Nine of the ten respondents indicated that they would go back to the particular health care provider in future, whilst all the respondents reported that, in going to their particular health care provider, they had received the care that they wanted and/or needed in order to resolve their health problem. This is important, as it highlights the fact that once the respondents have overcome the numerous barriers in accessing health care, they were mostly satisfied with the care that they received.

4.2 Testing for HIV and knowledge about ART

All the respondents knew where someone from Sol Plaatjies could be tested for HIV. The closest testing facility was the local clinic in Sol Plaatjies. All the respondents reported to knowing what ART was and where it could be accessed from. The RENEWAL household survey, on the other hand, found that more than 50% of internal migrants did not know where ART could be accessed from (Vearey, Nunez, Palmary, 2008).

It is important to note that the respondents in this study were individuals who have disclosed their HIV status and were willing and able to talk about HIV and ART. Because of this, they might have been more likely to have knowledge about ART.

The local clinic in Sol Plaatjies provided services for voluntary testing and counseling for HIV, but some of the respondents highlighted the issue of testing as a barrier in accessing health care services and antiretroviral treatment. This is illustrated in the following quote:

“There are lots of people who would love to be tested, but access is a problem. They put it down there (at the end of the corridor); you should feel the breeze of the graveyard before you get to the testing room. It affects you psychologically and some people don’t even get to the end of the corridor. It is not accessible to be tested. It should be fun to be tested, but young people aren’t motivated to know their status.” (Male respondent)

These findings are echoed in data from the RENEWAL household survey, which showed that 36% of respondents had never tested for HIV. Of the respondents that had tested for HIV, only 5% indicated encouragement by an awareness campaign as the principal reason for testing (Vearey, Nunez, Palmary, 2008).

4.3 Stigma and HIV/AIDS

From the interviews it emerged that stigma surrounding HIV/AIDS remained an obstacle and might deter people from using health care services. Some of the respondents remarked that, at most of the government health care facilities, there were separate queues and waiting areas for people wanting to make use of 'general' health care services, and those people living with HIV wanting to access antiretroviral treatment. The respondents reported that this separation added to the stigma that surrounds HIV. The following quote illustrates this:

“At the clinics there are two lines, one for HIV positive people and one for the rest. I think that is bad. There should only be one line for both HIV positive and HIV negative people.” (Female respondent)

The need of people living with HIV to not be stigmatised or discriminated against is further illustrated by the fact that all the respondents indicated that people with HIV do not need special forms of care, as this special care could potentially lead to further stigma and discrimination.

5. Summary of the difficulties the respondents faced in accessing health care services in general and ART

All the respondents received the care that they wanted and or/needed when they consulted their particular health care provider. Furthermore, all of the respondents who reported being eligible for receiving ART and wanted to take ART, were indeed receiving ART. However, half of the respondents rated their health as 'poor' and faced numerous barriers in accessing health care services in general and ART. These barriers are summarized below using the 'Access framework':

1. Availability: All of the respondents, who sought care, did so at a government health facility in the first instance. The respondents reported that, the local clinic was too small, overcrowded, lacked the necessary medication, didn't supply ART and had a shortage of health care personnel. Therefore most of the respondents preferred to go to health care facilities further away.

2. Affordability: Most of the respondents reported that they at some stage had to borrow money or sell personal items to pay for health care. Most of the respondents remarked that they found it difficult to incur these expenses. None of the respondents reported having to pay fees for clinic consultations, medication or ART. As mentioned before, the majority of the respondents preferred to not go to the local clinic and those respondents who reported receiving ART had to travel to other clinics as the local clinic did not supply ART. Therefore respondents reported the cost of transport to be a major barrier in accessing health care services and ART. Furthermore, respondents remarked that the cost of food was a problematic, especially when taking ART. In light of these barriers, some of the respondents called for a review of the HIV Disability Grant.

3. Acceptability: As mentioned earlier, the majority of the respondents were satisfied with the quality of care that they received from their particular health care provider. All of the respondents knew where someone could be tested for HIV and reported knowing what ART was. Some of the respondents remarked that testing for HIV and the stigma surrounding HIV/AIDS could be potential barriers for people living with HIV in accessing health care services and ART.

Chapter 5: Recommendations

Inequity in health remains a global problem. Worldwide there have been renewed calls on policy makers in the health field to closing the gap in health equity by addressing the social determinants of health (WHO CSDH, 2008). When considering the South African context, the country is still characterized by huge inequities, despite the fact that the right to equity and health is enshrined in the South African Constitution. The Constitution is also explicit in acknowledging the importance of the social determinants of health (Heywood, 2007).

From this study it emerged that the respondents in Sol Plaatjies were aware of the negative impacts of poor living conditions and the lack of basic services on their health. Respondents struggled with their health and faced numerous barriers in accessing health care services in general and ART.

Key recommendations will be made under three headings:

1. Recommendations for addressing access to basic services
2. Recommendations for addressing access to health care services and ART
3. Recommendations for further research

It is hoped that these recommendations might impact on narrowing the inequities characterizing the South African society.

1. Recommendations for addressing access to basic services (Social Determinants of Health)

Local government authorities in South Africa have a Constitutional duty to be developmental in their approach and are responsible for improving the living conditions of all citizens, including those living in informal settlements. Therefore the following recommendations are made to local government authorities:

- Local government needs to step up its developmental mandate to improve the living conditions of all people living in informal settlements
- Local government must act upon the social determinants of health. This will require a multisectoral response to in situ informal settlement upgrading
- Local government needs to actively involve communities in the upgrading of informal settlements. Communities need to become active partners to local government in improving basic service provision, such as water, sanitation and waste removal.

2. Recommendations for addressing access to health care services in general and ART

Addressing people living with HIV in informal settlements' access to health care services in general and ART, requires input from a variety of role players. These include local government, the National Department of Social Development and the national, provincial and local Departments of Health. Each of these role players have their own specific mandate, but they have to work together in improving people living with HIV in informal settlements' access to health care services in general and ART. Therefore the recommendations below are addressed to all the role players in general.

2.1 The 'Availability' dimension of access

-Primary health care facilities in informal settlements need to be enlarged, be equipped with the necessary medication and the shortage of health care personnel at these facilities needs to be addressed.

-There is an urgent need to address the issue of human resources within the public health system as a whole. This could include:

- Offering health care professionals financial incentives to remain working in the public health system
- The setting up of partnerships between the public and the private health systems

2.2 The 'Affordability' dimension of access

-People living with HIV in informal settlements and taking ART, struggle with the cost of transport to access ART. There is a need for more clinics to be able to rollout ART, so that these people don't have to travel that far and incur high transport costs in order to be able to access ART.

-Food security in informal settlements needs to urgently be addressed. This need becomes even more acute for people living with HIV who need to take ART.

- People living in informal settlements could be assisted in setting up food gardens at home
- NGOs could become more involved in food security in informal settlements
- There is a need for the eligibility criteria for the HIV Disability Grant to be reviewed

2.3 The 'Acceptability' dimension of access

- There is a need to further address the stigma that still surrounds HIV/AIDS in informal settlements

3. Recommendations for further research

In this study all the respondents who reported being eligible for receiving ART and who wanted to take it, reported that they were indeed receiving it and taking the treatment as prescribed.

Further research is needed to identify those people living with HIV in informal settlements who aren't accessing ART and the reasons for this, as this study highlights the challenges in identifying these individuals.

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References

- Bloom, G. and McIntyre, D. (1998). Towards equity in health in an unequal society. *Social Science Medicine*, 47(10), 1529-1538
- Boraine, A., Crankshaw, O., Engelbrecht, C., Gotz, G., Mbanga, S., Narsoo, M., Parnell, S. (2006). The state of South African cities a decade after democracy. *Urban Studies*, 43(2), 259-284
- Brodie, N. (2008). *The Joburg Book: A guide to the city's history, people and places*. Johannesburg, Pan Macmillan and Sharp Sharp Media.
- City of Johannesburg. (2005). *Human Development Strategy: Joburg's Commitment to the poor*. Johannesburg, Office of the City Manager, Corporate Planning Unit .
- City of Johannesburg. (2008). *Joburg City Slide Pack*. Available at: City of Johannesburg, www.joburg-archive.co.za/2008/pdfs/overview2008.pdf (Retrieved 16 September 2008).
- CSDH (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health*. Geneva, World Health Organization CSDH.
- Czegledy, A. P. Villas of the Highveld: A Cultural Perspective on Johannesburg and its "Northern Suburbs". In: Tomlinson, R., Beauregard, R. A., Bremmer, L. and Mangcu X., eds. (2003). *Emerging Johannesburg: Perspectives on a Postapartheid City*. London, Routledge.
- Davie, L. (2007). *Shack settlements: not here to stay*. Available at: City of Johannesburg, <http://www.joburg.org.za/content/view/1949/204/> [Retrieved 15 October 2008]
- De Wet, T., Patel, L., Korth, M. and Forrester, C., eds. (2008). *Johannesburg Poverty and Livelihoods Study*. Johannesburg, Centre for Social Development in Africa (University of Johannesburg).
- Department of Health. (2007). *HIV & AIDS & STI Strategic Plan for South Africa 2007-2011*. Pretoria, Department of Health.
- Donnelly, L. (2007). *Sol Plaatje gets a facelift*. Available at: Mail & Guardian online, <http://www.mg.co.za/article/2007-09-04-sol-plaatje-gets-a-facelift> (Retrieved 15 September 2008)
- Editorial. (2006). Health inequalities: The Black Report after 25 years. *Public Health*, 120, 185-6.
- Editorial. (2007). Medical Students as champions for social justice. *The Lancet*, 370, 457.

- Giacomini, M. K. and Cook, D. J. (2000). Users' guides to the medical literature XXIII. Qualitative Research in Health Care A. Are the results of the study valid? *Journal of the American Medical Association*, 284(3), 357-362.
- Gwatkin, D. R. (2000). Health inequalities and the health of the poor: What do we know? What can we do? *Bulletin of the World Health Organization*, 78(1), 3-18.
- Heywood, M. A background to health law and human rights in South Africa. In: Hassim, A., Heywood, M. and Berger, J., eds. (2007). *Health and Democracy: A guide to human rights, health law and policy in post-apartheid South Africa*. Cape Town, Siberink.
- Huchzermeyer, M.; Baumann, T. and Salah, M (2004): Background Report 3: Informal Settlement Practice in South Africa's Metropolitan Cities. *Study into the support informal settlements for the Department of Housing, Pretoria*.
- Human Sciences Research Council (HSRC). (2004). *Fact Sheet No. 1. 26 July, 2004: Poverty in South Africa*. Pretoria, HSRC.
- Joint United Nations Programme on HIV/AIDS (UNAIDS).(2008). *2008 Report on the global AIDS epidemic*. Geneva, UNAIDS.
- Krishnan, S., Dunbar, M.S., Minnis, A. M., Medlin, C. A., Gerdtts, C. E. and Padian, N. S. (2008). Poverty, gender inequities, and women's risk of Human Immunodeficiency Virus/AIDS. *Annals of the New York Academy of Sciences*, 1136, 101-110.
- Marais, H. (2007). The uneven impact of AIDS in a polarized society. *AIDS*, 21(3), S21-S29.
- McIntyre, D. and Gilson, L. (2000). Redressing dis-advantage: Promoting vertical equity within South Africa. *Health Care Analysis*, 8, 235-258.
- McIntyre, D. and Gilson, L. (2002). Putting equity in health back into the social policy agenda: experience from South Africa. *Social Science & Medicine*, 54, 1637-1656.
- McIntyre, D. and Thiede, M. Health Care Financing and Expenditure. In Harrison, S., Bhana, R. and Ntuli, A., eds. (2007). *South African Health Review 2007*. Durban, Health Systems Trust.
- Medical Research Council (MRC). (2008). *Joburg Connections: an integrated community approach to addressing HIV/AIDS. Process evaluation Report*.

National Department of Housing South Africa. (2004). *“Breaking New Ground”: A comprehensive plan for the development of sustainable human settlements*. Pretoria, National Department of Housing South Africa.

Office of the High Commissioner for Human Rights (OHCHR). (2005). *Universal Declaration of Human Rights*. Available at <http://www.unhcr.ch/udhr/lang/eng.htm> (Retrieved 12 September 2008).

Ohkubo S. (1997). *IMF Structural Adjustment*. Available at <http://wwwnew.towson.edu/polsci/ppp/ppp.html> (Retrieved 15 September 2008)

Parnell, S. and Robinson, J. (2006). Development and Urban Policy: Johannesburg’s City Development Strategy. *Urban Studies*, 43(2), 337-355.

Paton, NI et al. (2006). The impact of malnutrition on survival and the CD4 count response in HIV-infected patients starting antiretroviral therapy. *HIV Medicine*, 7(5):323–330.

Piot, P., Greener, R. And Russell, S. (2007). Squaring the circle: AIDS, poverty, and human development. *PLoS Medicine*, 4(10), 1571-1575.

Posse M., Meheus F., Van Asten H., Van der Ven A., Baltussen R. (2008). Barriers to access to antiretroviral treatment in developing countries: a review. *Tropical Medicine and International Health*, 13(7), 904-913.

Random House Unabridged Dictionary(2009). *Equity*. Available at: <http://dictionary.reference.com/browse/equity> (Retrieved 10 September 2008)

Richards, R., O’Leary, B. and Mutsonziwa, K. (2007). Measuring quality of life in informal settlements in South Africa. *Social Indicators Research*, 81, 375-388.

Ruger, J. P. (2004). Health and social justice. *The Lancet*, 364, 1075-1080.

Schneider, H., van Rensburg, D. and Coetzee, D. (2007). *Round-table Conference Report. Health systems and antiretroviral access: Key findings and policy recommendations*. Bloemfontein, Centre for Health Systems Research and Development (University of the Free State).

Seeking, J. (2007). *Poverty and inequality after apartheid. Working Paper 07/200*. Cape Town, Centre for Social Science Research (University of Cape Town).

Shisana, O., Rehle, T., Louw, J., Zungu-Dirwayi, N., Dana, P. and Rispel, L. (2006). Public perceptions on national health insurance: Moving towards universal health coverage in South Africa. *South African Medical Journal*, 96(9), 814-818.

- The Presidency Republic of South Africa (2007). *Development Indicators: Mid-term Review*. Pretoria, Policy Coordination and Advisory Services (PCAS) in The Presidency.
- The Presidency Republic of South Africa. (2000). *Local Government Municipal Systems Act*. Cape Town, The Presidency Republic of South Africa.
- The World Bank Group. (2009). *South Africa: country brief*. Available at <http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/SOUTHAFRICAEXTN/0,,menuPK:368086~pagePK:141132~piPK:141107~theSitePK:368057,00.html> (Retrieved 10 September 2008).
- Thiede, M., Akweongo, P. and McIntyre, D. Exploring the dimensions of access. In: McIntyre, D. and Mooney, G., eds. (2007). *The Economics of Health Equity*. United Kingdom, Cambridge University Press.
- Thomas, E. H. HIV/AIDS: Implications for Local Governance, Housing and Delivery of Services. In: Tomlinson, R., Beauregard, R. A., Bremmer, L. and Mangcu, X., eds. (2003). *Emerging Johannesburg: Perspectives on a Postapartheid City*. London, Routledge.
- United Nations (UN). (2008). *The Millennium Development Goals Report*. New York, UN.
- United Nations Development Programme (UNDP). (2005). *Human Development Report 2005*. New York, UNDP.
- Vearey J., Núñez L., Palmary I. (2008). HIV, migration and urban food security: exploring the linkages. *RENEWAL (Regional Network on AIDS, Livelihoods and Food Security) South Africa Report*. Johannesburg, Forced Migration Studies Programme (University of the Witwatersrand).
- Vearey, J. (2008) *Revised PhD Protocol submitted to the University of the Witwatersrand's Faculty of Health Sciences Postgraduate Committee*.
- Vearey, J., Palmary, I. (2008). *Forced Migration Studies Programme: Assessing non-citizen access to antiretroviral therapy in Johannesburg*. Johannesburg, Forced Migration Studies Programme (University of the Witwatersrand).
- Wadee H., Khan F. Human Resources for Health. In Harrison, S., Bhana, R. and Ntuli, A., eds. (2007). *South African Health Review 2007*. Durban, Health Systems Trust.
- Whitehead, M. (1991). The concepts and principles of equity and health. *Health Promotion International*, 6(3), 217-228.
- World Health Organization (WHO). (1986). *Ottawa Declaration: Prerequisites for health*. Geneva, WHO.

Appendix 1

Participant Information Sheet



The University of the Witwatersrand (WITS)



Medical Research council (MRC)

Name of the study:

TO INVESTIGATE THE DIFFICULTIES PEOPLE LIVING WITH HIV IN INFORMAL SETTLEMENTS FACE IN ACCESSING BASIC SERVICES AND HEALTH CARE, WITH THE FOCUS ON ACCESS TO ANTIRETROVIRAL TREATMENT, USING SOL PLAATJE INFORMAL SETTLEMENT IN JOHANNESBURG, SOUTH AFRICA, AS A CASE STUDY

Introduction:

Good day! We are Simon Mporetji and Jacques Bezuidenhout from the Wits Centre for Health Policy. We want to better understand the difficulties HIV positive people living in Sol Plaatje informal settlement face in accessing basic services and health care. We would like to invite you to participate in a study about this. This will involve asking you questions on themes around HIV and access to basic services and health care, guided by a semi structured questionnaire. In this sheet you will find information about the study and what we are hoping to discuss with you.

We have embarked upon a study on HIV and access to basic services and health care in informal settlements in Johannesburg, and we will use Sol Plaatjies as an example of such an informal settlement. In this study we want to explore the difficulties HIV positive people living in Sol Plaatjies face in accessing basic services and health care. We will specifically focus on access to antiretroviral therapy (ART).

Urban informal settlements in South Africa are known to have the highest HIV prevalence rate of all household types of 25.8%, and despite the government's policy of universal access to ART, a large proportion of people who are in need of ART still don't have access to it.

Semi structured interviews with key informants will be conducted during this study. The purpose of the key informant semi-structured interviews is to get them to answer questions that relate to their experiences of accessing basic services and health care, particularly ART, in the context of HIV in the Sol Plaatjies informal settlement.

The information from the key informant semi-structured interviews will help with policy recommendations that will be made at the local level. The recommendations will consider HIV positive residents of urban informal settlements.

What is involved in this study? This study involves HIV positive respondents in Sol Plaatjies informal settlement. The study involves a contextual understanding of the difficulties HIV positive people face in accessing basic services and health care, with a specific focus on access to antiretroviral therapy (ART).

Length and place of interview: The key informant semi-structured interviews will take place in Sol Plaatjies, at a venue convenient to both the participant and the researcher. The researcher will contact you in advance of the interview to arrange a convenient time and place.

The interviews will be conducted in a private place that is agreeable to both the participant and the researcher. The interview will be undertaken once with each participant. Each questionnaire will last about 45 minutes. The maximum time you will be needed to participate is 1 hour. You will be able to ask the person interviewing you to stop the interview at any time, without any consequences to you.

Jacques will be the main interviewer and will conduct the interviews in English, but Simon is able to speak a number of African languages and will be present during the interviews if translation and/or clarification should be needed.

Number of Participants: 10 key informants are expected to participate in this study. All participants will be HIV positive, 18 years or older, and have given informed consent to participate in the study.

Procedures: If you agree to participate in this study, you will be interviewed by a trained researcher. The researcher will ask you questions and allow you to answer the questions in your own words.

Confidentiality: The information that is obtained in the interview will be kept confidential. At the end of the data collection process, a report will be written up. This report will include information that you have given to us, but your name will not be used. No one apart from the researchers in this study will know that any particular information obtained was provided by you.

If you want to know more about this study, please contact facilitators:

Jacques Bezuidenhout Research student

071 350 9832

j.b.bezuidenhout@student.ru.nl

Simon Mporetji

Staff member, Wits Centre for Health Policy

082 058 8566

dmporetji@yahoo.com

Dr. Liz Thomas

Senior researcher, Wits Centre for Health Policy
And Medical Research Council (MRC)

082 447 2293

(011) 242 9909

liz.thomas@nhls.ac.za

Appendix 2:

CONSENT FORM: PARTICIPANT SEMI- STRUCTURED INTERVIEW

Study Title:

TO INVESTIGATE THE DIFFICULTIES PEOPLE LIVING WITH HIV IN INFORMAL SETTLEMENTS FACE IN ACCESSING BASIC SERVICES AND HEALTH CARE, WITH THE FOCUS ON ACCESS TO ANTIRETROVIRAL TREATMENT, USING SOL PLAATJE INFORMAL SETTLEMENT IN JOHANNESBURG, SOUTH AFRICA, AS A CASE STUDY

Researcher: Jacques B. Bezuidenhout, BSc (Medicine)

Organisation: MRC and Wits Centre for Health Policy

Telephone Numbers: 011 242 9909
.....

Name of Participant: _____

Date interview: _____

Introduction:

Good day! I am _____ from Wits Centre for Health Policy and we are trying to better understand the difficulties HIV positive people living in informal settlements in Johannesburg face in accessing basic services and health care.

I the undersigned, agree to participate in the study conducted by Mr. J.B Bezuidenhout, a student doing his research elective under the supervision of Dr. E.P Thomas. Dr. Thomas is a senior researcher at the Medical Research Council (MRC) and the Centre for Health Policy which forms part of the School of Public Health at the University of the Witwatersrand, Johannesburg. This study seeks to explore the difficulties HIV positive people living in informal settlements in Johannesburg face in accessing basic services and health care.

My participation in this study is hereby acknowledged as voluntary, and the researcher has assured me that the information that is obtained in the interview will be kept confidential, and will protect my individual identity. I am also aware that I can withdraw from participating at anytime during the session. No individual names will be linked to any information whether the results of this study are published or not. On this note:

I consent to the use of tape recorders during the interview:
YES___ NO___

I consent to the use of direct quotes in the final document, in so far as my identity is **NOT** linked to them: YES___ NO ___

Participants who have concerns regarding the study can contact **Dr. E.P Thomas** at **(011) 242 9919** or email her at liz.thomas@nhls.ac.za

Signature of Participant: _____ **Date:** _____

Researcher's Signature: _____ **Date:** _____

Audio Taping Informed Consent Form

The researcher explained the purpose of the study to me and I have read and understood the information sheet. I give my consent to be audio taped and have been informed that the voice clips from the tapes would only be used for the study:

TO INVESTIGATE THE DIFFICULTIES PEOPLE LIVING WITH HIV IN INFORMAL SETTLEMENTS FACE IN ACCESSING BASIC SERVICES AND HEALTH CARE, WITH THE FOCUS ON ACCESS TO ANTIRETROVIRAL TREATMENT, USING SOL PLAATJE INFORMAL SETTLEMENT IN JOHANNESBURG, SOUTH AFRICA, AS A CASE STUDY

I was made aware that the voice clips would be kept for two years after publication or up to six years if no publication has been made. All voice clips would be kept under lock and key, to which only researchers in this study would have access.

I understand also that I can withdraw my consent at anytime, without being prejudiced

Name of Participant: _____ **Signature** _____ **Date** _____

Name of Researcher: _____ **Signature** _____ **Date** _____

Appendix 3:

RESEARCH QUESTIONNAIRE:

Title of study

TO INVESTIGATE THE DIFFICULTIES PEOPLE LIVING WITH HIV IN INFORMAL SETTLEMENTS FACE IN ACCESSING BASIC SERVICES AND HEALTH CARE, WITH THE FOCUS ON ACCESS TO ANTIRETROVIRAL TREATMENT, USING SOL PLAATIJES INFORMAL SETTLEMENT IN JOHANNESBURG, SOUTH AFRICA, AS A CASE STUDY

Checklist (To be completed before commencing interview)

1. Information sheet discussed (Attach information sheet as an appendix)
2. Informed consent obtained (Attach informed consent form as an appendix)
 - Consent to participate in the interview
 - Consent to the interview being audio taped

Section A: Administration

1. Respondent number (The person used as entry point will be assigned the number 01, the following respondents will receive a number in a chronological order)
2. Short notes on how the respondent was met, in order to be able to link the respondents (this information will be confidential and will only be used by the researcher for logistical purposes)
3. Date of the interview
4. Interview start time and end time

Start:

End:

Total duration:

Section B: Demographic information

1. Respondent's sex: Male/Female
2. Year of birth

Section C: Socioeconomic background

Questions derived from:

REACH study (Researching Equity in Access to Health care)	RENEWAL study (Regional Network and AIDS, livelihoods and food security)	Non-citizen access to ART study (Wits Forced Migration Unit)	Author self (assisted by supervisor)
1, 2, 3, 4, 5,6, 9	8, 9	-	7

1. Including yourself, how many adults (18 years and older) live in your household? When I talk about your household, I am including all the people who live in your house and who share the same food with you.
2. How many children (younger than 18 years) live in your household?
3. Who is the head of your household? By this, I mean, who is the person who usually makes the important decisions in the household. Indicate relationship e.g. father, mother, husband
4. What is your position in the household, in relation to the head of the household?
 - Head
 - Husband/Wife/Partner
 - Son/Daughter/Stepchild/Adopted child
 - Brother/Sister (or step brother or step sister)
 - Father/Mother (or step father or step mother)
 - Grandparent/Great grandparent
 - Grandchild/Great grandchild
 - Other relative (e.g. in laws, aunt/uncle)
 - Non-related persons (tenant, boarder, lodger)
 - Other, specify
5. Are you currently working or earning money? If the person is not the head of the household, ask 'is your head of household, e.g. husband/father/mother currently working or earning money?'

Type of employment	You	Your Head of Household
Yes, full-time		
Yes, part-time		
No		
Don't know		

6. If the respondent or head of household is not employed, what are the reasons?

7. If you or the head of the household isn't working, please tell me how you (or the head of the household) pay for housing, food and school fees?

8. During the last 12 months, have you or any other member of the household received money or goods by means of the following:

	Money	Goods	Which goods?
Social grant			
NGO			
Religious group			
Other, specify			

9. Does your household have any of the following items (in good working order)?

Type of asset	Yes	No
Telkom/landline phone		
Cell phone		
Radio		
Television		
Video recorder/DVD player		
Personal computer at home		
Fridge		
Electric stove with oven		
Bicycle		
Car/Truck/Bakkie		
Sewing machine		
Cattle		
Other livestock, e.g. chickens		
Vegetable garden		

Section D: Migration History

Questions derived from:

REACH study (Researching Equity in Access to Health care)	RENEWAL study (Regional Network and AIDS, livelihoods and food security)	Non-citizen access to ART study (Wits Forced Migration Unit)	Author self (assisted supervisor) by
1	1, 2	1	3

1. Where were you born?
2. Have you always lived in this residence? Yes/NO
 - If NO, where did you live before you came to Sol Plaatje? This is the place that you last lived in before you moved to Sol Plaatje.
 - Was it urban/rural?
 - When did you arrive at this residence?
 - Why did you come to this residence?
 - Are you satisfied with this residence? Please explain why/why not.
3. What is your home language?

Section E: Access to Basic Services

Questions derived from:

REACH study (Researching Equity in Access to Health care)	RENEWAL study (Regional Network and AIDS, livelihoods and food security)	Non-citizen access to ART study (Wits Forced Migration Unit)	Author self (assisted supervisor) by
1.1, 1.2, 2.1- 2.3, 3.1-3.4,	1.1, 1.2, 2.1-2.3, 3.1-3.4, 4	1.1	5.1-5.3

1. Housing:

1.1 Observation of the type of housing:

- Reconstruction and Development Programme (RDP) house
- Former mine managers' houses
- 'Silvertown': Temporary shack settlement whilst renovations are being done to the old mine housing units

Type of dwelling the households lives in:

- House or brick structure on a separate stand or yard
- Town/cluster/semi detached house (simplex, duplex, triplex)
- Flat
- Dwelling/house/room in backyard
- Traditional dwelling/hut/structure made of traditional materials
- Informal dwelling/shack in backyard of a formal house
- Informal dwelling/shack in an informal/squatter settlement
- Worker's hostel

1.2 How many rooms, including kitchens are there in this household?

- How many rooms are used for sleeping?
- How many households live in this dwelling?

2. Electricity:

2.1 Does the household have electricity? Yes/No

2.2 What is the main type of fuel that the household uses for cooking?

- cow dung
- wood
- paraffin
- gas
- coal/antracite
- electricity
- charcoal
- kerosene
- other, specify

2.3 What is the main type of fuel the household uses for lightning?

- Wood
- Candles

- Paraffin lamp
- Gas lamp
- Electricity
- Kerosene

3. Water and sanitation:

3.1 Does the household have running water inside the household? Yes/No

3.2.1 If NO, where does the household obtain water?

- Communal tap/standpipe
- Storm drain
- Buy water from water seller
- Inside tap, but not inside this household
- Buy water from the landlord
- Surface water (Lake, pond, stream)
- Borehole
- Water carrier/tanker

3.3.2 How many households share this water source?

3.3 Does the household pay for water?

3.4 What kind of toilet facility does the household use?

- Flush toilet connected to the main sewer inside the dwelling
- Flush toilet connected to the main sewer outside the dwelling (communal)
- Toilet not connected to main sewer, inside the dwelling
- Toilet not connected to main sewer, outside the dwelling (portable toilet)
- Pit latrine (household)
- Pit latrine (communal)
- Bucket
- No facility/bush/field

4. Waste:

4. How does the household mainly get rid of waste or rubbish?

- Burn the rubbish
- Dump rubbish outside the yard
- Put on rubbish dump nearby
- Rubbish gets collected weekly
- Rubbish gets collected irregularly
- Throw rubbish on the streets
- Other, specify

5. General:

5.1 Are you satisfied with the level of basic service delivery in your community? By this I mean are you satisfied with the manner in which you receive water, waste removal and sanitation?

5.2 Would you say that your HIV positive status has/had an influence on your access to basic services? For example, do HIV positive people access water differently than HIV negative people? Please explain.

5.3 Have the problems in accessing services impacted on your health?

Section F: Access to health services

Questions derived from:

REACH study (Researching Equity in Access to Health care)	RENEWAL study (Regional Network and AIDS, livelihoods and food security)	Non-citizen access to ART study (Wits Forced Migration Unit)	Author self (assisted supervisor) by
6.3-6.9, 7.8-7.12	6.1-6.7.4, 7.1-7.6,	7.1-7.4, 7.6, 7.7	7.7.2: 3 rd bullet

General:

6.1 How would you rate your general state of health, in relation to your age?

- Excellent
- Good
- Fair
- Poor

6.2 Where is the nearest primary healthcare clinic? Name of clinic

6.3 When was the last time you felt sick enough to seek care?

6.4 Can you tell me more about this illness?

6.5 Did you seek care for this episode of illness? Yes/No

6.5.1 If YES, where did you first seek care for this particular episode of illness?

- Government clinic
- Government hospital
- Private clinic
- Private hospital
- Private doctor
- Pharmacy
- NGO
- Traditional healer/Faith healer
- Church/ pastor

Please explain why you decided to seek care and why you decided to seek care at this specific person/location.

6.5.2 If NO, what are the reasons why you decided not to seek care?

6.6 If you went to seek care, how did you get to this healthcare provider?

- Walked
- Taxi (Combivan)
- Bus
- Metered cab (private)
- Train
- My own private car
- I got a ride with someone

6.7 .1 In going to see this health care provider, how much did you pay for:

- Transport (one way)
- Clinic/Provider fees
- Medicines
- Someone to take over your tasks while you were away, including childcare
- Accommodation if you needed to stay the night
- Food during visit
- Phoning
- Other, specify

6.7.2 Did you have to borrow money to pay for this health care?

6.7.3 Did you have to sell personal or household items in order to pay for this health care?

6. 7.4 Did you find it easy or difficult to incur these expenses?

Easy	
Difficult	
Neither easy nor difficult	
Don't know	

6.7.5 If you went to a government clinic for this health care, was it the closest facility to your home that offers health care services for this particular illness? If it wasn't the closest, please explain why you decided to go to a clinic farther away.

6.8.1 Can you tell us about your relationship with the provider/staff at the facility?

- How were you treated at the facility?
- Why do you think you were treated in this way?
- Who made the decisions in choosing the particular path of care?
- Would you go back to this provider/facility in future?

6.9 In seeking the assistance of the specific health care provider, did you receive the care that you wanted or needed in order to resolve your problem? What did you do after this?

Questions relating to HIV/AIDS and antiretroviral therapy (ART):

7.1 Do you know where someone from this community can be tested for HIV? Please tell me where

7.2 Testing for HIV:

7.2.1 When did you first test for HIV?

7.2.2 Where did you first test for HIV?

7.2.3 Why did you decide to test?

7.3 When did you first find out that you were HIV positive?

7.4 At which site did you find out that you were HIV positive?

7.5 Are you currently receiving any support?

- Home based care
- Support group
- Support from household
- Support from friends
- Grant
- Food
- Nutritional supplement
- Other, specify

7.6 Do you know what antiretroviral drugs are? Yes/No

7.6.1 If yes, where did you get this information?

7.6.2 How did you get this information? (From a friend, neighbour, awareness campaign etc.)

7.6.3 Do you know where someone from this community can get access to antiretroviral drugs?

7.7 Are you currently receiving ART? Yes/No

7.7.1 If YES,

- Since when?
- Which facility are you receiving it from?
- Follow-up procedures, e.g. how often do you have to go to the clinic or for blood tests (CD4 count, viral load)
- Do you take the medication as prescribed?
- Do you suffer from any side effects of the medication?
- How has being on ART influenced your life?

7.7.2 If NO,

- Do you know why not?
- Have you ever been examined to ascertain whether or not you are eligible to receive ART?
- If you were to be found to be eligible to receive ART and you are not receiving it, how do you feel about this? Please explain

7.8 I would now like to discuss your history of treatment/care-seeking. (At this stage the interviewer already knows that the respondent is HIV positive, since when, which support he/she is receiving and whether or not he/she is on ART)

- Have you at any stage become sick since the time that you have known that you are HIV positive? When did you first get sick and what did you/others do?
- What happened next?
- And then?
- When was the last time that you sought care?

7.9 For the last care-seeking event, the interviewer will explore:

- Who were the decision-makers in choosing this particular path of treatment?
- Why did you/they choose this path?
- Were there any problems experienced in accessing this form of treatment?
 - Was money a problem in accessing treatment? If so, what did you do?
 - Was time a problem in accessing this treatment? If so, what did you do?
 - Can you tell us about your relationship with the provider/staff at the facility?
 - How were you treated at the facility? Why do you think you were treated in this way?
 - Would you go back to this provider/facility in future?

7.10 Perceptions of the health system generally:

- Do HIV positive people need different forms of care today? If so, what?
- What sort of care are they actually getting?
- What can be done to improve this?
- How do you feel about the health system today?

7.11 Ideal care pathway:

- What would make it easier for you to treat your illness?
- If you could afford any sort of treatment (if money wasn't a problem), how would you treat your illness today?

- Do you have any suggestions for making access to treatment (for all aspects of your health) easier?

7.12 Is there anything else you would like to discuss?

Thank the respondent and conclude the interview

Appendix 2:

CONSENT FORM: PARTICIPANT SEMI- STRUCTURED INTERVIEW

Study Title:

TO INVESTIGATE THE DIFFICULTIES PEOPLE LIVING WITH HIV IN INFORMAL SETTLEMENTS FACE IN ACCESSING BASIC SERVICES AND HEALTH CARE, WITH THE FOCUS ON ACCESS TO ANTIRETROVIRAL TREATMENT, USING SOL PLAATJE INFORMAL SETTLEMENT IN JOHANNESBURG, SOUTH AFRICA, AS A CASE STUDY

Researcher: Jacques B. Bezuidenhout, BSc (Medicine)

Organisation: MRC and Wits Centre for Health Policy

Telephone Numbers: 011 242 9909
.....

Name of Participant: _____

Date interview: _____

Introduction:

Good day! I am _____ from Wits Centre for Health Policy and we are trying to better understand the difficulties HIV positive people living in informal settlements in Johannesburg face in accessing basic services and health care.

I the undersigned, agree to participate in the study conducted by Mr. J.B Bezuidenhout, a student doing his research elective under the supervision of Dr. E.P Thomas. Dr. Thomas is a senior researcher at the Medical Research Council (MRC) and the Centre for Health Policy which forms part of the School of Public Health at the University of the Witwatersrand, Johannesburg. This study seeks to explore the difficulties HIV positive people living in informal settlements in Johannesburg face in accessing basic services and health care.

My participation in this study is hereby acknowledged as voluntary, and the researcher has assured me that the information that is obtained in the interview will be kept confidential, and will protect my individual identity. I am also aware that I can withdraw from participating at anytime during the session. No individual names will be linked to any information whether the results of this study are published or not. On this note:

I consent to the use of tape recorders during the interview:
YES___ NO___

I consent to the use of direct quotes in the final document, in so far as my identity is **NOT** linked to them: YES___ NO___

Participants who have concerns regarding the study can contact **Dr. E.P Thomas** at **(011) 242 9919** or email her at liz.thomas@nhls.ac.za

Signature of Participant: _____ **Date:** _____

Researcher's Signature: _____ **Date:** _____

Audio Taping Informed Consent Form

The researcher explained the purpose of the study to me and I have read and understood the information sheet. I give my consent to be audio taped and have been informed that the voice clips from the tapes would only be used for the study:

TO INVESTIGATE THE DIFFICULTIES PEOPLE LIVING WITH HIV IN INFORMAL SETTLEMENTS FACE IN ACCESSING BASIC SERVICES AND HEALTH CARE, WITH THE FOCUS ON ACCESS TO ANTIRETROVIRAL TREATMENT, USING SOL PLAATJE INFORMAL SETTLEMENT IN JOHANNESBURG, SOUTH AFRICA, AS A CASE STUDY

I was made aware that the voice clips would be kept for two years after publication or up to six years if no publication has been made. All voice clips would be kept under lock and key, to which only researchers in this study would have access.

I understand also that I can withdraw my consent at anytime, without being prejudiced

Name of Participant: _____ **Signature** _____ **Date** _____

Name of Researcher: _____ **Signature** _____ **Date** _____