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RESEARCH REPORT

MASTERS IN PUBLIC HEALTH

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REVIEW OF PATIENT FOLLOW UP MECHANISMS IN THE TWO
EKURHULENI METROPOLITAN HOSPITALS PROVIDING
ANTIRETROVIRAL TREATMENT

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Declaration

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I hereby declare that this research report is my own work. It is being submitted for the degree of Master of Public Health at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signature: _____

Date: _____

Dedication

This research is dedicated to my family, my mother Christine, my fiancée Pinky, my two daughters Duduzile and Tshepiso for being the inspiration for all I do in life. To my sister Tshidi Ncholo who suffers from advanced and metastatic Cervical Cancer, to my beloved brother and friend Tshepo “Mze” Ncholo who was hijacked and killed in 2003. May God bless them and shine His Eternal light on them for ever and ever.

Abstract

Introduction

Patient retention and loss to follow-up in the antiretroviral programmes in South Africa and indeed the world is important as failures to reduce these lead to higher drug resistances and treatment failures. In the light of the few drugs available to treat HIV and AIDS it is imperative that patients lost to follow-up be traced and brought back into the programme. The objectives of the study were to quantify the number of patients enrolled in the programme between 01st June 2004 and 31st December 2004; determine the demographic profile of enrolled patients with regard to age; sex; education; employment and area of residence; to determine compliance and defaulter rates at every monthly appointment up to 6 months of follow-up and to describe follow-up systems in place for tracking patients on ARVs; identifying those who fail to comply with scheduled appointments; and ensuring compliance and finally to identify challenges faced by the hospitals in tracking patients on ARV therapy.

Material and Methods

The two hospital chosen were the first public hospitals to rollout antiretroviral treatment in Ekurhuleni in 2004. This was a descriptive study involving review of health facility records and primary data collection through key informant interviews at two district hospitals in Ekurhuleni. The study reviewed mechanisms employed by the two hospitals in tracking those patients who started on the programme during the first six months of the ARV programme (June 2004 to December 2004).

Results

The two hospitals had after six months of starting with the rollout a combined number of 378 patients on treatment. Far East Rand Hospital (FERH) had registered 208

patients and Natalspruit (NSH) had 170 patients on their register. Most of the patients started on treatment were from Townships (82%), and 81% of all patients started on treatment were unemployed. The male(33.7%) to female (62.7) ratio was 1:2. Even though on average 90% of patients at both hospitals kept their first six appointment, defaulter rates at FERH was 23,2% and NSH was sitting at 33,1%.

Discussion

Our results show tha the two hospitals fall short on achieving the requierements by the Departmentof Health's HIV plan that states under Priority Area 2, point 6.2, that accredited facilities must have the capacity to increase the retention of children and adults on ART – actively trace people on ART who are more than a month late for clinic/pharmacy appointment. The hospitals do not have proper tracking mechanisms in place, they lack important resources like transport, telephones and get wrong addresses. Based on the evidence we have gathered the hospitals' defaulter rates and loss to follow-up are a concern but they are also not far off when compared to other places and countries whose defaulter rates are 20% on average.

Conclusion and Recommendation

Retention of patients in the programmes is an essential health imperative. It is therefore necessary that we make the following improvements to our hospital programmes: Make resources like telephone and transport available to healthcare workers; employ a dedicated team of workers doing only patient tracing and follow-up; invest in technology that would alert health care workers immediately a patient misses an appointment and finally educate the patients themselves of the importance of adherence to treatment and follow-up.

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Nomenclature / Abbreviations

AIDS:	Acquired Immunodeficiency Syndrome
ARVs:	Anti-Retroviral(s)
CBO:	Community Based Organisations
DoH:	Department of Health
FERH:	Far East Rand Hospital
HIV:	Human Immunodeficiency Virus
MEMS:	Medication Event Monitoring System
NGO:	Non-Governmental Organisations
NHS:	Natalspruit Hospital
HBC:	Home Based Care
SANAC:	South African National Aids Coalition

Definitions

Defaulters: This here would refer to those patients that have missed one or more clinic follow-up appointments.

Defaulter Rate: The number of patients who miss one or more clinic follow-up appointments over the total number of patients ever registered on the program.

Loss to Follow-up: used in medicine to describe patients who you can no longer locate, despite your best efforts and are thus lost to the programme or treatment¹

Treatment Adherence: Refers to how closely patients follow a prescribed treatment regimen². This will include follow-up clinic appointments

Chapter 1 INTRODUCTION

1.1 BACKGROUND

HIV/AIDS has become a major challenge to all health care practitioners as well as to governments and the communities they serve. Acquired Immunodeficiency Syndrome (AIDS) was first diagnosed in 1981 in homosexual men in New York and Las Vegas in the United States of America and in 1983 Barre-Sinoussi et al reported HIV as the causative virus of AIDS at the Institut Pasteur, France³. In 2007, the World Health Organisation (WHO) and UNAIDS said there were an estimated 33,3 million people living with HIV worldwide and of these, 22,5 million live in Sub-Saharan Africa⁴. It is estimated that in South Africa alone, there are an estimated 5,6 million (18% of the population) people living with HIV/AIDS and the disease claims about 600 lives every day and in 2006, 47% of adult deaths were due to AIDS⁵. No treatment was available for this infection until the discovery of antiretroviral drugs in 1987.

In South Africa, ARV treatment was introduced in the public sector in 2004 as part of the comprehensive HIV/AIDS Programme⁶. Because of the complexity of these drug regimens and the lack of experience with ARV service provision in the public sector (side effects and adherence difficulties), only a limited number of sites were identified for initial implementation of ARV services. In Gauteng, Johannesburg General, Helen Joseph, Coronation, Kalafong and Chris Hani Baragwanath hospitals were initially accredited to provide treatment beginning in April 2004. In June 2004 two hospitals in the Ekurhuleni Metropolitan Health District (Far East Rand and Natalspruit) also began providing ARV⁷.

The 2008 Report on the global AIDS pandemic released by the UNAIDS/WHO/UNICEF in July 2008⁸ reported that South Africa in 2007 had an estimated 362 ARV sites throughout the country. It also reported that in 2007 there were 460 000 people on ARV in South Africa, which is an antiretroviral coverage of about 28%. More recently, it has been indicated that there are currently 420 service points (hospitals and clinics) providing HIV/AIDS treatment and care in 53 health districts across South Africa, providing treatment and care to about 510 000 South Africans who are enrolled on the ARV programme⁹.

Commencing on treatment is one thing, but staying on it is a challenge for many patients. It is absolutely imperative that patients adhere to treatment, as failure to do so will lead to drug resistance, greater morbidity, and higher mortalities. The rapid development of HIV resistant strains due to poor patient adherence is one of the greatest challenges faced by health care practitioners. It has been estimated that a 20% reduction in adherence to treatment may result in 80% reduction in drug efficacy¹⁰. This reduction in efficacy is quite significant and therefore there is a need to ensure that all patients that are started on treatment adhere to it and do not abscond from the programme. Poor adherence also has grave consequences for health services in that the whole ARV programme is rendered ineffective, and health care resources are as a result wasted. Patients on the other hand end up with poor clinical outcomes, and eventually this leads to an increase in the burden of ill health, rather than an improvement as initially intended¹¹.

It has been demonstrated that there is a strong correlation between virologic response (at an average follow-up of 6 month) and adherence as monitored by medication event

monitoring system (MEMS)¹². MEMS shows that a 95% adherence correlates to 78% reduction in viral load; an 80% - 90% adherence correlates to 45% Viral Load reduction and <70% adherence correlates to a viral load reduction of 18%¹³. This clearly demonstrates the importance of compliance and adherence to ARVs if HIV and AIDS is to be controlled. Therefore it is absolutely vital that accredited sites for the treatment of HIV/AIDS patients have good patient follow up and tracking mechanisms to retain patients in treatment programmes and try to achieve greater than 95% adherence to drug therapy.

According to the Department of Health's Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa⁵, as accepted by Cabinet in 2003, one criterion for accrediting facilities to provide ARV treatment was the availability of a "*system to track patients/treatment*". Even though this document does not specify what methods are to be followed in tracking patients, it does point out the importance of community care and support services such as transportation, home-based care, and hospice services (sometimes provided by NGOs and CBOs) that will help keep people in care and encourage their adherence to treatment.

1.2 PROBLEM STATEMENT

The availability of Antiretroviral (ARVs) drugs for treatment was supposed to alleviate the burden of HIV/AIDS; however more challenges emerged with regard to the introduction of this treatment. Patients on ARVs need regular follow-up to track their progress and to monitor treatment adherence. Health services need this information to monitor programme performance.

The comprehensive plan stipulates that an ARV treatment programme includes, among other things, the following⁵:

- Patients taking the medications at home;
- Ensuring the availability of treatment support partners either family members or friends who will ensure that the patient takes medication appropriately;
- Coming for scheduled visits and follow-ups at the hospital every month to collect medicine and for continued counselling.

In the Ekurhuleni metropolitan district, the first selected sites to provide ARVs were Natalspruit Hospital and Far East Rand Hospital. The two hospitals had between them 384 patients on antiretroviral treatment registered with their respective programs in the first 7 months of the programme, from June 2004 to Dec 2004. In terms of the Comprehensive Plan, the ARV programmes in the two hospitals should ensure and monitor adherence to the ARV programme by putting in place excellent follow-up and tracking mechanisms for all their patients.

Ensuring good adherence is however not only a responsibility of the patient and his/her family, but also a huge responsibility of the healthcare system because the effectiveness of the ARV programme is largely dependent on this. In the context of the ARV programme, adherence to the programme includes: taking the medicines correctly; attending the scheduled appointments where clinicians monitor clinical and virologic response; and collecting more drugs at scheduled times. Patients need to keep their scheduled appointments in order for health professionals to monitor clinical progress and adherence to drugs. Therefore, an important component of ARV

programmes that needs to be in place is a good patient follow-up and tracking system, necessary for tracking patients on treatment, and tracing defaulters and putting them back on the treatment programme.

However, anecdotal evidence suggests that these hospitals may not have followed this plan to the letter. Personal communication with staff at these facilities just before commencement of this study suggested that:

- Natalspruit hospital did not have a stipulated way of tracking patients who abscond treatment. Their estimated defaulter rate was reportedly as high as 30%¹⁴.
- Far East Rand Hospital was reported to have a 5-10% defaulter rate, despite their attempts to track patients on treatment¹⁵.

These observations suggested that there may have been a problem with patient tracking mechanisms in these healthcare facilities. This necessitated an investigation to confirm these anecdotes, identify problems, and remedy the situation before loss to follow-up of patients on ARVs increased beyond acceptable proportions and leads to drug resistance.

Thus, this study was done to determine whether the health services in the two hospitals had mechanisms in place to effectively track and follow-up patients on the ARV programme: to assess whether existing mechanisms work; and to help outline the main challenges they face, if any. The results will be used to inform monitoring of the ARV programme in Ekurhuleni and perhaps provincially and nationally.

1.3 JUSTIFICATION

The defaulter or loss to follow-up rates at these hospitals have not been accurately quantified. However, anecdotal evidence suggests that defaulter rates may be high enough to be worrying and necessitate a closer look at what is happening before more patients are enrolled and lost, thus leading to grave consequences for patients and health services. The percentages as given above are merely estimates; both hospitals have not taken proper assessments of loss-to-follow-up rates since the inception of the ARV treatment programme. We therefore need to know exactly what the loss-to-follow-up rates are, and at which visit/s these patients disappear from the programme. It is also important to describe the existing follow-up mechanisms, if any, and identify problems and challenges with these, so that health authorities early on in the programme may take appropriate steps to ensure compliance.

1.4 LITERATURE REVIEW

For the ARV programme to be successful, once a patient is registered on treatment, several processes need to be followed¹⁶:

- Patients need to adhere to therapy and keep scheduled appointments;
- Mechanisms must be in place to monitor/track patients on therapy and readily identify those who default and
- Mechanisms must be in place to trace defaulters and bring them back on track

Several factors may be crucial in influencing patients to keep or not to keep appointments. These include things like transport, treatment side effects and general stigma^{16,17} A study in the USA found that patients with 95% or greater adherence were statistically significantly more likely to be older, to be white, and to have lower

psychiatric morbidity¹⁷. A higher monthly income was also associated with higher adherence, but this was not statistically significant. It has also been noted that where payment or co-payments are required and in households where more than one person is infected, there is bound to be poor adherence to follow up and treatment due to cost such as for transport and access to a health care facility.¹⁸

The South African experience is best exemplified by the study by Booysen, Anderson and Meyer (2006)¹⁹ where they assessed patient compliance to the ARV programme in the Free State Province. Their results showed that in accordance to literature, ancillary and social support often translated in higher patient retention and adherence. They further reported that patients receiving nutritional supplements were significantly more likely to have visited the clinic site once a month or more often, compared to those not receiving anything. They further report that patient retention and adherence were positively associated with income and patients' satisfaction with health care services. Booysen et al. also reported that transport was not always a negative factor since most of their patients who visited the clinic more often had to travel significantly further away from the clinics. They conclude by saying in their case they observed that patients who have a greater need for treatment are willing to travel further and are more likely to be retained in the ART programme.

Patient retention in ARV programmes is an essential element of HIV treatment programmes. It is therefore important to understand some of the factors that influence patient retention in ARV programmes before making any recommendation as to the best way to ensure or promote adherence. Experience shows that patients do drop out of ARV programmes over time²⁰. Therefore we need to make sure patients stay in

programmes and to have ways of detecting quite early that they have dropped out, and ways of finding them and bringing them back to continue ARV. However, in South Africa there is not much data available in routine health service delivery settings to assess the availability of follow-up mechanisms for patients on ARVs, or determine whether these work. Medical insurances providing ARVs like Aid For Aids (AFA) view their follow-up mechanisms as privileged information that they are not comfortable sharing with their competitors²¹.

Data from research settings however may be useful. A recent review of ARV programmes in Africa reports that about 60% of patients on ARV over a two year period of follow-up are retained in treatment programmes with loss to follow-up being the main cause for dropping out of the programme, followed by death²⁰. The ARV project in Khayelitsha, Cape Town²² employed a program strategy that included using local NGOs like the Treatment Action Campaign in educating their patients and the community as well as tracking those patients that were absconding from treatment. Those patients that they could track down but not get back on the program, they would note and keep their statistics and record them as lost to follow-up.

The importance of treatment follow-up and tracking down patients who default cannot be over-emphasised. A study which looked at resistance profile and adherence at primary virological failure in three different highly activated antiretroviral therapy regimens demonstrated that treatment interruption or poor compliance accounts for 74% of ARV treatment failure.²³ If ARV services do not have efficient mechanisms to track patients and prevent defaulting and identify defaulters early on, there will be a high risk of high failure rates and even resistance²⁴.

One of the ways to prevent patient defaulting is to send patients reminders of their appointments. A study reported in September 2002, before nation-wide roll-out of ARV services in the South African public sector, showed that, between 40% and 80% of patients receiving reminders responded to them as seen by decreasing numbers of missed appointments²⁵. The reminder mechanisms used in this study, included the use of cell phone messages, posting reminders to patients and also actively sending health personnel to the homes of patients to remind them of their appointments. The report goes further to suggest that a 40% to 80% improvement in response to follow up is worth pursuing. It has been reported that elsewhere in Africa defaulter rates are as high as 80% and therefore new technology such as low cost satellite internet access, personal digital assistants and cell phones are helping to expand the reach of follow-up systems²⁶. They further conclude by saying that effective information systems as mentioned above, play an important role in supporting and monitoring HIV and TB projects as they scale up from thousands to hundred of thousands of patients. Variava et.al²⁴ however report that patient follow-up mechanisms are affected by a number of issues such as lack of resources like telephones, transport for staff and general shortage of human resources and poor systems of recording patient information.

Another mechanism that is also used to minimise defaulting is assessment of patients' socio-economic environments. In the Khayelitsha ARV programme for instance, they did home visits to review family environments that enabled them to allocate NGOs to those families that lacked resources and were unlikely to afford travelling and transport for follow-ups. The NGOs were to do follow-ups for them and thus ensure compliance²². This is further illustrated by research undertaken on the Helen Joseph

Hospital ART programme, where they demonstrated that the leading cause of loss to follow-up was financial (in 34% of patients)²⁷. They telephoned 182 patients who missed appointment and asked them why they were not coming for follow-up, 34% indicated financial constraints as the cause of their non-attendance. In this study, patients cited transport costs and having to pay to open a file at each visit as the biggest monetary obstacles to obtaining treatment and adhering to follow-ups.

In conclusion, patients' defaulting on their ARV treatment and losses to follow-up are important problems amongst facilities treating HIV/AIDS patients. The WHO recognises a successful ARV programme as that which involves far more than just getting pills into the mouths of patients. ARV programmes must be linked to strong systems such as follow up systems and counselling to prevent defaulting from treatment programmes and enhance adherence²⁸. The aim of this study was to describe the follow-up of patients on ART in two Ekurhuleni district hospitals, describe the mechanisms employed in these two hospitals to monitor or track patients on the antiretroviral rollout program, and to determine whether health providers feel that these mechanisms are effective, with a view to providing information for health authorities.

1.5 OBJECTIVES OF THE STUDY

This study focused on the first six months of the ARV rollout programme in NSH and FERH. The objectives of the study, with reference to the FERH and Natalspruit hospital ARV programmes were to:

1. Quantify the number of patients enrolled in the programme between 01st June 2004 and 31st December 2004.
2. Determine the demographic profile of enrolled patients with regard to age; sex; education; employment and area of residence.
3. Determine compliance and defaulter rates at every monthly appointment up to 6 months of follow-up.
4. Describe follow-up systems in place for: tracking patients on ARVs; identifying those who fail to comply with scheduled appointments; and ensuring compliance.
5. Identify challenges faced by the hospitals in tracking patients on ARV therapy.

CHAPTER 2: METHODOLOGY

The study was conducted at the first two public hospitals to start providing ARVs to the community of Ekurhuleni District. These hospitals, Far East Rand Hospital (FERH) and Natalspruit Hospital (NSH) both run their respective ARV clinics from specially designated areas within their yards.

2.1 STUDY DESIGN

This was a descriptive study involving review of health facility records and primary data collection through key informant interviews at two district hospitals in Ekurhuleni. The study reviewed mechanisms employed by the two hospitals in tracking those patients who started on the programme during the first six months of the ARV programme (June 2004 to December 2004).

2.2 SITE SELECTION AND DESCRIPTION

The two hospitals chosen for this study were the first two public hospitals to provide free ARVs in this district. In 2004 when government decided to start rolling out ARVs, Ekurhuleni had six hospitals, but only two were deemed ready to manage the programme efficiently. FERH and NSH were accredited to start rolling out ARVs in June 2004 and hence the study assessed patients enrolled on ARV from that time. The ARV clinics at FERH and NSH are called “Osizweni clinic” and “Faranani clinic” respectively. Both clinics operate from Monday to Friday starting at 07H00 to 16H00. Osizweni clinic closes a bit earlier at 13H00 on Fridays and there is no special reason given why it is like that. They (Faranani) also reserve their Wednesdays for paediatrics and hence they see children only on this day. Like most South African hospitals’ outpatient services Saturdays and Sundays are closed for consultations and

business. The clinics even though being part of the hospitals, have their own staff including nurses, doctors, social workers, pharmacists and lay counsellors. These staff complement is shown in Table 1.

Table 2.1: Staff complement at FERH and NSH ARV clinics

Cadre of health worker	Number working at the ARV clinic	
	FERH	NSH
Medical Officer	1	2
Professional Nurse (matron)	1	1
Professional nurse at clinic	2	2
Social worker	1	1
Lay counsellor	2	3
Administrative clerk / data capturer	2	2
Pharmacist	1	1
Total staff	10	12

Even though this study is based on adult patients over the age of 12 years, table 4.1 above includes the whole staff establishments working at the ARV clinics, including doctors who see paediatric patients.

2.3 STUDY POPULATION AND SAMPLING

The clinic records of all patients over 10 years old who were first registered on the ARV programmes between June 2004 and December 2004 formed the sample of this study. The two hospitals had a small number of patients with FERH having 208 and NSH with 170 and thus sampling was not required, so all records for patients enrolled on HAART during this period were included.

Key informant interviews conducted included all employees working with adult patients at both clinics. Table 2.2 below shows the composition of the key informant who participated in this study.

Table 2.2: Key informants interviewed at FERH and NSH ARV clinics

Designation	Number of key informants interviewed		
	FERH	NSH	Total
Professional Nurse (matron)	1	1	2
Professional nurse at clinic	1	1	2
Social worker	1	1	2
Lay counsellor	2	1	3
Medical Officer	0	1	1
Total interviews done	5	5	10

At FERH the doctor had just resigned and was not available for the interview. Only one doctor was interviewed at NSH since the other one does paediatrics. The second lay counsellor at NSH was on leave and therefore not available for the interview. Even though not all employees were interviewed, the number of those interviewed seems sufficient for the purpose of this study. Since this was a record review, no patients were interviewed. All the necessary patient information was obtained from the patients' medical records (files).

2.4 DATA COLLECTION:

Data for the study was collected using two methods: record reviews and key informant interviews.

2.4.1 Record reviews

This was a review of hospital records looking at all new patients (age 10 years and above) registered on the ARV program from 1st June 2004 until 31st December 2004, to quantify the number enrolled and their demographic profile; and to establish degree of compliance with scheduled appointments. The variables collected were age sex, physical address, availability of treatment support partner, date of registration on the program and date started on ARVs.

Osizweni clinic keeps all patients' medical records with the rest of the hospital patients' files at the general records department of the hospital. This is where the records for patients for this research were extracted. According to the people at the general records department, mixing these records with the rest of the hospital files was done to avoid stigma. From the data collection experience in this study, it was very difficult to trace patient files at general records as some records were actually missing and could not be found.

Faranani clinic on the other hand keeps all its patients' records at their ARV clinic. They are not mixed with the rest of the hospital records and are therefore easy to find and keep safe. This however sometimes creates problems when patients consult at the main hospital casualty on weekends, as they cannot get access to these files for the doctors to get information on their diseases since they are locked up at the clinic.

Getting these patients' files was a lengthy process starting at the clinic and ending up at records where patients' files are kept (for Osizweni). At both clinics, data was first

extracted from the patients' register where all the clinic patients' details are entered at their first visit to the clinic. This register is a ledger book that contains information such as the patient's file number, Identification number or date of birth, date of admission, full names, address, next of kin or treatment support partner and contact details.

After getting this information from the registers the next step was to go to the records departments where the files are kept and individually look for the required files using the patients' file numbers as recorded in the register. Once these files were recovered, verification was done to ensure that they were the correct ones by comparing the identity number or date of birth, name and surname as well as the address for some patients. In those patients where it was difficult to ascertain the correctness of the file, one had to open it and look for the date of admission as well as the doctor's notes to check if it fell within the dates of our study. Thus, a total of 378 out of a possible 384 were available for inclusion in this study.

At FERH about six files could not be traced and were declared lost at records, these were therefore excluded from our study. It is not known whether the patients whose files were missing at FERH are still enrolled on their programme or have since dropped out. NSH had all their files from the day they started enrolling patients on their HAART programme.

Once all files were found, these were manually reviewed, going through every page of the file searching for follow-up dates. At both hospitals doctors who saw the patients determined their follow-up dates. Follow –up dates were written as “To come back in

so many weeks or months” easily abbreviated as “TCB”. There is no separate register of follow-up appointments kept by the clerks or the clinics, patients were given appointment cards and this is where their return dates were recorded.

All the necessary patients’ data was recorded on the data extraction sheet designed for this study (see Appendix I). Patients’ names and surnames were not recorded on the data extraction sheets to protect their identity and observe the confidentiality of their HIV/AIDS status. This sheet was first filled at the clinic with information received from the register, and then taken to records where files were recovered and the required information then extracted.

2.4.2 Key informant interviews

Key informant interviews were conducted with health workers at both facilities during the months of August and September 2006. Information obtained from these key informant interviews was very critical as it answered a number of questions for this study. Key personnel at the ARV clinics including: the doctor in charge, professional nurse, and social worker were interviewed with a structured questionnaire (see AppendixII) in order to describe, for their respective facilities: the ARV programme; the mechanisms in place for ensuring compliance with appointments; mechanisms in place for tracking patients and follow – up of patients and identifying those who default; and the challenges faced by the hospital. The study also sought to determine the key informants’ perceptions of the follow-up methods used; which methods they thought work best in their settings; and what they thought could be done to improve on these.

An assessment of the existing resources available for follow-up was also done. During the key informant interviews, a walk through assessment, using a checklist (included in Appendix II), was made in each ARV clinic to document and determine:

- Resources available for patient follow-up: i.e. telephones, staff, and transport availability; and
- Record-keeping systems: whether records, including follow-up records, are in place, and the type of data collected for patient follow-ups.

2.5 LIMITATIONS OF THE STUDY

Clinic records are not always accurate and often lack information on patient's demographic variables. The limitation in this study is that these patients' records are as accurate as the person who completes them. Information might differ from patient to patient depending on the clerk who entered it. Again, as shown above and with personal experiences of public hospitals, patient's files often get lost or misplaced, and duplications are common. It was hoped that patients in the ARV programme would have minimal problems with files; unfortunately FERH had exactly the problem of the missing six patients' files.

2.6 DATA ANALYSIS

Data collected using the data extraction sheets was post-coded and captured onto an Excel spreadsheet, and exported to the SPSS Program for analysis. Descriptive statistics were employed to analyse the data collected from record reviews. Numerical data (age) was categorised into age groups and was presented as frequencies, in terms of percentages. All record review was thus categorical and was analysed as

proportions. The total number of patients registered at each hospital during the study period formed the basis (denominators) for the analysis of defaulter rates.

Patients' socio-demographic data was summarised and presented as frequencies (proportions by age, sex, race and area of residence), and presented as aggregated data for the two hospitals. To determine defaulter rates each appointment from month 1 to month 6 was looked at and the following rates were then calculated. The study looked at the total number of people who were enrolled on the programme, the number of patients who showed up for their appointments and the number of people who died. Patients who did not show up for their appointments are considered to be those that are not known what happened to them and are therefore considered lost to follow-up.

During analysis of the follow-up appointments, patients who died subsequent to every visit were removed from the denominator in determining the percentages of defaulters at each appointment. The proportion of defaulters/compliance at every monthly appointment up to 6 months were analysed and presented as disaggregated data for the two hospitals, and as an aggregate. Cross-tabulations were done to describe defaulters by age, sex and residence. Data collected by key informant interviews and facility audit was presented thematically according to health facility.

2.7 ETHICAL CONSIDERATIONS

HIV and AIDS are regarded as very confidential illnesses; therefore a research into anything on this disease is bound to have ethical issues. All the necessary precautions were taken to protect the identity of patients and to protect the staff that participated

in the interviews, who remained anonymous except where it is not possible due to the nature and position of their occupation in relation to the study.

Since this was a record review, the researcher had no direct contact with patients, and so no informed consent was required. The data extraction sheets also did not have patients' names and surnames so as to ensure that they remain anonymous except for their file numbers and perhaps the identity document numbers. File numbers and identity numbers were however not revealed in the analysis and reporting because this was pooled data.

Permission to undertake this study and to review patients' records was sought and obtained from the relevant hospitals' superintendents as well as from the necessary health authorities in Gauteng Province. Ethical approval was obtained from the University of the Witwatersrand Committee for Research on Human Subjects (Medical), as well as the Gauteng Health Department Ethics and Research Committee.

To ensure confidentiality, the researcher kept all the documents with patient details as confidential and private. Data from the patient records was extracted onto a data sheet and the original files were returned to the records departments at each hospital. No patients or any person's name was used in this research except for the clinic's file numbers. No link can be made to individual patients because the researcher used be using pooled data.

Key informants, being part of the public service are always bound by their respective profession's codes of ethics that bind them to confidentiality on patients' records and information. For the purpose of this research their ethical rights are protected by the authority of their respective Superintendents and the Department of Health that give permission for the study to be conducted. The informants were also given the option to participate willingly and those who did gave their written consents (Appendix III).

CHAPTER 3: RESULTS

This chapter presents the results of analysis of data that was retrieved from patient files at the first two hospitals to start providing ARV services in the Ekurhuleni Metropolitan District. The data that is presented here describes the socio-demographic profile of all patients who started ARV treatment during June to December 2004, and documents the loss to follow up among these patients. The results are reported in the form of tables and graphs where appropriate, as well as in a narrative manner in the case of key informant interview data.

3.1 SOCIO-DEMOGRAPHIC PROFILE OF PATIENTS ON ARVs

The results show that during the period 1st June 2004 to 31st Dec 2004, a total of 378 patients were started on ARV at the two hospitals (Far East Rand Hospital (FERH) with 208 patients and Natalspruit (NSH) with 170 patients). As shown in table 3.1, the mean age of all patients started on ARV was similar between FERH at (38.7 years) and NSH at (37.1 years). The majority of patients were between ages of 30 and 49 years; and about three quarters were female.

Most patients lived in a township and were unemployed (Table 3.2). Data for educational level was not available for this research. Our record review failed to find any information on the educational status of our sample since it was not captured upon admission of these patients.

**Table 3.1: Socio-demographic profile of patients commenced on ARV at FERH
and NSH: June - December 2004**

	FERH		NSH		COMBINED TOTAL OF PATIENTS AT HOSPITALS	
Age (years) Mean (SD)	38.69 (8.91)		37.05 (8.52)			
Age category (years)	No.	%	No.	%	No.	%
10-20	3	1.4	0	0.0	3	0.8%
20-29	21	10.1	31	18.2	52	13.8%
30-39	106	51.0	80	47.1	186	49.2%
40-49	54	26.0	42	24.7	96	25.4%
50-59	19	9.1	14	8.2	33	8.7%
> 60	5	2.4	3	1.8	8	2.1%
Total (all ages)	208	100%	170	100%	378	100%
Sex	No.	%	No.	%	No.	
Male	69	33.2	72	42.4	141	37.3%
Female	139	66.8	98	57.6	237	62.7%
Total	208	100%	170	100	378	100%
Area of residence	No.	%	No.	%	No.	
Town	36	17.3	10	5.8	46	12.2%
Township	161	77.4	149	86.7	310	82%
Suburb	6	2.9	11	6.5	17	4.5%
Informal	5	2.4	0	0	5	1.3%
Total	208	100%	170	100%	378	100%
Employment	No.	%	No.	%	No.	
Employed	38	18.3	30	17.6	68	18%
Unemployed	170	81.7	139	81.8	309	81.7%
Not specified	0	0	1	.6	1	0.3%
Total	208	100%	170	100%	378	100%

3.2 PATIENT COMPLIANCE WITH FOLLOW –UP APPOINTMENTS

This section presents data for the first six follow-up appointments for patients commenced on ARV at FERH and NSH during June to December 2004. Of the 378 patients, a total of 21 patients (6,8%) who were commenced on ARV during this period died in their first six months On treatment, with NSH recording 16 deaths and FERH recording 5 (Tables 3.2 to 3.7).

The first follow-up appointment was well attended and there were no defaulters or deaths – all patients returned for this visit (Table 3.2).

Table 3.2: Compliance with first follow-up appointment: patients commenced on ARV at FERH and NSH: June to December 2004

Follow up visit 1	FERH		NSH		TOTAL	
	No	%	No	%	No	%
Kept Appointment	208	100	170	100	378	100%
Defaulted	0	0.0	0	0.0	0	0
Deceased	0	0.0	0	0.0	0	0
Total	208	100	170	100	378	100%

Four patients died by the second follow- up date (2 from each hospital). Six patients at FERH missed their second appointments, compared to 11 at NSH (Table 3.3).

By the third follow-up visit, at both the hospitals, the number of patients who missed appointments had increased. Ten patients missed the third appointment at FERH, and 19 at NSH (Table 3.4). As shown in Table 3.4, there were also five more deaths (FERH = 3 and NSH = 2) reported by the third appointment.

Table 3.3: Compliance with second follow-up appointment: patients commenced on ARV at FERH and NSH: June to December 2004

Follow up visit 2	FERH		NSH		TOTAL	
	No	%	No	%	No	%
Kept Appointment	200	96.2	157	92.4	357	94.4%
Defaulted	6	2.9	11	6.5	17	4.5%
Deceased	2	1.0	2	1.2	4	1.1%
Total patients	208	100	1170	100	378	100%

Table 3.4: Compliance with third follow-up appointment: patients commenced on ARV at FERH and NSH during June to December 2004

Follow up visit 3	FERH		NSH		TOTAL	
	No	%	No	%	No	%
Kept Appointment	193	92.8	147	86.5	340	90%
Defaulted	10	4.8	19	11.2	28	7.7%
Deceased	3	1.5	2	1.2	5	1.3%
Total patients	206	101	168	100	373	100%

By the fourth follow-up visit, at both hospitals, there was again an increase in the number of defaulters, especially at FERH where the number increased from 10 in the previous follow –up to 19 during the fourth follow – up (Table 3.5). No deaths were reported at the two hospitals at the fourth appointment.

Table 3.5: Compliance with fourth follow-up appointment: patients commenced on ARV at FERH and NSH during June to December 2004

Follow up visit 4	FERH		NSH		TOTAL	
	No	%	No	%	No	%
Kept Appointment	184	90.6	147	88.6%	331	89.7%
Defaulted	19	9.4	19	11.4	38	10.3%
Deceased	0.0	0.0	0	0	0	0
Total patients	203	100	166	100	369	100%

By the fifth follow-up visits, FERH had 28 defaulters and at NSH 27 patients defaulted on their fifth follow-up visits (Table 3.6). FERH did not report any deaths at this point, while 6 more patients had died at NSH by the fifth follow-up appointment date leaving only 160 live patients at NSH (Table 3.6).

Table 3.6: Compliance with fifth follow-up appointment: patients commenced on ARV at FERH and NSH during June to December 2004

Follow up visit 5	FERH		NSH		TOTAL	
	No	%	No	%	No	%
Kept Appointment	175	86.2	133	80.1	308	83.5%
Defaulted	28	13.8	27	16.3	55	14.9
Deceased	0	0.0	6	3.6	6	1.6%
Total patients	203	100	166	100	369	100%

The results show that at the end of the first six follow-up visits, 80% of the cohort of patients who had started their ARV treatment during June to December 2004 attended the sixth appointment at NSH, compared to 83.3% at FERH (Table 3.7).

Table 3.7: Compliance with sixth follow-up appointment: patients commenced on ARV at FERH and NSH during June to December 2004

Follow up visit 6	FERH		NSH		TOTAL	
	No	%	No	%	No	%
Kept Appointment	169	83.3	128	80.0	297	81.8%
Defaulted	34	16.8	26	16.3	60	16.5%
Deceased	0	0.0	6	3.8	6	1.7%
Total patients	203	100	160	100	363	100%

At FERH and NSH, 76.8% and 66.9% respectively of patients who started their ARV treatment during June to December 2004 complied with all six follow-up appointments during their first six months on ARV. The figures below demonstrate this point and they also show that out of six appointments, only 0,5% and 0,6% attended only one appointment out of the possible six at FERH and NSH respectively and therefore missed the other five appointments. Equally, out of six appointments at both hospitals only 5,9% and 5,8% kept only two appointments.

If one excludes patients who died; 156 out of 203 (76,9%) and 103 out of 154 patients (66,9%) at FERH and NSH respectively, complied with all six follow-up appointment dates (Figure 3.1). Therefore 23,1% and 33,1% of patients who are alive at FERH and NSH respectively missed one or more clinic visit appointments.

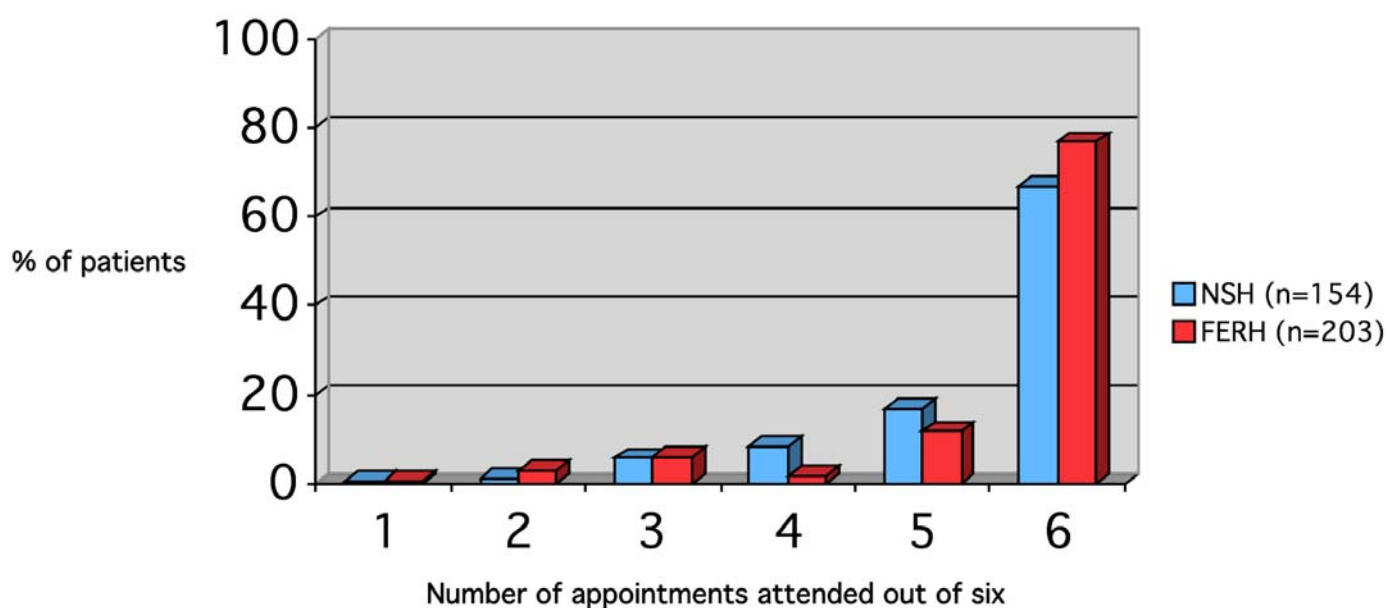


Figure 3.1: Number of appointments attended during the first six follow-up appointments by patients commenced on ARV during June to December 2004 at FERH and NSH

At both FERH and NSH, a higher proportion of females attended all six appointments compared to their male counterparts. These figures exclude the deceased. These differences were more marked at FERH than at NSH. FERH had 80.6% of females attending all six appointments as compared to only 69.6% of males (Figure 3.2)

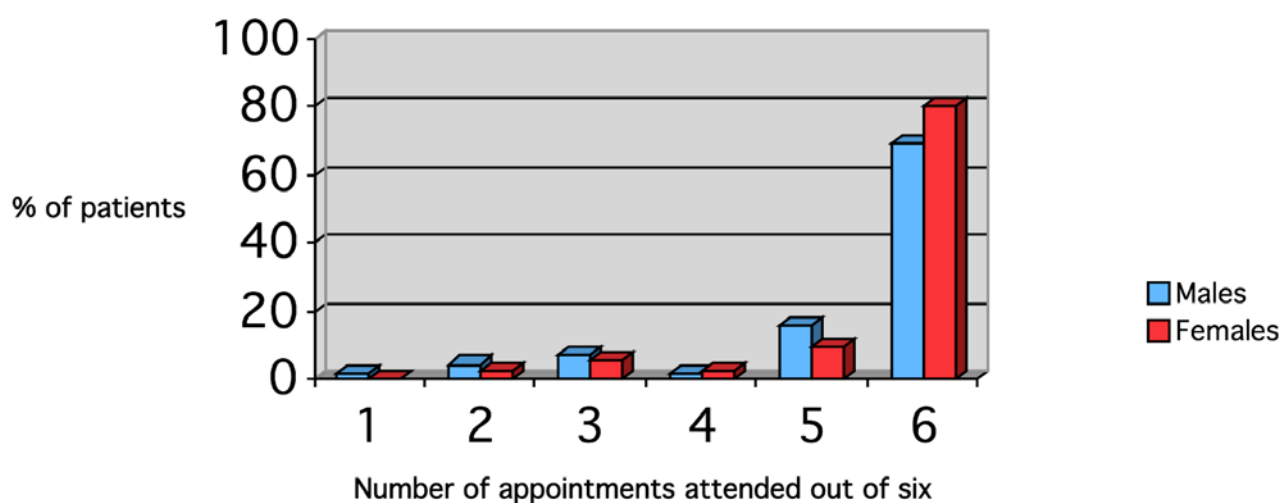


Fig 3.2: FERH. Number of appointments kept by males (n = 69) and females (n= 139) respectively

NSH on the other hand has almost an equal number of females and males who attended all their six appointments during the period of this study. There were 66.9% females compared to 65.6% males who attended all six appointments. This is depicted in figure Fig 3.3).

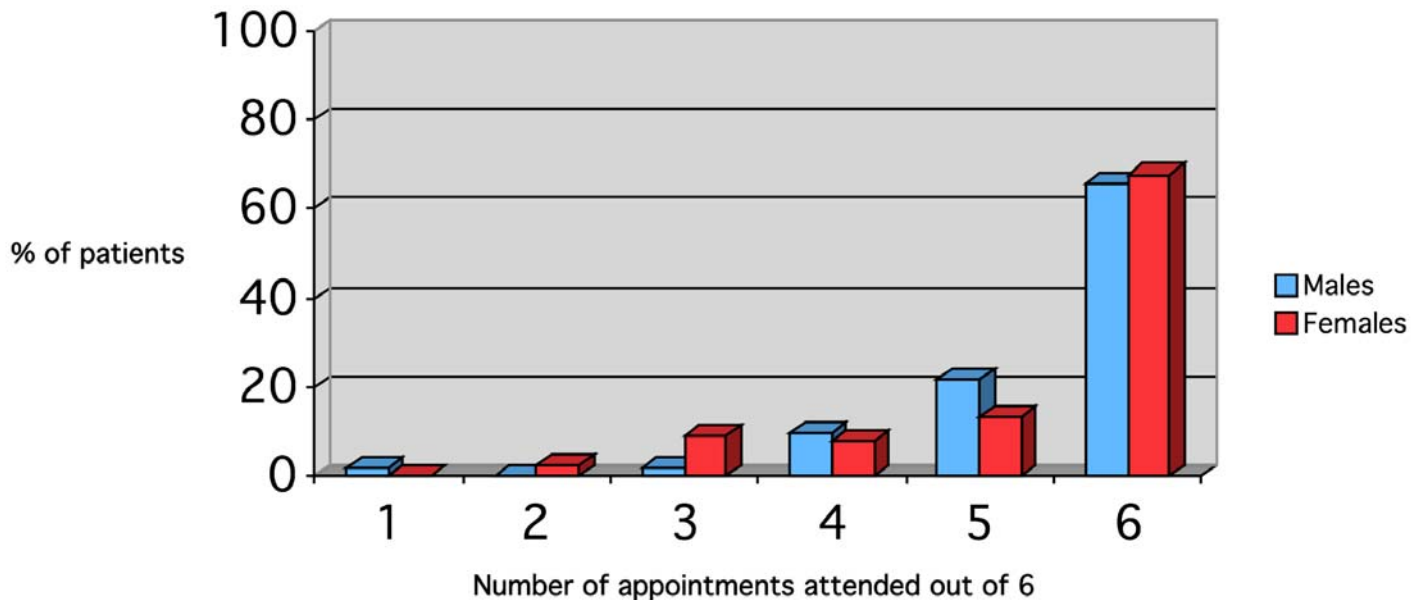


Fig 3.3: NSH. Number of appointments kept by males (n= 72) and females (n=98) respectively during their first six appointments

When further looking at the number of appointment kept , it can be seen from the table below that at FERH 76,4% of patient over the age of forty (>40) adhered to all their six clinic visit appointment compared to 73,8% of those less <40 years.

FERH		1	2	3	4	5	6	Total
<40 years	Count	2	9	6	2	15	96	130
	%	1.5	6.9	4.6	1.5	11.5	73.8	100
>40 years	Count	1		5	2	9	55	72
	%	1.4		6.9	2.8	12.5	76.4	100

Table 3.8: Number of appointments out of six kept by patients per age (under 40 years and over 40years)

NSH on the hand had only 59,3% of patients over the age of forty (>40) adhering to their appointment as compared to 62,2% of those less than forty years (<40).

NSH		1	2	3	4	5	6	Total
<40 years	Count	4	4	7	13	14	69	111
	%	3.6	3.6	6.3	11.7	12.6	62.2	100
>40 years	Count	1		3	5	13	32	54
	%	1.9		5.6	9.3	24.5	59.3	100

Table 3.9: Number of appointments out of six kept by patients per age (under 40 years and over 40years)

When comparing by employment status, it can be seen that at FERH, it can be seen that the figure of employed people (76,3%) who attended all six of their follow-up appointments is not that different from that of the unemployed (74,7%).

FERH		1	2	3	4	5	6	Total
Unemployed	Count	2	9	10	3	19	127	170
	%	1.2	5.3	5.9	1.8	11.2	74.7	100
Employed	Count	1		2	1	5	29	38
	%	2.6		5.3	2.6	13.2	76.3	100

Table 3.10: Number of appointments out of six kept by patients in terms of employment

The figures are however statistically significant for NSH where 70% of the employed adhered to all their six appointments as compared to only 58,3% of the unemployed.

NSH		1	2	3	4	5	6	Total
Unemployed	Count	5	3	9	18	25	81	170
	%	3.6	2.2	6.5	12.9	16.5	58.3	100
Employed	Count		1	1	1	6	21	38
	%		3.3	3.3	3.3	20	70	100

Table 3.11: Number of appointments out of six kept by patients in terms of employment

3.3 SYSTEMS FOR TRACKING PATIENTS ON ARVs

This section presents results of key informant interviews that were conducted at FERH's Osizweni clinic and Natalspruit hospital's Faranani clinic. A total of five key informants were interviewed at each hospital and this included nurses, doctors, lay counsellors and social workers. The doctor at FERH had just resigned and was therefore not available for the interview. Almost all the informants interviewed at FERH's Osizweni clinic had a minimum of 2 years working experience at this hospital's ARV clinic. The least experienced was the one lay counsellor who only had 1-year working experience at this clinic. Natalspruit's health workers on the other hand had a minimum of 1.5 years working experience at the Faranani clinic except the project Manager who was serving the longest at two years.

3.3.1 ORGANISATION OF SERVICES AT FERH AND NSH

Both these ARV clinics operate from Monday to Friday starting at 07H00 to 16H00. Osizweni clinic closes at 13H00 on Fridays and there was no special reason given for this. On Saturdays and Sundays both clinics are closed for consultations and business.

Staff complement at FERH and NSH ARV clinics

The number of staff that worked at the two ARV clinics, and their designations, are depicted in Table 3.8 below. Both clinics have an inter-disciplinary team that undertakes medical, nursing, counselling, and social work duties.

Table 3.8: Staff complement at FERH and NSH ARV clinics

Cadre of health worker	Number working at the ARV clinic	
	FERH	
Medical Officer	1	2
Professional Nurse (matron)	1	1
Professional nurse at clinic	2	2
Social worker	1	1
Lay counsellor	2	3
Administrative clerk / data capturer	2	2
Pharmacist	1	1
Total staff	10	12

- **Doctors**

Osizweni clinic had a full-time paediatrician looking after the children under the age of 13 years and their full-time medical officer, who saw all the adults, had just resigned at the time of this study. Faranani clinic on the other hand had two medical officers that saw adult patients. They had a designated day (Wednesday) for seeing children under the age of twelve years and a different and separate medical officer saw them. In both clinics, the doctors' duties included assessing patients to start antiretroviral treatment, starting patients on ARV, assessing patients' progress and monitoring side effects from drugs.

- **Nurses**

The duties of the professional nurses included patients' adherence training and administration of fluids when need. The nurses also helped with venesection, assessing stable patients due for treatment, taking vital signs like blood pressure and temperatures and referring patients who complicate while on routine check-up and treatment collections. At FERH the nurses also have to do monitoring of side effects whereas at Faranani nurses also do disease staging.

- **Lay Counsellors**

The lay counsellors at both clinics assist patients with pre- and post – test counselling, ARV adherence, disclosure counselling and HIV/AIDS education.

- **Social Workers**

The social workers' functions at both facilities are: promoting social and emotional wellbeing of patients; conducting interviews and assessments aimed at identifying patients' social and economic conditions that may render them vulnerable to defaulting treatment. They also assist with tracking defaulting patients. Social workers at both institutions are also responsible for helping patients on treatment to register for the social support grants and food parcels. Finally they are responsible for finding placement of terminally ill patients at various hospices and NGOs.

- **Admin Clerks / Data Capturers**

Osizweni clinic has two administrative clerks whereas Faranani refer to theirs as data capturers. The job descriptions for these two positions are similar; these include: registering all patients coming to the clinic, documenting their personal details on

standardised demographic forms, booking appointments for them and doing stock taking for the clinic's consumables. They also capture data of all patients receiving ARVs, do all the statistical work, and do patient transfers from their clinic to others clinics or facilities that would be closest to the residences.

- **Pharmacists**

Both clinics have their own pharmacists: their jobs being to dispense the ARVs to patients as prescribed by the doctors. It is also their role to inform patients and their treatment support partners of the correct dosages and frequencies for the drugs to be taken.

3.3.2 MECHANISMS TO PROMOTE PATIENT COMPLIANCE WITH FOLLOW-UP

APPOINTMENTS

Table 3.9 summarises the availability of mechanisms to promote patients' compliance to follow-up appointments, as reported by key informants at their respective clinics.

Although informants at both clinics reported that most of these mechanisms to promote patient compliance were in place, on further questioning, it was found that these mechanisms did not necessarily function as envisaged.

Table 3.9: Mechanisms for ensuring patient compliance with follow-up appointments after starting ARV treatment: FERH and NSH

Mechanism for promoting compliance	Mechanisms in place?	
	Yes [✓]	No [X]
	FERH	NSH
Adherence counselling	✓	✓
Treatment support partners	✓	✓
Support groups	✓	X
Education groups	✓	X
Home visits	X	✓
Request home-based care organisations to do home visits	✓	✓

- **HIV/AIDS Adherence Counselling**

According to key informants at both clinics, all patients receive pre – treatment adherence counselling and HIV/AIDS counselling. At both ARV clinics, patients receive this from both the lay counsellors and the professional nurses. At both sites, the counselling includes education on the importance of timing, dosages, potential side effects and drug interactions.

- **Treatment support partners**

Even though most informants report that patients have treatment support partners (appointed at the first visit), according to the social worker at Osizweni, this is not so in practice as: some support partners are not even aware of their role, and some patients prefer to exclude the support partners from further participation in the program and as a result do not have anyone helping them collect their treatment when they themselves cannot come. In some cases, people who are chosen to be support

partners tend to not be closely related to the patient and so when they are needed to trace a patient they often report that they have not seen or spoken to the patient for some time and therefore do not know of their whereabouts.

The doctor at Faranani clinic concedes that not all patients come with treatment support partners. Some patients come on their own as they do not want relatives to know their status. These patients, according to the doctor, are therefore started on treatment without support partners even though the lay counsellor reports that they do not start patients on treatment without the support partners. According to social workers, counsellors, and nurses at both clinics, not all treatment support partners received the necessary counselling and education, although it was envisaged that they would receive this information.

- **Support Groups**

At Osizweni clinic, there seemed to be no agreement amongst the key informants as to whether treatment support groups were established. Two informants reported that the clinic had “support groups” while two other informants reported that these did not exist. According to the latter, the clinic used to run support groups in its early years, but these have since disappeared due to the following reasons:

- Most patients who failed to attend support group sessions had excuses ranging from not having money to travel to support group sessions, not able to wait at long queues at dispensary due to being physically weak, or hunger
- Some stopped attending, claiming to be attending support groups at their towns.

- Some patients had indicated that they would join support groups only if it would provide them with something tangible to take home, for example: a skills like needlework, beadings, baking, and cooking.

Faranani clinic did not have support group sessions at the time of this study. According to one key informant, patients reported to be attending these sessions at non-profit organisations (NPOs) closer to their homes and they also do not like staying at the hospital for long periods especially because they already spend some time waiting for their treatment and monthly monitoring.

- **Education Groups**

Osizweni clinic had health education group sessions that were conducted by another patient who had been seconded to them by the Treatment Action Campaign. This education session was run in the clinic's corridor whilst patients were waiting to be served by the nurses or waiting for medicines from the dispensary. Faranani clinic on the other hand did not have such health education sessions. The health education sessions at Osizweni were reported to be successful because patients did not have to spend extra time at the hospital for health education, but rather they killed two birds with one stone as patients were educated while waiting on the queue for treatment and assessments.

- **Home Visits**

Home visits were done as a means to retain patients in the programme. The two clinics differed vastly when it came to their approaches to home visits. Osizweni clinic did not do home visits but rather referred patients to Home Based Care

Organisations (HBC) to do their drug adherence monitoring and follow-ups. Faranani clinic on the other hand makes use of HBCs and also their social worker who does home visits. This, he did in person and was provided with transport to do so. The social worker however reserved these visits for those patients that the clinic was informed were too sick to travel, were neglected, or had no social support systems. Both clinics used HBC organisations from local areas close to patients' homes. According to the nurses and social workers at both ARV clinics, the biggest challenge with HBC was that the clinics did not get feedback after HBC staff visited patients at their homes.

3.3.3 PATIENT MONITORING AND TRACKING MECHANISMS

Both clinics differed in methods employed to trace defaulting patients. However to summarise the overall findings we discovered that the mechanisms that used included patients' register, home visits and telecommunications; these were not always as effective as can be seen from the results of the interviews below.

- **Patient Register**

Both clinics kept a patients' register that is basically a ledger book that records vital demographic data and clinic visit information of all clinic patients (Table 3.10). This register forms the core of every patient's file (individual files contain each patient's medical records) that is opened at both clinics. The patients' details including treatment given, and follow – up schedule is supposed to be recorded in these patients' files.

Table 3.10: Routine data that is captured in clinic-held records of patients who start ARV treatment at FERH and NSH

Type of routine data	Data is routinely captured in register?	
	Yes [✓]	No [X]
	FERH	NSH
Patient's name and surname	✓	✓
Date of birth (and identity number where applicable)	✓	✓
Home address	✓	✓
Telephone numbers (including mobile where applicable)	✓	✓
Next of kin or treatment supporter if available	✓	✓
Exact date when patient is supposed to return for follow up	X	X

Even though Table 3.10 indicates that the details of the next of kin should be collected routinely, some patients' files and registers did not have this information.

At both clinics, facility-held patient records did not reflect the exact date on which patients were supposed to come back for follow up treatment. The only entries found were those from the Doctor's notes which reflected the next scheduled follow-up date as "two weeks (2/52) or four weeks (4/52)". However, specific appointment dates were reflected only in patient-held cards. According to informants at both hospitals, patients are given the exact dates of the next follow-up appointment: nurses and the clerks tell patients and enter these dates in personal appointment cards that they (patients) take home and keep with them. On inspection, these patients' appointment cards did indeed reflect the appointment dates as indicated by the nurses and the clerks.

- **Tracking defaulting patients**

Both hospitals use their social workers to trace defaulting patients albeit differently. The social worker at Osizweni was able to track defaulting patients only after consulting with the pharmacist to check which patients had not collected their medicines. She also got some assistance from the admin clerks to identify those who defaulted on appointment: the clerks would give her the daily register which recorded patients that actually came. At Faranani clinic, the social worker also got help from the pharmacist who checked defaulters by the number of medication packs that had not been collected for the month.

- **Home Visits**

As stated earlier, home visits and home based care organisations were used for patient monitoring, but are also crucial in tracking defaulting patients. This however has not been used to any effect as for the reasons given by the social workers below. A key informant at Faranani also indicated that referrals to HBC were problematic for them since these organisations do not report back to the clinic to indicate as to whether they found the patient or not.

3.4 RESOURCES AVAILABLE FOR TRACKING DEFAULTERS

- *Telephone*

Both clinics use landline telephones to trace patients. According to key informants at both facilities, this is very expensive and therefore they had limited access to it. For example, a key informant at Faranani reported that at the time of this study (2006), they had well over a thousand patients and it would therefore have been heavy on the telephone bill if they were to phone all of these to remind them of appointments. Both

clinics did not use mobile phones to send text messages to remind patients to come for appointments. There were also no resources available to email patients.

- *Transport, time, and staff for home visits*

The social worker at Faranani did home visits, but this however was hampered by the high patient turn over at the clinic and therefore there was not enough time for travelling to all defaulters' homes. At Osizweni the social worker did not do home visits at all because she had no transport; she felt that even if she had transport, she would not have time to travel either. Both clinics also reported that they also did not have enough staff to do home visits.

3.5 CHALLENGES IN TRACKING PATIENTS WHO DEFAULT

Social workers at both clinics raised the following as being the main challenges in tracking defaulting patients:

- o Patients giving wrong addresses and telephone numbers.
- o Patients hide their HIV status, as they do not want their families and other people to see them with the healthcare workers.
- o At Osizweni the social worker indicated problems with those patients that come from the Correctional services since when they are released from prison, they return home and do not come back for treatment and the clinic cannot trace them since they do not have their home addresses in their records.

Key informants at both Osizweni and Faranani clinics also reported the following challenges with referring patients to HBC organisations to assist them with tracking patients.

- Patients did not want Home Based Care organisations to visit them because of the fear of stigmatisation from the community.
- At Faranani clinic, the social worker sometimes cannot find the addresses in the informal settlements when he does his home visits.
- HBC not reporting back to the clinic i.e. whether patients or their homes have been found or not.

Chapter 4 DISCUSSION

This study describes the mechanisms employed by the first two Ekurhuleni District ART service points (FERH and NSH) for monitoring and tracking patients on ARV treatment to ensure compliance. These hospitals were the first public hospital in this district to be accredited in 2004 when the roll out was started in public facilities. The study results show that a total of 378 patients started ART in the first 6 months of ART roll-out, of whom just over two thirds were compliant with all their six monthly follow-up appointments; and 1% of patients died within first six months on treatment. FERH seems to have had better patient compliance with appointments, and compliance was also higher in women than men. The study also found that both hospitals have established mechanisms to promote patient retention in their ARV programmes, such as support groups, relationships with home based care organisations and social workers' follow-up systems including home visits and telephones. The following sections further discuss these results in the context of the literature.

Patient compliance with follow-up appointments

When considering the overall results of this study, it has been found that out of six appointments that patients were supposed to attend scheduled visits, only 76,8% of all patients at FERH who were still alive after the first six months of starting ARV from June 2004 to December 2004 attended all six of their scheduled appointments. During the same period only 66.9% of such patients at NSH attended all of their scheduled appointments. These figures are of concern since they represent a defaulter rate of about 23,2% and 33.1% at FERH and NSH respectively. Such high defaulter rates are worrying in the light of the rising resistance that develops in patients taking ARVs. In

their study Patterson et al (2000)¹² showed that adherence of 95% was significantly associated with successful virological outcome (viral loads below 400 copies/ml). It goes without saying that once patients default on follow-up visits they are bound to subsequently miss treatment, as they would not have collected it.

Equally worrying with these results is that other studies done elsewhere in Africa suggest that ARV programs in Africa are retaining on average, roughly 80% of their patients after 6 months on ARV¹¹. Given the technological and infrastructural advantage South Africa has on other African states, it can be said that the retention rate of 76,6% and 66,6% for FERH and NSH are therefore way below expectation.

We note that during the first two months of treatment, defaulter rates were very low, with no defaulters in the first follow – up at both hospitals. It is interesting to note that defaulter rates in this study are much lower than those reported by Dr Jembia Mosoko²⁹ of the CDC in Cameroon whereby 22% of patients dropped out of care after the very first clinic visit. Variava et al²⁴ found that at Tshepong hospital in Klerksdorp, 70% of patients who defaulted did this in the first six months of initiating ARVs. At FERH hospital and NSH, we discovered that during the first six month, patients defaulter rates varied; the highest defaulter rates were noted in the fifth and sixth appointments where FERH had 13,8% defaulters and NSH 16,3% defaulters during the fifth follow-up and this increased to 16,8% at FERH and NSH levelled during the sixth month.

This study results are not that different from what others have found in Africa. The defaulter rates found in our study (21,2% of patients at FERH missed (defaulted) an appointment at some stage during the treatment period and at NSH 31,1% of patients

missed (defaulted) some appointments) raise concern in terms of their adherence to treatment. Our key informant interviews also indicate that if these patients do not come back on the programme on their own, it is very difficult let alone being possible for the clinics to trace them and return them. This would therefore translate into loss to follow-up of these patients. This is of interest because when compared to a study at King Edward VIII Hospital in Durban, 27% of patients enrolled on the programme after April 2004 failed to return for prescription refills (missed appointments) for 90 days or more within 12 months of starting ARV³⁰.

Studies done at project sites managed by the International Centre for Aids Care and Treatment at Columbia University have shown that loss to follow-up at their sites has been anything from 1% - 17%. They have however indicated that some of their sites including South Africa had losses to follow-up of over 20%²⁹. This has been seen as a challenge to the ARV programmes in the developing world, and South Africa is no different. Wools-Kaloustian et al³¹, report in their study in Kenya, a loss to follow-up of 24,5% after just 40 weeks of starting ARVs.

Even though the prevalence rates of HIV in South Africa are reported to be levelling out, this remains as the country with the highest number of PLWHA³². While South Africa remains the country with the highest number of PLWHA, the latest UNAIDS report confirms that the country has the highest number of people on treatment globally³³. The report also provides encouraging data on the trend of HIV and AIDS epidemic in the country and the African continent. It states that the prevalence of HIV in the Southern Africa region is falling and South Africa is one of the three countries in the region where the epidemic has stabilized. (The other two countries are Malawi

and Zambia). The report indicates that of the 3 million people put on antiretroviral treatment worldwide by 2007, South Africa accounted for close to 429 000 (14%). It shows that the number of people on ARV treatment in South Africa rose sharply from 55 000 in 2004 to 429 000 in 2007.

Therefore, a defaulter rate of 21,2% and 31,5% at FERH and NSH who missed at least one appointment at the two hospitals in this study is indeed a cause for concern. It is important to ensure that the those who start treatment finish it because poor retention in programmes means the coverage is effectively less than the 14% stated by the UNAIDS report. These results suggest that the accreditation process, though excellent in approach may not have assisted the facilities enough to put in place effective mechanisms to ensure patient compliance with appointments and reduce defaulter rates. A need therefore exists to review the accreditation processes to ensure all sites have in place ways of ensuring that those patients who start ARVs are encouraged to continue on the programme and if they default they can be traced immediately to avoid them being lost to follow up and to the programme as a whole.

The experience with public sector hospitals is that patients are given medication that would last them only one month and therefore their appointments are usually structured such that they coincide with the days that the supplied medication would have been finished. This defaulting is also worrying when considering that these ARV need to be monitored regularly for adverse effects and some for their accumulative toxic effects over time. It is very important that patients adhere to their monthly follow-up schedules since some studies have shown that side effects can indeed lead to non-adherence³⁴. The importance of adhering to follow-up appointments is further illustrated in studies which show that non-adherence to medical appointments is

associated with increased plasma HIV RNA and decreased CD4 cell counts in a community based HIV primary care setting³⁵.

It has been demonstrated that non-adherence to medical regimens is a critical threat to the health of HIV-infected individuals³⁶. Patients who do not adhere to routine medical care cannot fully benefit from the increasingly efficacious treatments available to them. Consistent attendance at medical appointments plays a central role in both prolonging life and enhancing quality of life for persons living with HIV/AIDS. This is supported by the findings of a very strong association of treatment failure with variables that could be surrogates for ARV adherence, including one or more missed appointments in the prior year³⁷.

FERH and NSH had 66,8% and 57,6% of their total patients enrolled between June 2004 and December 2004 being women. In 2005 about 5.54 million people were estimated to be living with HIV in South Africa, with women accounting for approximately 55% of HIV-positive people³⁸. This research has shown that more women came to these ARV clinics for treatment than men and that they are indeed more compliant to follow-up appointments. Experience shows that men in general have been shown to be reluctant to attend facilities, and this has been shown for health care utilisation in general, not necessarily only for HAART³⁹.

Most of the patients in our study come from townships 77% at FERH and 86,7% at NSH and are therefore mainly Black South African. In 2002, the Human Science Research Council (HSRC) released statistics indicating that the prevalence of HIV in South Africa was highest amongst Blacks³⁹. This study is no different since most

patients at both clinics came from the townships which generally has low and middle income earners in our society. The bidirectional relation between poverty and HIV makes our townships vulnerable. In their report HIV, Joseph Inungu and Sarah Karl⁴⁰, they claim that poverty is a key factor in the transmission and that HIV and AIDS can impoverish people in such a way as to intensify the epidemic itself. Unemployment as a contributor to poverty has directly resulted in the high levels of HIV and AIDS.

When taking the economical demographics of South Africa, it is worth noting that a majority of Blacks are poor and most are unemployed. This fact leads to poor adherence and follow-up to chronic medications as several studies have shown^{21, 24,32}. At both clinics the unemployment rates were high; 81.7% at FERH and 81.8% at NSH. Since most of these patients have to travel to get to the hospitals for their monthly appointments, this may explain why a good number of them defaulted on their appointments at least once. It has been demonstrate that patients with greater than 95% adherence were more likely to have a higher monthly income¹². Socio-economic status indeed is thus a factor that needs to be addressed when looking at improving patients' compliance with appointment schedules.

Mechanisms for ensuring compliance with follow – up appointments

According to the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa⁵ one of the requirements for ARV accreditations service point is to have mechanisms in place for following up patients and adherence to treatment. The most recent plan launched in 2007 has rephrased this goal and has referred to it under Priority Area 2, point 6.2, “Increase the retention of

children and adults on ART – actively trace people on ART who are more than a month late for clinic/pharmacy appointment⁶ .

When these two hospitals were accredited in 2004, the assumption was that they had mechanisms for ensuring follow-up were in place and as a result would be able to reduce defaulters and loss to follow-up. These mechanisms have not been assessed until this study, which has established that these mechanisms are indeed in place, including: adherence counselling, use of treatment support partners, support groups, education groups, and home visits.

There is general consensus that pre- and post- treatment counselling is important in the management of HIV and AIDS. Studies by Hosseinipour et.al⁴¹ looked at the challenges in delivering ART in resource poor countries and they have shown that patients that receive adequate counselling are less likely to default on treatment. This however is not the only determinant of a good adherence and follow-up system, several other factors mentioned above are equally important and have to be used concurrently with adherence counselling to achieve excellent results. In these two study hospitals this pre- treatment counselling is offered by lay counsellors who are community members trained by the Department of Health. To avoid patients defaulting on treatment and follow up, clinics need to put in place mechanisms that will ensure that they have an open communication system with their patients. They need to be able to know their languages, and have addresses as well as their next of kin in cases where patients disappear or are lost to follow-up.

The fact that the hospitals in question, the lay counsellors are from the community and thus able to communicate effectively with patients, has not helped reduce the

losses to follow-up as expected. Instead this has been shown to be a deterrent as patients worry about confidentiality and stigmatization.

A good patient-healthcare worker relationship is highly important as Sigrid Vervoort et al.³⁴ have shown. In their study they indicate that having faith in the healthcare provider and the experience of a good relationship with the healthcare provider that is based on trust and professional support seem to influence adherence positively. These characters they say include a caring attitude, effective and frank communication and clear instructions, being responsive, accessible, and showing respect to patients encourage good adherence and limits defaulting. At NSH the characteristics referred to here are lacking as seen by the community protest march in 2004⁴². It is therefore possible that these defaulter rates and loss to follow-up are as a direct result of this poor patient-healthcare worker relationship.

The use of trained lay community counsellors in the HIV treatment and care has been found to be very efficient in the management of HIV and AIDS. A community project in Malawi showed good results in managing HIV positive patients and ensuring their excellent adherence⁴³. This intervention reduced the need for more qualified personnel, it is a cost efficient measure as the numbers of people needing counselling, and treatment far outweighs the number of professional healthcare practitioners who can provide healthcare. Lay counsellors at these facilities are trained by the department of health and are paid by them as such.

The clinics are not always able to use treatment support partners ensuring compliance because some of these partners do not stay with the patients. In other cases the

treatment support partners even though they brought the patient for consultation they do not give the clinic their valid telephone or home addresses. Key informants revealed that treatment supporters do not actually want to take responsibility for the patients.

The social workers at both clinics are supposed to do home visits, however challenges exist such as lack of time and transport to visit defaulting patients, and patients giving wrong addresses and telephone numbers. Using Home Based Care Organisations (HBC) has also not worked because the clinic is expected to keep the patients' HIV status confidential and by involving HBC organisation they would be breaking that confidentiality. For the ARV programme to be successful, there is a need to be able to track patients who default even to a single appointment, re-counsel them and make sure that they are fully prepared to adhere to the programme and committed to taking their ARVs without fail. This tracing has proven successful in other countries like Brazil where telephones, sms and personnel were used to track patients who default⁴⁴. These studies have previously reported adherence and patient retention of 60 – 69% prior to them introducing follow-up mechanisms listed above as well as Home Based Care Programmes like “assistencia Domiciliar Terapeutica (ADT). After the introduction of such programmes their adherence and retention figures improved drastically to well over 85 – 90%. Therefore even for FERH and NSH these mechanisms can be used to a greater effect. Even though the social worker at NSH indicated financial limitations relating to high telephone bills, we note that these can never be equated to a good patient retention as witnessed in Brazil.

In FERH and NSH patients are expected to remember their appointment dates when they are given to them on their hospital cards. Should the card get lost, so is the date

of the next appointment for this patient. In countries where reminders have been used, they have reported very low defaulter rates and have thus shown that patients need to be kept alert at all times. Patients' defaulting and non-adherence has always been associated with blaming patients. WHO reports that clinics can no longer rely on the patients' own commitment but reducing losses to follow-up and non-adherence requires a systems approach, blame cannot be put on patients alone but also on providers⁴⁵.

It is evident from this study that the personnel who are supposed to do patient follow-ups at FERH and NSH do not have the necessary resources to be efficient and effective. Therefore the high defaulter rates and missed appointments noted earlier is not surprising. McGrath⁴⁶, indicates that things like poor communication, poor office management can create ill-will among patients and can actually contribute to the negligence itself. He stated that it was imperative that every office must have a system for tracking test results and referrals to ensure that patients do not "fall through the cracks." He concluded by saying that the key to a good follow-up system is to use the system.

Looking at the results from FERH and NSH, it is clear that the patients that default on appointment adherence are easily lost to follow-up since no one is able to track them. The hospitals in this instance are lucky in that some of the patients default one or two months and then return to the programme on their own. Some patients return because they get sick again and are therefore forced to consult again.

Based on this study, it is not possible to clearly attribute better patient compliance in FERH to more effective patient follow-up mechanisms there. Both hospitals had

challenges in implementing patient follow-up and tracking systems. Further research is also needed to determine the determinants of patient defaulting from the ARV programme.

Limitations of the study

This study has its own limitations, and in considering the results it is important to note these limitations. Since the study is a record review, it is only going to be able to capture information that was collected at the time the records were established. The information contained in the patients' files is as accurate as the person who entered it. In discussing our results we must bear in mind that patients' follow-up appointments were not clearly indicated as dates but as durations in terms of weeks or months. Therefore I had to look at their consultation dates as follow-up appointments. In most of patients files, these consultation dates coincided with the duration of weeks or months indicated as the "to come back (TCB)" dates by the doctors.

This study's lack of data on patients' educational levels or status is another limitation since it would have given us an idea of which patients were at the highest risk of defaulting and being lost to follow-up, it would also have given us a predictive idea as to which patients were most likely to attend their scheduled appointments. In a 2002 study in Uganda and Zambia it was found that higher education was associated with greater risk of HIV infection⁴⁷ and therefore a probable need to attend clinics. This has however since been revised as in 2005 another study released results of a study conducted at the Masaka District in Uganda that showed that higher education has significantly been associated with less HIV infections⁴⁸. Several studies have shown that educational attainment can be an invaluable asset when reducing losses to follow-

up and poor adherence¹⁷. Barragan on the other hand found that low literacy patients appear more willing to comply with health care providers' recommendations⁴⁹. Taking into account that health care providers would encourage follow-up, then it would be interesting if this study could show which of the defaulters were more at risk based on their educational levels.

Another limitation of our study is that at FERH we were not able to interview the doctor to get her views on the defaulting and how it affects her treatment course of patients. The absence of information from the other counsellor at NSH was another limitation; her views would have been appreciated in collaborating what other informants gave as their perceptions of the follow-up mechanisms at the hospital.

Not being able to meet with the patients themselves as well as the home-based care groups is a limitation on its own. They would have been able to verify some of the issues and concerns and challenges raised in the key informant interviews. Studies done on patients' compliance and adherence have shown that some patients indeed have genius excuses and it would have been great to get these from the patients themselves.

Chapter 5

CONCLUSION AND RECOMMENDATIONS

Clearly FERH and NSH are trying to achieve the objectives of ensuring high patient retention in the ART programme, and have instituted a range of mechanisms for tracking defaulting patients. However as it can be seen from our research results, the hospitals lack key resources. They also do not seem to have the support of hospital management to provide the resources needed in curbing their growing list of patients in the program.

Recommendations

- It is evident that these two hospitals need the necessary resources without reference or emphasis on costs (telephone and transport) for them to be able to track patients and keep them on the program.
- There is a need for them to employ a dedicated team of workers whose job will be solely tracking patients and reminding them of their regular follow-up appointments. Until such time that this group of workers installed, it will forever be a problem getting patients adhering and complying to their treatment and not defaulting when they feel better or when they do not have money for transport. The availability of this team will ensure fewer drug resistances, that state resources used for acquiring ARV drugs are not wasted, and that the country's much needed skilled workers are treated fully without defaulting. It is imperative that those that provide care for HIV and AIDS should implement policies that are realistic and achievable.

- It is important to invest in a good computer software that will alert the healthcare worker once a patient has failed to turn up for an appointment. An internet programme like “You Asked” would be helpful because doctors and nurses would be notified on the same day that a patient has not turned up.
- It would also be helpful if HBC can be engaged right at the beginning of the patient's consultation, this would enable patient to develop a trust relationship with their nearest HBC and thus eliminate issues of fear of stigmatization.
- Social workers need to be provided with transport so as to enable them to travel freely in their search for defaulting patients.
- They should equally be allowed to use the telephone and mobile phone accessories like text messages to communicate with patients as that would facilitate a good rapport and trust that would in turn translate into good adherence as other studies have shown.
- There should be continuous education of staff especially those taking patient details like clerks to enable them to know the importance of taking all details including educational levels, household income, age, etc as this data is helpful in flagging suspect patient for monitoring purposes.
- Patients themselves need to be educated on the importance of adherence, so that they understand the implications of non-adherence like drug resistance and cost implications.

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APPENDIX 1: Data Extraction Sheet

Client study code	
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Hospital Name	
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Hospital No:	
--------------	--

Socio-demographic data

Age	
-----	--

Gender:	Male	Female
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Home Address					
(Suburb)	(Sub-district)				
		YES	NO		

Treatment data

Treatment support Partner	Yes	No
Date of registration		
Date Started on ARVs		

Appointment Dates		Appointment attended?		Reminders			
	Date	Yes (and date)	No	Yes	No	Date	How sent? E.g. Phone
1 st							
2 nd							
3 rd							
4 th							
5 th							
6 th							

APPENDIX II: Key Informant Questionnaire

A. Description of ARV Rollout site

Hospital Name

Clinic Name

Date:(DD / MM / YY)

Respondent details

Position held:

Years in this position at clinic:

Qualifications:

Organization of services

1. Days of the week that facility offers ARV clinic services:

<u>Day</u>	<u>Time</u>	
Monday		to
Tuesday		to
Wednesday		to
Thursday		to
Friday		to
Saturday		to
Sunday		to

2. How many staff and what cadre of staff are assigned to work at this clinic, and what are their main responsibilities?

Category	No.	Responsibilities
Professional nurses		
Doctors		
Counsellors		
Social workers		
Others (specify) _____		
Others (specify) _____		

B. Mechanism for ensuring adherence

1. Counselling and treatment support	YES	NO
1. Do all patients receive pre-treatment counselling?		
2. Have you ever started treatment without counselling?		
3. Are patients trained and counselled on ARV side effects?		
4. Do patients have treatment support partners?		
5. Do treatment support partners receive counselling?		
6. Are treatment support partners trained / counselled on side effects?		
7. Do you conduct HIV / AIDS support groups at this facility?		
8. Do you do home visits to ARV patients?		

If yes, explain who (which staff) does the home visits and which patients get home visits?

.....

.....

.....

.....

	YES	NO
9. Do you refer to Home Based Care Organisations and CBO etc.?		

If yes, please explain in which circumstances you refer?

.....
.....
.....
.....

2. Adherence support	YES	NO
10 Do you send patients reminders?		

If yes, do you:

10.1. Send them letters? Y N

10.2. Send them text sms? Y N

10.3 telephone them? Y N

10.4 do home visits Y N

10.5. Other mechanisms. (please specify).

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.....
.....

	YES	NO
11. Do you think patient adherence is a problem at this facility?		

Pease explain:
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.....
.....
.....

12. In your opinion, what can be done to improve adherence?

.....
.....
.....
.....

C. Mechanisms for follow-up and tracking patients

	Yes	No
1. Do you maintain a register/s for patients on treatment?		

If yes, ask the informant to show the register/s and check whether the following types of data are collected routinely:

1.1. Patients' physical address and other contact details

1.2. contact details of next of kin or treatment support partner

1.3. Patient appointment dates

1.4. Treatment regimen each patient is on

1.5. Side effects

1.6. whether returned or missed appointment

2. Does your clinic have a protocol dealing with defaulting patients?		
3. Does your clinic have a system for tracing defaulters?		

3.1. If yes, please describe how it is done

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3.2 Who (which cadre of health worker) is responsible for tracing these patients?

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3.3. How successful do you think your system is in finding these patients and bringing them back into the programme?

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3.4. Please describe the main challenges you face (if any) in tracking defaulting patients

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3.5. In your opinion, what can be done to improve patient follow-up?

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D. Resources for follow-up and tracking patients

1. Material resources

	YES	NO
1. Do you have access to telephones to contact defaulting patients?		
2. Do you have transport for home visits to reach defaulters?		

2. Human resources

3. Do you engage community social workers in tracing patients?		
4. Do you engage community health workers in tracing patients?		

APPENDIX III

PARTICIPANT INFORMATION AND CONSENT FORM

Dear, my name is **Dr Kgotso Ncholo** I am a Postgraduate student at Wits University doing my Masters degree in Public Health. We are conducting a study to review current ARV program follow up mechanisms of Natalspruit and Far East Rand Hospitals.

This questionnaire is aimed at identifying mechanisms that are used by your clinic in tracing patients who are on ARV and yet fail to come to the clinic for their scheduled appointments. It is also aimed at finding out how many patients on ARV have since been lost by the clinic since starting the rollout process; these will exclude patients who are known to have died from any cause.

You are kindly invited to participate in this study by helping us in filling in the accompanying questionnaire to the best of you knowledge and capability. The information you give will hopefully add to all efforts taken in improving our quality of healthcare in particular ARV rollout and patients' keeping scheduled appointments.

Permission for this study had been sought and granted by the Department of Health as well as by the University of Witwatersrand. Please also note that your participation is voluntary and all information will be kept confidential. Your contribution will only be used in enhancing our quality of healthcare and only once approved by the Department of Health and the University. You are free to decline or to stop the interview at anytime, and nothing will be held against you if you do so.

I _____ hereby consent to being part of the study on the clinic's follow-up mechanisms for patients on Antiretroviral treatment. I have been reassured that this questionnaire will be kept confidential and only used for the purpose of the study. I also give consent to the researcher **(Dr. Kgotso Ncholo)** to share this information with his supervisors, the School of Public Health (Wits) the relevant University research committees and the Department of Health in order to further our advances in improving healthcare in the country.

I have been reassured that participating in this study will not in any way whatsoever affect my work position or be used against me in my workplace. My participation will also not jeopardise my employment and function at the hospital as well as the clinic.

I also wish to state that I participate in this research out of my own free will. I have not been coaxed, paid or forced in making my submissions.

Signed at _____ on this _____ day of _____ 200_

Signature _____ Name: _____

Witness: _____ Date _____

Witness: _____ Date _____