Models of Care for Antiretroviral Service Delivery

Research Report
June 2006

Infectious Disease Epidemiology Unit, School of Public Health and Family Medicine, University of Cape Town

Department of Health, Provincial Government of the Western Cape

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Table of Contents

Annexures

Tables

Figures

Case studies

Glossary of abbreviations and terms

ARK: Absolute Return for Kids – an NGO who support a range of antiretroviral services, and in particular have provided counselling and clinical staff at Hout Bay and Paarl, two of the sites included in this study.

ART: Antiretroviral therapy

ARV: Antiretroviral, used to refer to the antiretroviral drugs

CNP: Clinical nurse practitioner

CHC: Community health centre

Community-based Counsellors (CC): A system through which trained workers supply adherence support (often by emphasising good adherence in one-on-one discussions or by performing pill-counts) to ART patients mostly outside of the clinic, usually through a process of visiting at a patient's home or at a mutually agreed upon place between patient and worker.

Counsellor: A term used frequently during provider interviews, generally meaning a lay person who has been trained in HIV/AIDS/ART knowledge and who imparts this knowledge to patients through one-on-one counselling sessions or through group sessions. Most counsellors discussed in this report were facility-based

DG / Disability grant: A government grant provided to patients with temporary or permanent disability, generally available to patients with AIDS or CD4 counts below 200 cells/µl. At the time of writing valued at a maximum of R820 per month.

DOT: Directly observed therapy for tuberculosis. DOT supporters are lay health workers who supervise the tuberculosis treatment of patients in the community

DTHC: Desmond Tutu HIV Centre – an academic centre at the University of Cape Town that has set up and continues to support the antiretroviral services in Guguletu

EN: Enrolled nurse. Enrolled nurses usually perform a range of clinical functions, but do not generally provide diagnostic and curative care.

Facility-based: With reference to adherence, a system through which trained workers (counsellors) supply adherence support to ART patients at the clinic concerned. Usually this is through a process whereby the attending clinician identifies adherence problems and refers the patient to the facility-based counsellor for re-emphasis of adherence education.

Hannan-Crusaid Treatment Centre: Another name for the Guguletu site, referring to the building that was supported by a United Kingdom charity.

Lifeline: An NGO who provide training, supervision and employment of counsellors, and who employ the counsellors working in Khayelitsha

MO: Medical Officer

MSF: Médecins Sans Frontières, an NGO that has assisted the services at Michael Mapongwana Clinic for the past five years

Model: A representation of processes, activities, relationships, and constraints which together constitute the package of ART care delivered at a particular facility

PA / Patient advocate: A name used at certain facilities to describe the person who provides community-based adherence support. They also often perform minor administrative functions at the clinics concerned.

PGWC: Provincial Government of the Western Cape

PMO: Principal Medical Officer

PMTCT: Prevention of mother-to-child transmission

PN: Professional Nurse, not necessarily with additional clinical nurse practitioner qualifications, but often performing clinical work

Primary care: A term used extensively in this document to refer to clinics and community health centres as opposed to hospitals

Sizophila: A community-based organization linked to the Desmond Tutu HIV Centre that directs community-based adherence support for patients on ART at the Guguletu CHC

SMO: Senior Medical Officer

STI: Sexually transmitted infections

TB: Tuberculosis

VCT: Voluntary counselling and testing for HIV, referring in this document to an activity that some of the counsellors are responsible in addition to the antiretroviral adherence work.

Executive summary

Seeking to capitalize on the diversity and relative maturity of existing antiretroviral therapy (ART) services in the Western Cape Province, this project's aim was to examine the major differentiating features of current approaches to service provision.

Components of the provincial HIV/ART health service were investigated from various perspectives including those of the providers of health care, patients on antiretroviral therapy and the health system itself. Issues examined included access and barriers to care, level of care, adherence support models and adherence to therapy, staff roles and responsibilities in the extended care process, service management and integration of ART with other services.

Methods
Five well-established clinics were purposively chosen to reflect different service delivery characteristics. The study comprised a set of inter-related research activities, including exit interviews with over 700 patients across the five sites, interviews with providers, counsellor diaries, and observations of clinic functioning.

Overview of facilities
Clinics differed in terms of their placement (free standing structures within a community or outpatient departments in a hospital), their clinical support networks, their staff profiles, their patient education and adherence systems and their hours of opening.

Analysis of routinely collected laboratory monitoring data suggests that there are no significant differences in the proportion of patients retained in care at six months duration on ART at each site. Rates of virological suppression are uniformly high, with at least 90% of patients attaining viral loads below 400 copies/ml at 6 months in all sites.

Overall, the analysis of routinely collected data on patient outcomes does not distinguish one model of care from any other with respect to the sites studied. These data suggest that all the sites are performing well in terms of retention in care, immunological response and virological suppression.

Patient demographics, access to care and setting
Patients were predominantly female (77%), young (median age 33) and unemployed (53% on a grant). The median time on ARVs was 7 months. Compared to general township residents, the patients were clustered in the lower socio-economic quintiles as measured by an asset index.

Patients attending primary care services were more likely to travel on foot, spend less on travel, and travel for a shorter time in order to access services. There were generally no user fees incurred at any sites. Opening times were more favourable at the primary care sites. Providers were in agreement that secondary level services are critical as referral sites for patients with specific medical complications and for supporting the primary care platform in general. Although a small proportion of patients initiating ART would need to do so at this level, the consensus from both primary and secondary level providers was that the bulk of ART service delivery should be at primary care sites.

General approach to service delivery within ART services

Structure of the clinical team
Each site differed in the numbers of doctors employed, from one doctor working half-days to four doctors working full-time. Their roles were largely clinical with some administrative

responsibility. Nurses played more varied roles at the clinics, including but not limited to facility manager, adherence counsellor and clinical practitioner. Adherence counsellors and community outreach counsellors/support workers, in addition to their designated roles, performed a number of minor administrative and clinical functions. Role definition seemed more uncertain for lay health workers and management of counselling services was identified as a problem. The variety of functions performed by pharmacists in the ART programme illustrates the flexibility of roles played by a single staff category, and some of the opportunities for configuring the utilisation of human resources in new and creative ways.

Patients seemed to prefer the practitioners they were used to, with those in doctor driven clinics preferring to see doctors as their clinicians, generally due to perceptions that doctors were more skilful/knowledgeable. Those in nurse driven clinics preferred nurses, citing reasons of language, more holistic attitudes by nurses and shorter waiting times.

<u>Analysis of staffing costs</u>
The cheapest clinics to operate (in terms of an economic cost of staff per patient month) were those using the least number of doctor hours and making use of clinical nurse practitioners. In general doctor's salaries were the largest cost driver of the clinical care costs at each clinic. Overall the clinical care staff costs on ART ranged from R159 to R406 per patient month.

<u>Staff, facility and district management</u>
The ART services, although vertically managed, are not free from the problem of different staff in the same facility being supervised by different managers. The presence of NGO-employed staff at each site contributed to the multiple lines of accountability. Counselling and administrative staff were expected to be both 'task-flexible' on a daily basis and answerable to a number of different people's needs. Where the management of NGO-employed staff and the clinical service were closely aligned, fewer frustrations were expressed. Burnout was a common theme mentioned by staff, and some linked it to the lack of clarity at a district level as to the future of the services. Some facility-level managers expressed concerns about not being able to see themselves as part of a district-level response.

Adherence support provided to patients

<u>Overview of adherence differences</u>
All sites share a principle of intensive patient education prior to ARV initiation. Where this approach differs between clinics is whether the delivery of information is to a group of patients, or to an individual or some combination of the two approaches. Once ARV treatment starts, adherence tools become more diverse across the clinics: some clinics have the opportunity to interact with patients at the clinic only, while other clinics maintain an extensive outreach component.

<u>Community-based versus facility-based adherence support</u>
Discussion with providers seems to suggest that it is not so much the design of the 'adherence model' that impacts on adherence, but how well the adherence support system is organised and managed. Few differences were seen in adherence outcomes between the community-based and facility-based approaches to adherence support. Counsellor salaries were the major cost driver in the community adherence support model, and the costs of this support were higher per visit than the cost of the facility-based counselling. This most likely reflects the low level of input received by stable patients from facility-based counsellors.

Long-term adherence support
The concern was expressed that all current adherence plans are effectively 'short-term' (6 months to 2 years) and new approaches might need development if long term adherence were to be adequately addressed.

Self-reported adherence outcomes

Self-reported adherence was good across all sites, with between 86% and 97% of patients reporting complete adherence in the 3 days preceding the questionnaire. Multivariate analysis did not demonstrate any of the measured patient or facility variables being strongly associated with self-reported adherence. The exception to this is adherence at one of the hospital sites where the high proportion of missed doses may be explained by more complex clinical cases at this referral facility (where treatment stoppages may be directed by health care providers).

According to patients who used them, pillboxes were considered the most helpful adherence tool (94% of users considered them 'very important' as an adherence tool), thereafter, in order, were: a clinic-based support group, a community-based support group, a patient-chosen treatment supporter and a home visit by a clinic counsellor.

Stigma and disclosure

Disclosure and a social environment that is conducive to disclosure were thought critical contributors to adherence by clinicians and counsellors alike. Some providers suggested that a broader context that assists in destigmatising HIV would have adherence benefits.

Integration

Providers' attitudes towards integration
Discussions around integration focussed mostly around TB/HIV integration. Most, but not all, respondents agree in principle with the concept of integration of services. Integration was perceived as a solution to the problems of communication that were affecting TB management, which were referred to frequently. On-site (clinic-level) and district-level management, as well as programmatic vision, are seen by providers as the necessary driving force behind the integration process. At one site where integration has been reasonably successful, it has been due to intensive and sustained training and personal input from both the attending physician and the clinic manager. Some respondents felt that ARV treatment needs rapid demystification for all health workers and district-wide normalisation, and that integration into the TB services would assist with this.

In clinics where TB and HIV services are separated, complaints of delays in TB diagnosis and treatment are common. A specific problem that was mentioned on many occasions was the reluctance of nurses to deviate from the "sputum-positive protocol", that is, nurses not initiating TB treatment, despite a physician referral letter requesting it, unless the patient had sputum positive TB. It was felt that these delays were creating 'bottleneck' situations in the decision making process around ARV initiation.

Health seeking behaviour beyond the public sector
Overall, only a small proportion of patients accessed other (non public sector) services. Nevertheless it appears as if the problems that led them to other points of care could have generally been managed at a primary care clinic.

Specialist HIV primary care versus integrated HIV/ART care
STIs and condoms/safe sex information seem to be adequately managed at the ARV sites, while TB management remains a problem to patients and ARV clinicians alike. Similarly,

most women appear inconvenienced by the unavailability of a full range of family planning choices at their ARV site.

Barriers between health care service points
Most providers saw the lack of clear communication channels between the referring clinic and the referral site as negatively impacting on patient management. Many patients are returning to their primary ARV site without clinical information, evidenced by poor maintenance of patient-retained records. In addition, patient transport remains a problem, specifically with regard to investigations that cannot be done on site. This leads to delays in the clinical team's decision-making.

Social grants
Many providers expressed a desire for better communication with the department of social services and for greater clarity on the indications and long-term sustainability of disability grants for patients with HIV/AIDS. The need for greater input from social services was corroborated by patient interviews, with patients expressing a wish for waiting room food and for financial and skills assistance, in addition to their concerns about accessing and retaining their grants.

Needs expressed by providers and patients

Smaller requests from providers were for minor administrative needs to be met, including simple things such as stationery. In addition, providers frequently expressed the need for pillboxes for their patients.

More substantive requests were for more counsellors and better skills training for existing counsellors. Many providers further suggested additional nutritional support for patients. This concurred with patients' self-reported needs.

Physical space was almost unanimously mentioned as a constraint by all clinics, and all spoke of the problem becoming more severe with time. An interesting suggestion was that of implementing a clinical training program for nurses, in order that they might have a more direct hand in patient management and ARV initiation and in so doing potentially relieve some of the current physician 'bottlenecks'.

Interviews with patients revealed that their most frequently mentioned need revolved around access to services and was generally for more convenient opening hours and shorter waiting times. Second on the list of patient needs was for food assistance, either through receiving food at the facility itself or assistance with food parcels. Other needs included an expanded range of reproductive health services, the desire to be treated with dignity by staff, and very commonly, a request for clarity on who qualifies for disability grants.

Conclusions

Data collected from patients has demonstrated that those accessing ART are not privileged relative to the provincial population, and confirms the predominance of women in the patient population, who are on average younger than male patients.

Routine outcomes at six months duration on ART do not obviously differentiate the sites studied, with the outcomes in terms of virological suppression, self-reported adherence and patient retention all being good compared to international benchmarks. These data validate the functioning of the service as a primary care intervention, supported by data showing patient acceptance, and relatively low costs to patients in accessing care. Comparisons at longer durations on ART may be more appropriate as a measure of programme success in future studies.

The varying roles of nurses in providing clinical care in this study suggest that, if appropriately managed, care models in which nurses deliver a substantial proportion of clinical care are feasible, potentially more affordable, and acceptable to patients.

Well-functioning models of adherence support were described, both facility-based and community-based. Key to their success is effective and sustained management and integration with clinical care, rather than specific details of the adherence support model. The debate about whether or not the community-based adherence model is desirable and affordable is likely to be offset by the huge challenge of numbers requiring treatment. In seeking to make maximum use of limited resources, it is plausible to consider a model of targeted support that is directed towards individuals that clinic tracking systems have identified as having adherence difficulties. Such a system could utilise facility or community-based adherence supporters depending on individual circumstances and requirements. This presupposes effective identification of those having adherence difficulties, which is in turn a reflection of efficient site management, well-directed transit through the care process and dependable record keeping and information systems.

The dominant theme around service integration is around TB/HIV services due to the overlapping burdens and clinical challenges, with most providers favouring it in principle, but with varying concerns about the impact it could have on vertical services which currently function well. Integration with other chronic care services, while theoretically desirable, was not prominent in the discussions with providers.

Common themes across the sites not pertaining to differences in the model of care include the desire for more visible district level management, particularly to allay concerns about burgeoning patient loads, which was implicated as contributing to staff burnout. An ancillary concern raised through this study is the variability of clinical record keeping evidenced by numerous incompletely maintained patient-retained records. Patients, counsellors and doctors alike raised the issue of uncertainty around qualification for disability grants, and its possible future impact on adherence.

The service configuration at the time of the study did not allow for the evaluation of any attempts at outward referral of stable patients, but the general findings around primary care and nurse-involvement support the notion of an expanded primary care antiretroviral service in which care is shared by clinical teams, rather than a two-tier doctor-nurse service. The future burden that each of the districts included in this study are likely to face (at over 5,000 patients per clinic in two of the larger clinics in 2011) makes such expansion virtually unavoidable, unless an alternative "super-clinic" model (single, resource-intensive clinic designed to initiate and maintain thousands of patients on treatment) is anticipated.

Either way, an active process of planning for service expansion will both allay the fears of health workers and help prepare the Provincial Department of Health for the foreseeable quadrupling of the antiretroviral patient load over the next five years.

Introduction

Background to the project

Over the past five years a number of different programmes have developed independently in the Western Cape to provide antiretroviral therapy (ART) to HIV-infected individuals. Many of the programmes began before the national roll-out of ART, and approached the provision of care in very different ways. The programmes which began during 2001-2003, are today reasonably mature and provide an opportunity to explore the impact of different approaches to ART service delivery.

There are currently 43 sites delivering public sector ART services in the Western Cape, treating approximately 19,000 individuals in total. It is anticipated that provincial services providing antiretroviral therapy will increase substantially in size and number in the next 5 years. To help inform this planned scale-up of services, the Provincial Government of the Western Cape (PGWC) commissioned the Infectious Disease Epidemiology Unit (IDEU) at the University of Cape Town to undertake this research. The overall goal of this project is to help identify the key programmatic elements that may be included in future public sector HIV care services, with a view to designing a service that can cope with high patient numbers while maintaining quality of care.

The clinical aspects of ART provision in the Western Cape are reasonably uniform across sites, and are guided by a number of protocols and guidelines. However other aspects of care vary considerably between sites. For instance, there are major differences in the adherence support systems used across sites, several with significant cost implications. In addition, the combination of service providers employed within each service can have significant implications for both quality of care as well as resource utilization. Some sites in the Western Cape have relied heavily on clinical nurse practitioners to provide routine clinical care, whereas in others the role of nurses has been more narrowly defined and doctors provide the bulk of clinical care. This research focuses on these and several other key areas of service delivery, seeking to identify features which contribute to efficient and effective service delivery.

ART is increasingly recognised across South Africa as a chronic care service, and the burden of HIV disease means that this service must be widely available at a primary care level. There is generally a concern about vertical programmes, and policy makers are seeking ways of drawing parallels between ART and other established forms of chronic care service delivery such as services for hypertension, epilepsy, diabetes and asthma. Unlike these conditions however, HIV is an infectious disease with a hugely overlapping burden with tuberculosis, and an alternative axis for integration of care is integration with tuberculosis services(Coetzee et al. 2004c;Corbett et al. 2006). Some attempts at linking HIV and tuberculosis services have been made in the Province, creating a further opportunity for learning from the diversity of existing sites.

Models of care for ART service delivery in South Africa
One of the first pilot projects to offer ART in the Western Cape, in Khayelitsha, was based on a model of a vertical infectious disease service with a facility-based team of a doctor, a nurse and a counsellor, expanding in later years to include more nurses and counsellors (Coetzee et al. 2004b;Coetzee et al. 2004a). Key advocacy messages from this project were the feasibility of ART in the setting, and the importance of patient-centredness as an approach to adherence. In Guguletu, a township with a similarly high prevalence of HIV, a model was developed which emphasised the role that people living with HIV could play as community-based counsellors, and how a single service point could receive eligible patients from a

number of facilities providing general HIV care (Bekker et al. 2003;Lawn et al. 2005;Orrell, Bekker, & Wood 2001). Substantial experience had also been gained in the private sector, where individual care provided by private practitioners was subject to the oversight of disease management programmes.

When the South African Department of Health announced a comprehensive plan for HIV management that included ART (South African National Department of Health 2003), one service point per district was initially envisaged. The plan and subsequent clinical guidelines emphasised the clinical content of care, and the broad approach to patient preparation without being specific as to the exact service model. Provinces made differing choices. In Gauteng large academic hospitals with existing clinical capacity demonstrated how high throughput hospital outpatient clinics could rapidly enrol thousands of patients into ARV care. In the Free State Province, a province-wide system of nurse and clinic-based ART was initiated with defined roles for district hospitals at particular junctures in the care process.

Understanding the provincial burden of HIV care

It is important to recognise the context in which ART services are being developed in the Western Cape, as this emphasizes the future requirements for ART that the province will be facing, and has implications for the most appropriate model of service delivery.

The Actuarial Society of South Africa maintain an integrated demographic and HIV model which is the *de facto* standard for estimating the size and composition of the HIV-infected population in the country (Actuarial Society of South Africa 2005). The Western Cape version of this model was used to calculate the number of new patients becoming AIDS symptomatic each year, a rough denominator for patients *newly* requiring ART in a given year. This number was adjusted to reflect the patients likely to seek care in the public sector.

Key outputs are summarised below (Table 1). It is instructive to consider the implications for adults, bearing in mind that the same issues apply on a smaller scale for children. Currently it is estimated that around 250,000 adults are living with HIV in the Western Cape (line 1), and that 20,000 adult patients will develop symptomatic AIDS between mid-2006 and mid-2007 (3). Accounting for the private sector, and even allowing hypothetically for a massive impact of prevention programmes, this number does not change markedly (4 & 5). Of these 20,000 adult patients, about 11,500 are anticipated to start ART in the public sector between mid-2006 and mid-2007 (6).

Table 1. HIV projections for the Western Cape

Western Cape HIV projections		2006	2007	2008	2009	2010	2011
Adults							
1	Total adults living with HIV at mid-year	255,836	270,783	283,311	293,497	301,455	307,338
2	New adult infections over previous year (Jul - Jun)	27,605	26,943	26,264	25,583	24,947	24,367
3	Entered Stage IV over previous year (Jul - Jun)	18,018	20,206	22,002	23,368	24,307	24,851
4	Newly in stage IV and likely to use public sector	16,678	18,661	20,272	21,480	22,290	22,740
5	Newly in stage IV assuming 40% reduction in incidence from mid'06	16,678	18,657	20,229	21,288	21,755	21,629
6	Projected number starting ART in previous year to maintain mortality	9,687	11,566	13,133	14,526	15,241	15,716
7	Total adults on ART, assuming median 6.3 years survival on ART	19,286	27,408	35,707	43,950	51,928	59,468
8	Total adults on ART, assuming median 8.8 years survival on ART	19,286	28,953	40,079	52,350	65,493	78,228
Children							
9	Total children living with HIV at mid-year	11,453	12,960	14,358	15,605	16,660	17,499
10	Infected by MTCT over previous year (Jul-Jun)	2,993	3,058	3,082	3,073	3,036	2,979
11	Entered AIDS over previous year (Jul-Jun)	2,073	2,273	2,466	2,623	2,726	2,769
12	Projected children started on ART (Jul-Jun)	1,251	1,446	1,624	1,785	1,856	1,886
13	Total children on ART mid-year, assuming median 8.8 years survival on ART	2,252	3,100	4,019	4,984	5,964	6,804
14	Total number of patients newly eligible for ART (Jul-Jun)	20,091	22,479	24,468	25,992	27,033	27,620
15	Projected patients starting ART in public sector prev. year (Jul-Jun)	10,939	13,012	14,757	16,311	17,097	17,602
16	Projected number of patients on ART public sector	21,538	32,053	44,097	57,335	71,457	85,032

(Source: Adapted from ASSA2003 model)

According to the model, in order for the number of HIV-infected adult patients dying in the public sector without ever accessing ART to remain constant at around 7,000 a year, the Western Cape Province will need to continue enrolling upwards of 1,000 patients a month onto ART (15). Combining with children, between 65,000 and 85,000 (16) patients are anticipated to be in care and on ART in the middle of 2011.

In summary, the ART service in the province would need to expand four fold over the next five years to prevent an increase in morbidity and mortality. The current enrolment capacity in the province is close to being able to achieve this scenario, and the largest challenge is likely to be adapting to an ever-increasing number of patients who have progressed beyond the early months on ART.

Study aim and objectives

The aim of this project was **to assess the strengths and weaknesses of current approaches to the provision of ART in the Western Cape to both adults and children, from the perspectives of health systems, health care providers, and patients**.

Objectives included:
- Describing the profile of patients accessing ART
- Exploring differences in service provision with respect to
  - Patient education and adherence processes
  - Facility staffing structures and staff roles
  - Integration of ART and other services
- Describing the programme outcomes with respect to
  - Routine reporting of patient survival, patient retention and virological outcomes
  - Patient self-reported adherence
  - Patient-perceived quality of care
  - Process indicators such as completeness of record-keeping
- Exploring provider experiences of different models of care
- Identifying aspects from the studied models that could inform future service planning

Methods

Study design

A multi-method evaluation was undertaken, including a cross-sectional survey of patients on ART, a qualitative exploration of provider experiences of the services through interviews and focus groups, and observations by research staff.

Population and sampling

The target research sites were public sector facilities providing ART.   Five sites were purposively chosen after consultation with PGWC, on the basis of :

o   The most established services in the province with large numbers of patients on ART.

o   A range of approaches to different aspects of service delivery (provider mix, approaches to counselling, and the location in primary care versus hospital-based).

Selected facilities (described in detail below and summarised in Table 2, page 14):

  o   GF Jooste Hospital (JO)
  o   Guguletu Community Health Centre (GG)
  o   Hout Bay clinic (HB)
  o   Michael Mapongwana Day Hospital (MM)
  o   TC Neumann Hospital, Paarl (PA).
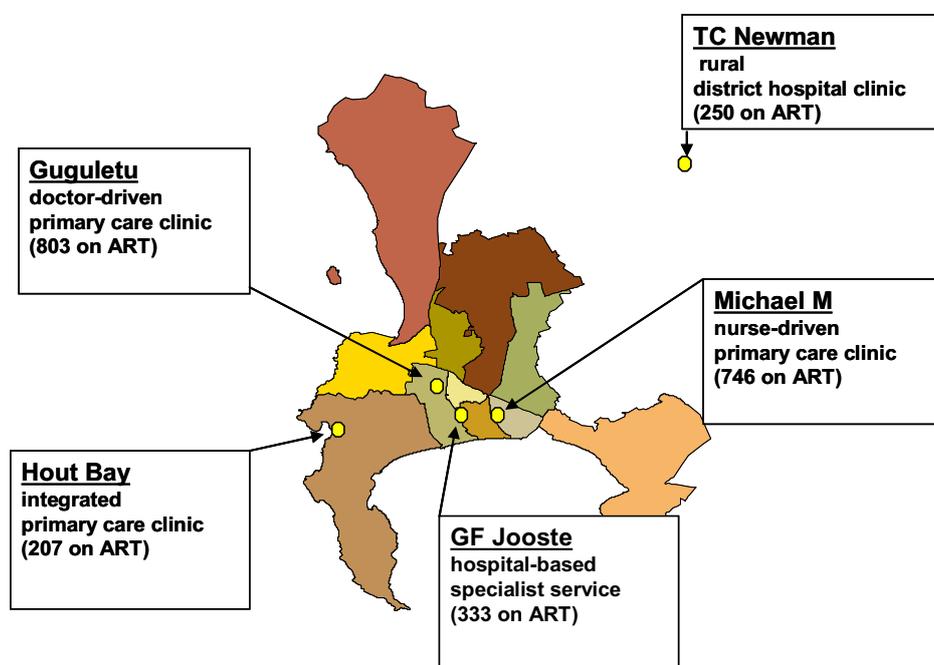
Figure 1. Selected service delivery sites

A sample size of 120 exit interviews per clinic was sought in order to provide adequate precision around expected responses.

Data collection and analysis

At each site, data collection took place between May and October 2005

Provider interviews
At each facility, the project leader interviewed 4-8 health care providers to investigate impressions regarding key hurdles to effective and sustainable service delivery, the perceived strengths and limitations of service delivery models, and related topics. Interviews lasted 30-45 minutes and were recorded and transcribed for analysis. In addition, two focus groups were conducted at the end of the research to explore themes that had emerged in previous interviews. The number of interviews conducted with each category of service provider was:
- *Doctors*: 11 interviews
- *Nurses*: 5 interviews
- *Counsellors*: 8 interviews and 1 focus group
- *Pharmacists:* 3 interviews and 1 focus group

Transcripts were analysed and coded for dominant themes, and representative quotes were selected to illustrate key themes.

Facility assessments
Each facility was visited at least three times during the data collection period with a standard checklist to observe overall service operations, staffing patterns, patient flow, and pharmacy logistics.

Exit interviews with patients attending ART services
A minimum of 110 semi-structured patient interviews were conducted at each facility to generate insights into patient demographics and patients' perspectives on different aspects of service delivery, including adherence support and health seeking behaviour. Patients were sampled consecutively with refusals recorded. Interviews were conducted in patient's home languages by trained interviewers. Interviews lasted 20-30 minutes and responses were recorded onto a pre-coded questionnaire which was piloted prior to data collection. Data were entered into Microsoft Access and analysed using Stata 9.0. Survey responses were not weighted when combined as the facilities had not been selected in order to be representative of a broader population, but rather to allow comparison between facilities.

Expert observation
Over the course of the study, the project leader (D Pienaar) spent a substantial amount of time in each of the participating facilities, and kept detailed notes on his observations, impressions and experiences. This participant-observation approach to qualitative data has yielded valuable insights into the routine conduct of the services at each facility, including the interaction between patients and staff as well as logistical and organizational aspects of service delivery.

Counsellor Diaries
At three of the sites a number of counsellors were asked to keep diaries for a week. A total of 26 counsellors participated in this: 14 counsellors at Guguletu, 5 at Michael Mapongwana and 7 at Hout Bay participated. They were asked to record daily tasks, including the number of patients visited and administrative duties. For the purposes of verification, at least two counsellors at each site were randomly chosen to be followed by a fieldworker who kept a separate diary of events. The fieldworker assessments suggested that the diaries were a fair reflection of time usage by the counsellors.

Results – overview of facilities

General overview of individual clinics studied

Although sharing many similarities, the five clinics examined also exhibited a number of differences. Clinics differed substantially in terms of location, physical infrastructure, staff composition, and hours of opening.

In brief, there were two services within existing PHC facilities (even though services were delivered vertically in a separate space within the facility). One was a local authority integrated clinic, in which antenatal, chronic care, sexually transmitted infection (STI) and tuberculosis (TB) services predated the ART service. The ART service was staffed by a single doctor, working part time and the adherence support was a mixture of facility and community-based. The other ART service was located (although functionally separate) in a community health centre (CHC). In this clinic nurses carried a larger clinical responsibility than in any other clinic and the adherence support was largely facility-based but aided by universal provision of pill-boxes.

Thirdly, there was one free standing ART facility, taking referrals from several clinics in the area. In this service the clinical care was provided solely by doctors, whereas it had the largest number of community-based adherence supporters and the most structured system of patient education and adherence support management.

Finally, there were two ART services in the outpatient departments of secondary hospitals. One was characterised by having significant specialist input into the program, as well as having adherence support based only on-site. The other was more rurally situated, was run by medical officers and made use of pre-existing links with home-based carers in order to extend its reach into the community. This clinic therefore had a mix of facility-based and community-based adherence support mechanisms.

All studied clinics had been in continuous operation for a minimum of 18 months, some for significantly longer. In part this was one reason for their being selected for study, since it was imagined that 'teething problems' would have been overcome and the problems that were evident at this stage in the clinic's development could be assumed to be of a more systemic nature. It was also hoped that these services would be operating at scale, having overcome the inefficient use of resources that often accompanies services in a start-up phase. Similarly it was felt that positive lessons would have 'stood the test of time'. Another striking feature across all clinics was the level of commitment shown by staff to their patients, a feature which many interviewed health care workers modestly seemed to consider as standard but which nevertheless seemed integral to the clinic's success, scaling up and ongoing functioning.

A more detailed overview of differences is provided below in tabular form (Table 2, page 14). If unfamiliar with the service context, a more detailed description of each of the facilities studied is provided as an annexure (Annexure A).

Table 2. General overview of clinic features

	Description	Inception	Opening hours	Distinguishing features	Adherence overview
GF Jooste	Within dedicated space in secondary level hospital out-patient department	Early 2003	8.00-16.00 3 days/week	• "Academic" clinic • Good access to tertiary level investigative services • Weekly teaching forum on the hospital premises • Doctors as clinicians	• 5 counsellors, facility based. • Patient education concurrent to clinical work-up. • Tailored ongoing adherence counselling support after initiation
Guguletu	Separate building, at a CHC site	September 2002	8.00-16.00 5 days/week	• Largest number of community counsellors • Doctors as clinicians	• Clinic and community support • Patients assigned to individual counsellors
Hout Bay	2 rooms within an integrated local authority clinic	January 2004	8.00-13.00 5 days/week	• TB management on site • Single doctor clinician • CNPs from rest of clinic being trained to manage minor HIV morbidities	• On-site routine education • Community advocate support with home visits
Michael M	Dedicated space within a CHC	May 2001	8.00-16.00 5 days/week	• Nurses and doctors as clinicians • Comprehensive visit data-capture system	• On-site counselling and support groups • Very little community outreach • Tailored on-treatment adherence sessions • Every patient receives pillbox
TC Newman	Outpatient wing of secondary level hospital	February 2004	8.00-16.00 2 days/week	• Strong links with hospice • Heterogeneous patient population • Doctors as clinicians	• On-site tailored education and community advocate support with home visits • Home based carers have been incorporated into adherence support network

Results from routine reporting system across the five sites

There are two forms of routine reporting from ART sites – the first is monthly reporting of total patient numbers and new patients on ART to facilitate broad service and resource planning. The second form is quarterly cohort reports tracking the progress of cohorts of patients longitudinally. It allows for example the 3 month outcomes for patients started on ART between January and March of a particular year to be compared to those for patients started on ART between October and December. Comparisons can be made between time periods, between sites, or a combination of both. The cohort reports are the best opportunity we have to compare patient outcomes between sites, bearing in mind that the outcomes are not only a product of the services, but also the different patient populations themselves.

The major items tracked in the cohort reports are survival in care and laboratory outcomes. Patients are lost to care due to death, loss to follow-up (defined here as no contact with the services for 3 months or more), or being transferred to a different service. The cohort reports are limited to patients who are naïve to prior ART, ensuring that like is compared with like.

For the purpose of this exercise, we elected to look at the results for treatment-naïve adult patients started on treatment between July 2004 and December 2004, and to examine the outcomes at 6 months. These outcomes (Table 3), adjusted for patients transferred out to other sites, best reflect care provided as close as possible to the time when the research was conducted. We selected the first six months on treatment as the principle period of interest, as it is the first interval for which laboratory outcomes are available, and virological outcomes are almost entirely linked to adherence issues so soon after starting ART.

Looking at the proportion of adults with baseline CD4 cell counts below 50 cells/μl (line 2), it is lowest for Hout Bay and Paarl (Chi^2 p<0.001 comparing these two sites to the rest), suggesting that the patients started on ART at these two sites have on average less advanced disease than for the other sites. In terms of total numbers of patients started, Guguletu and Michael Mapongwana have the highest throughput (1). For all sites women predominate, which is characteristic of the entire programme both provincially and nationally (3).

Hout Bay has the lowest overall mortality (5), partially offset by a higher loss to follow-up (6). Overall, there is substantial variation in the proportion of patients that are known to have died versus those recorded as lost to follow-up.   Putting the two together though, the proportion of patients remaining in care at 6 months (7) is lowest for the hospital sites. The data from GF Jooste Hospital should be interpreted with additional caution due to some follow-up data being missing.

With the exception of GF Jooste Hospital (where under-reporting accounts for the scarcity of 6-month laboratory outcomes and where data for one quarter are missing), the majority of patients are receiving CD4 counts (10) and viral loads (14) appropriately at six months (over 98% viral load completion excluding G F Jooste). The rates of virological suppression (15) are uniformly high across the sites, with 93% attaining viral loads below 400 copies/ml at 6 months in all sites combined. Comparing across sites, the confidence intervals for this measure overlap given the numbers of patients included (16).

Table 3. Cohort report for adults starting ART at the 5 sites

	G.F. Jooste Hospital	Guguletu CHC	Hout Bay Clinic	TC Newman Hospital	Michael M CHC	Grand Total
Started ART and due to reach six months during study						
1 Total starting ART 01/07/2004 - 31/12/2004	105	167	61	93	200	**626**
2 Percentage with initial CD4 < 50 cells/µl	29.5%	29.3%	11.5%	19.4%	29.5%	**26.2%**
3 Percentage men	27.6%	21.6%	41.0%	29.0%	26.5%	**27.2%**
Reaching 6 months on ART during study period						
4 Total patients with data	43	167	61	93	200	**564**
5 Percentage died	0.0%	6.8%	0.0%	8.2%	6.2%	**5.5%**
6 Percentage lost to followup	18.6%	4.3%	6.8%	3.5%	3.6%	**5.3%**
7 Percentage remaining in care	81.4%	88.9%	93.2%	88.2%	90.2%	**89.1%**
8 CD4's done	9	138	52	69	168	**436**
9 CD4's >= 200 cells/µl	5	80	29	53	107	**274**
10 Percentage of patients with a CD4 result	27.3%	95.8%	98.1%	92.0%	98.8%	**91.8%**
11 Percentage of CD4's done that are >= 200 cells/µl	55.6%	58.0%	55.8%	76.8%	63.7%	**62.8%**
12 Viral loads done	7	138	52	74	170	**441**
13 Viral loads < 400 copies/ml	7	132	50	64	159	**412**
14 Percentage of patients with a viral load result	21.2%	95.8%	98.1%	98.7%	100.0%	**92.8%**
15 Percentage of viral loads done that are < 400 copies/ml	100.0%	95.7%	96.2%	86.5%	93.5%	**93.4%**
16 95% confidence interval for viral load suppression	(59.0 - 100.0)	(90.8 - 98.4)	(86.8 - 99.5)	(76.5 - 93.3)	(88.7 - 96.7)	**(90.7 - 95.6)**
Reaching 12 months on ART during study period						
17 Total starting ART 01/01/2004 - 31/12/2004		295			355	
18 Percentage remaining in care		86.3%			86.4%	
19 Percentage of patients with a viral load result		89.4%			90.1%	
20 Percentage of viral loads done that are < 400 copies/ml		93.6%			88.7%	
21 95% confidence interval for viral load suppression		(89.6 - 96.5)			(84.1 - 92.3)	
Reaching 18 months on ART during study period						
22 Total starting ART 01/01/2004 - 30/06/2004		128			155	
23 Percentage remaining in care		81.5%			81.1%	
24 Percentage of patients with a viral load result		66.3%			89.2%	
25 Percentage of viral loads done that are < 400 copies/ml		89.6%			90.9%	
26 95% confidence interval for viral load suppression		(79.7 - 95.7)			(83.4 - 95.8)	

(Note - the data for G F Jooste Hospital only refer to patients starting ART in quarter 3, 2004, since 6 month follow-up data were not available for patients started in the final quarter of 2004)

As the patient numbers and duration of operation of the Guguletu and Khayelitsha sites allows for comparison of outcomes at longer durations on ART, 12 and 18 months outcomes are presented just for these two sites. Once again it is restricted to cohorts which reached this duration during the study period.

Retention in care is similar at 12 and 18 months (lines 18 & 23) between these two sites. The proportion of patients with viral load results who have values below 400 copies/ml is higher in Guguletu at 12 months on ART (chi^2 p=0.06, line 20), although this difference is reduced by 18 months duration on ART (25). Missing data (24) in Guguletu at 18 months could be masking a continued difference in this outcome.

Overall, it is difficult to discern substantial differences in outcome between the models of care from this analysis of routinely collected data. These data suggest that all 5 sites are performing well in terms of retention in care, immunological benefits and virological suppression. If there is a discernable pattern, it is probably that the primary care sites are better able to ensure completeness of data, and may have better outcomes. When comparing both retention in care and virological suppression at 6 months on ART, and comparing the two hospital sites to the three primary care sites, the primary care sites have the better outcomes. Retention in care at 6 months at hospital sites was 85.9% versus 90.1% (p=0.18) at the primary care sites, and virological suppression to below 400 copies/ml was 87.7% versus 94.7% (p=0.02).

Results - Patient demographics, access to care and setting

This section explores the overall patient demographics, but also compares between sites, contrasting patient characteristics and issues of service access across different service settings such as primary care sites and hospitals.

Patient demographics

The interviewed sample represents 32% of the total on treatment at the 5 sites at the time of investigation.

Those undergoing interviews (see Table 4) were predominantly young (median age 33), single (only 33% married or cohabiting), female (77%) and Xhosa speaking (91%). Men were older than women, with a median age of 37 (IQR 31-43) compared to 32 (IQR 28-36) for women (Figure 2a).

Most people were born outside of the Western Cape (72%) and many (43%) remain highly mobile, spending considerable time every year outside of the Western Cape. Only a minority were employed (24%) of which less than half were full-time employed, the remainder being self-employed or engaged in casual work.   Fifty-three percent were on disability grants (DG's) at the time of interview, while a large proportion of the others had applied for a DG. Thirty percent of respondents were unemployed and not receiving any social assistance at the time of the interview (Figure 2b). Overall employment patterns were similar between men and women. Comparing between sites however, patients from Paarl and Guguletu were less likely to be formally employed, whereas patients in Khayelitsha were more likely to have occasional casual or self-employed work.
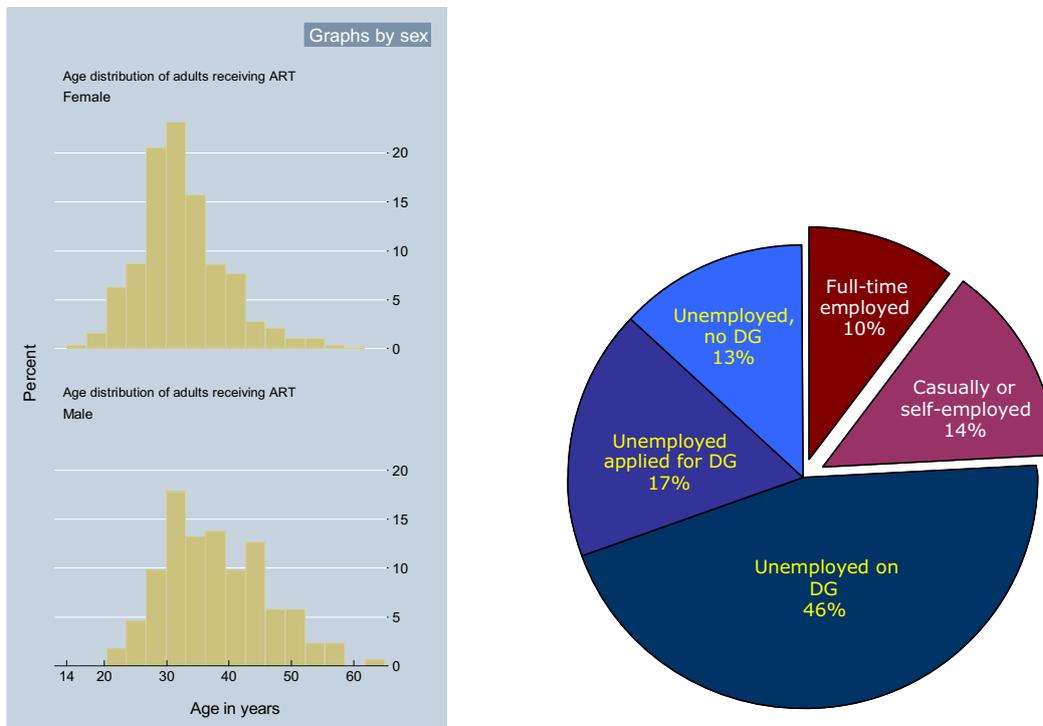
Age distribution

Employment status

Figure 2. a) Age distribution b) Employment status of patients accessing ART

The median level of education attained was Grade 10 or standard 8 (IQR Grades 8-11), and this was consistent across sites.

Almost exactly half the respondents (51%, 95% CI 47-55) live in informal dwellings, ranging from 74% in Hout Bay to 35% in Paarl. Three-quarters of respondents had access to clean water in their homes or yards, with the remainder having access to public taps.

The median duration on ART in the overall sample was 7 months.

Table 4. Social/Demographic profile of interviewed patient sample

	Total N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Estimated % of adult patients interviewed (denominator)	32% (2339)	53% (207)	28% (746)	23% (803)	40% (333)	46% (250)
Median age	33	33	32	34	34	34
% Female	77%	73%	81%	75%	72%	80%
Home language Xhosa	91%	80%	96%	94%	91%	85%
Median highest grade of education	10	9	10	10	10	10
Informal dwelling (%)	51%	74%	59%	46%	38%	36%
Median household size	4	3	4	4	4	5
Married/cohabiting	33%	32%	34%	34%	33%	28%
Born outside of WC	72%	86%	86%	60%	68%	59%
Travelled out of WC > 1 week in past year	43%	75%	34%	39%	42%	37%
Plan to move out of WC permanently in next 12m	7%	29%	7%	3%	5%	1%
Employed in previous 2w	23%	24%	35%	14%	24%	14%
Currently on social welfare grant	53%	61%	56%	34%	48%	36%
When HIV tested (year)	2003	2003	2003	2002	2003	2003
Medical referral for HIV testing (vs voluntary)	77%	74%	86%	64%	81%	81%
Median months on ART	7.0	9.8	6.6	6.5	10.0	6.3

Access to care

Most people only tested HIV positive relatively recently (36% of the total sample tested in 2004/2005 – Figure 3) and most tests were done because of medical advice to do so (77%) as opposed to voluntary testing (23%). The usual reasons for medical advice to test were in descending order concurrent TB, pregnancy and hospitalisation, reflecting the major entry points into care.
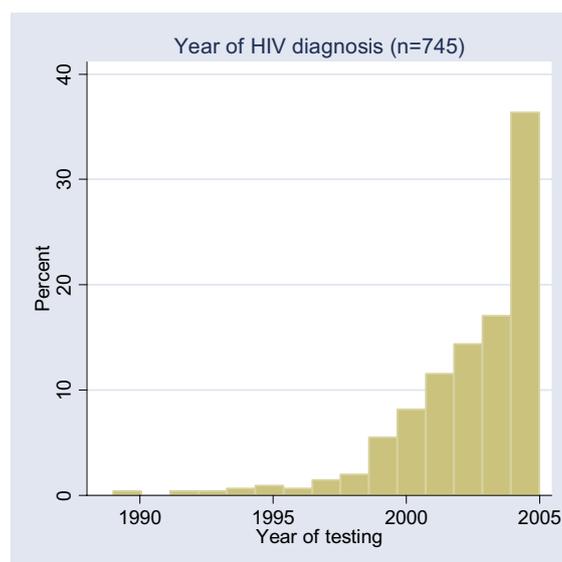
Figure 3. Timing of first positive HIV test

In order to gain insight into the socio-economic status of patients accessing ART, an asset index was constructed from questions pertaining to household structure, assets, appliances and access to electricity and water. This was compared to a sample from other township settings, divided into 5 quintiles, with quintile 5 having the most assets. In terms of this analysis, 45% of the sample are in quintile 1, and a further 22% in quintile 2, 18% in quintile 3, 7% in quintile 4 and 8% in quintile 5. By this measure patients accessing ART are impoverished compared to a representative township sample, concurring with the findings on employment status.

A group of questions pertained to the patient-costs associated with accessing care. Only 9 patients out of the entire sample reported having had to pay to access ARV care, 6 of these were at the Paarl site, and none reported paying for the service on the day of the interview.

Twenty-seven percent of those employed reported losing income when attending the clinic, including 31% of those casually or self-employed and 21% of those formally employed. The average time it took patients to travel to the clinics was 30 minutes. Travel to the clinics is almost entirely by taxi or on foot (Table 5). The average cost of travelling for those using transport was R5.15.

Patients get the bulk of their care from the public sector, with 15% reporting having visited a private doctor in the preceding 6 months in all sites except Hout Bay where 5% reported visiting a private doctor (chi[2] p=0.010).

Table 5. Patient specific implications of accessing care

Site	HO	MM	GG	JO	PA	Total
N	110	207	183	133	116	749
Travelled on foot (%)	85%	41%	27%	29%	6%	36%
95% CI	(76 - 91)	(34 - 48)	(21 - 34)	(21 - 37)	(2 - 12)	(33 - 40)
Lost income amongst employed (%)	0%	29%	43%	22%	42%	27%
95% CI	-	(18 - 41)	(24 - 63)	(10 - 39)	(20 - 67)	(20 - 34)
Average cost for those not on foot	R 10.87	R 3.49	R 3.45	R 5.75	R 7.81	R 5.15
Visited a private doctor last 6m (%)	5%	13%	15%	15%	16%	13%
95% CI	(2 - 11)	(9 - 18)	(10 - 21)	(9 - 22)	(9 - 23)	(11 - 16)

Further contrasting the service setting

The two clinics based at the outpatient departments of secondary level hospitals, GF Jooste and TC Newman, were compared with respect to various indicators, to the three clinics that were located within their communities.

Access, travelling time and cost of attendance

Forty-six percent of patients at primary care level walked to their ARV clinic compared to 18% at the secondary level (Table 5). When the two secondary level hospitals are studied individually, only 6% of patients attending the rurally placed TC Newman, and 29% of those attending GF Jooste, arrived there by foot. In comparison, 85% of patients attending Hout Bay Clinic walked to the clinic.

Patients took a significantly longer time to travel to the two clinics based at secondary level hospitals than they did to get to a clinic located within the community (39 minutes versus 26 minutes, p<0.001). Of those paying for transport, patients travelling to hospitals are paying slightly more on average, with the exception of Hout Bay where those not living in the township and accessing the clinic using transport are probably coming in from outside of Hout Bay.

As reported above, no patient from any of the clinics paid to attend their respective facility on the day of interview.

Opening times

Patients showed a distinct preference for clinics that were open every day of the week. As a general theme, in reply to a question about suggested improvements, most patients expressed a need for improved opening times and reduced waiting times. Twenty-eight percent of patients at TC Newman hospital (which operates only 2 days a week) expressed the desire for improved opening times. Interestingly, the other clinic that was open for only part of the week, GF Jooste, returned only 4.5% of patients wishing for improved opening times. Every clinic had a number of people who suggested more staff as an improvement, with TC Newman again recording the highest proportion (18%) of patients requesting more staff.

Provider experiences of levels of care

When interviewed, there was little disagreement amongst providers that care should be based at the primary care level. Even those based at the referral hospital were of the opinion that this was not the ideal place in which to manage ART in the long term.

At the same time however, clinicians had strong views on the role of the secondary level hospitals in terms of providing referral support.

Below is a brief summary of the clinical service (beyond that of ARV provision) that GF Jooste Hospital offers the surrounding community and its draining clinics, as a case study of the role of a secondary level facility in ART provision.

Case Study 1 - GF Jooste infectious disease referral clinic

The doctors at the GF Jooste ARV clinic are also involved in the running of an HIV referral unit. The unit is built around the clinical expertise of the specialists and medical officers involved and their access to secondary and tertiary level investigations.

It consists of a walk-in consultation space and 8 'virtual beds' that have been negotiated from the department of medicine. These beds are not restricted to a particular ward and are filled wherever a bed space becomes available in the hospital. The patients in these beds fall under the clinical responsibility of the HIV unit's medical officers and consultants.

The walk-in unit operates from the same space as the ARV clinic (the outpatient department) and is open daily. However, because the ARV clinic operates 3 days a week, the referral unit tends to be busier on the other two days of the week.

The unit serves the same drainage area as the hospital and has links with Guguletu ARV clinic, local GPs and local business staff-health programs.

It accepts complicated patients, either people on ARVs or those being worked up for ARVs at another site. Examples of the sort of cases seen there include: immune reconstitution inflammatory syndrome, occult opportunistic infections, diagnostic difficulties for further investigation and drug side effect problems like lactic acidosis and drug-induced hepatitis.

Referrals are made telephonically, with direct communication to the medical officer on call for the unit, who rotates weekly. Patients are usually seen the same day or on a 'next-day' basis.

A patient seen at the walk-in referral clinic usually will experience one of three outcomes:

1) If the clinical situation warrants it they are admitted as an in-patient to one of the 8 virtual beds, where investigation and management will proceed as the team sees fit. To be noted is that, besides the 8 virtual beds, the unit also offers a service to the rest of the hospital wards, with the medical officer on call reviewing patients from other specialities who are referred to them.

2) If the patient's condition does not warrant admission and they do not have easy access to an ARV site they might be offered GF Jooste as their site of ARV initiation.

3) If the condition or diagnostic problem is resolved the patient might be returned to their referring ARV clinic with instructions and advice

From a doctor at GF Jooste:

"The vision for our ID clinic is actually a very modest vision in terms of being an ARV rollout site because we don't want to be a site where we are putting lots of patients on treatment. What we want to be is a site where we can, in addition to being an ARV referral unit, we will be a site where complicated patients are started on treatment and so patients that have a recent complicated admission, have lots of co-morbidities, so it's essentially building up capacity and expertise, so that means having adequate staffing, but also adequate equipment to perform the role of a specialist service for starting patients."

From a doctor at a referring clinic:

"But in terms of sort of like consultant care and diagnostic support, there is adequate of that and really, ja we've got only praise for the Jooste ID Clinic… There's never any problem in terms of getting advice there. So it's more the capacity of Jooste as a Secondary Hospital to cope with in-patient workload that does impact…(on the health system's ability to manage very ill patients)"

Results - General approach to clinical service delivery

The next few sections focus on areas that reflect on the overall structural aspects of service design and comprise a synthesis of various data sources.

Structure of the clinical team

Overview of clinical staffing

Every site surveyed had a different staff composition (see Table 6). The most obvious difference was the number (and level) of doctors employed at each clinic. Hout Bay ARV clinic employs one doctor on a mornings-only basis, while Guguletu employs 4 doctors full-time, two of whom are principal medical officers and two senior medical officers. GF Jooste, by contrast, makes use of medical officers and specialists in running its service. Despite the differences seen in numbers of doctors employed across the clinics, they all seem to consider their primary role as being clinical, namely clinical decision making and clinical problem solving. In addition to this primary role some doctors have assumed management positions too.

Nurses, on the other hand, have taken on a diversity of roles that seems to vary with the clinic's history and needs. These roles appear to be crucial to the clinic's day-to-day functioning however. They range from facility manager at one end of the scale to adherence counsellor at the other, performing a range of clinical and administrative functions in between. Worth special mention here is the clinical role nurses perform at Michael Mapongwana and to some extent at Hout Bay, seeing patients before, during and after their ARV initiation, in a clinic visit that does not include doctors.

Another difference between the clinics was their access to, and use of, ancillary health care workers and other staff. Some clinics had pharmacists, dieticians and social workers at their disposal; others had the use of administrative clerks and data-capturers. It was clear that the presence of administrative staff contributed to the efficient functioning of the clinic, especially when high patient loads were experienced.

Finally, all the clinics differed in the structure of their counselling and adherence support staff component. In general these were lay people who had received some group training and were responsible for imparting HIV/AIDS information to patients and for providing support and encouragement. At some clinics, there was a clear delineation between an education counsellor and an adherence counsellor while at others these divisions were less apparent. Another point worth noting is that many of these people performed a variety of minor yet integral roles in the clinic's functioning, functions such as making bookings, performing pill counts, weighing patients and taking their temperatures and other minor administrative tasks.

Table 6. Summary of staffing plans at each participating facility
(Dark shading denotes posts that do not exist. FT=full time, FX=flexi-time, HD = half days, 5/5=5 days/week)

		GF Jooste			Guguletu			Hout Bay*			Michael M			TC Newman		
		Staff	Funder	Hours	Staff	Funder	Hours	Staff	Funder	Hours	Staff	Funder	Hours	Staff	Funder	Hours
Facility manager		1 consult-ant	PGWC	FT 1/5	1 CNP	PGWC vacant as of 7/10/05	FT 5/5				1 CNP	PGWC	FT 5/5	1 PMO	PGWC	FT 2/5
	Consultant	2	PGWC											As above		
Doctors	PMO	2	NIH	FT 3/5	3	PGWC 1 vacant as of 7/10/05	FT 5/5				2	PGWC	FT 5/5	4	2 PGWC 1 NGO 1 NGO/hospice	FT 2/5
	SMO	3	PGWC	FT 3/5	2	PGWC	FT 5/5	1	NGO	HD 5/5	1	Locum	FT 5/5	1	PGWC	FT 5/5
	PN	1 / 2	PGWC / NIH	FT 5/5 / FT 3/5	1	1	FT 5/5	1	NGO	FT 5/5	2 CNP	NGO/ PGWC	FT 5/5	1	NGO/ locum	FT 2/5
Nurses	EN				2	PGWC	FT 5/5							1	NGO/ locum	FT 2/5
	ENA	1	Locum	FT 5/5	1	Locum	FT 5/5									
Counsellors/ Educators	Facility	2 / 2	NGO / NIH	FT 5/5 / FT 3/5	4	NGO	FT 5/5	2	NGO	FT 5/5	6	NGO	FT 5/5	2	NGO	FT 5/5
	Community				21	NGO	FX	5	NGO	FX				5	NGO	FX
Pharmacists	Pharmacist	1	PGWC	FT 5/5	1	PGWC	FT 5/5	1	NGO	FT 1/5				1	PGWC	FT 5/5
	Pharmacy assistant				2	PGWC	FT 5/5									
Administration	Clerk	1	PGWC	FT 5/5							1	NGO	FT 5/5		Hospital staff	
	Data capturer	1	PGWC	FT 5/5							1	NGO	FT 5/5			
Nutrition	Dietician													1	PGWC	FT ?/5

Case Study 2 - **Nurse-based care at Michael Mapongwana CHC**

The evolution over time of clinical roles in the HIV service at Michael Mapongwana Community Health Centre (MMCHC) demonstrates the potential of integrated doctor-nurse care teams. When the clinic began operating in 2000, one doctor, one nurse and one counsellor were employed. As the service load increased, an additional nurse was brought on board and extra counsellors. Until late 2003, a second doctor only assisted on one day a week, with the usual clinical team comprising one doctor and two nurses.

The nurses employed were not formally trained clinical nurse practitioners, but professional nurses who received clinical HIV training and mentorship from MSF. Key to the success of the model, is the triage of patients each morning in order to determine who should see the doctor. The main content of the nurse-consultations is to screen patients for complications (principally weight and symptom and signs screen), to check on adherence, and to ensure blood work is up to date. Dispensing has until now also occurred during the consultations.

The consulting rooms are linked by a corridor at the back, allowing easy movement of practitioners. This has been key to mentorship and team work. Important enablers of the nurses fulfilling a clinical role have been a combination of stability (at the time of the study both professional nurses had been working in the programme for around two years) and the constant interaction with doctors (the turnover of doctors has been greater, but most doctors have stayed a full year). This form of clinical interaction assists both doctors and nurses alike in developing skills and insights into patients. The lack of continuity of care that results from a triage system (where the same doctor does not see the patient every visit unless there are complications) is mitigated by the ability of staff to consult each other about patients, which, in turn, is facilitated by the clinic layout.

The nurses, due to the nature of the consultations and language issues, typically see 30 to 40 patients a day each, whereas the doctors see between 10 and 20 complicated cases. Paediatric patients were more likely to be seen by doctors. This results in a service that is in relative terms more efficient than one relying solely on doctors for clinical care.

Short-term clinical rotations are standard for young doctors, who will often spend 6 months or a year doing a particular rotation before moving on to something different, whereas there tends to be more stability with nurses, as had been the case in this clinic until recently. This is also the source of one of the concerns with the system, that of burnout – seeing 40 patients a day, five days a week, and dealing at the same time with the ever changing environment and patient load, is a strain for nurses, and the first nurse at MMCHC HIV service in fact requested a transfer to the rape survivors clinic after two years for this reason. A second concern is that seeing the nurses becomes a fast-track for patients eager not to spend the entire day waiting to be seen by a doctor. Consequently without a system that explicitly ensures that each patient sees a doctor at least annually, it is possible for stable patients to be seen quarterly only by nurses for years, without the opportunity for a doctor to consider possible long term toxicities and other clinical issues. Explicit schedules to ensure at least annual review by a doctor are desirable in this context.

Although there have since been substantial staff changes, the model that has operated at this service reflects a successful example of shared care where the bulk of care is provided by nurse practitioners.

Analysis of staffing costs

Using the above staff template, human resource costs for running each particular clinic were calculated per patient on treatment per month, irrespective of the duration on ART of the patient population. Annual costs of employment were based on June 2005 PGWC salaries and included scarce skills allowances, as appropriate to each staff category.

Table 7. Summary of staff costs per patient-month (ZAR)

Financial cost (includes PGWC filled and vacant posts)	GJ	GG	HO	MM	PA
Facility manager	72,352	156,141		156,141	120,230
Medical officers	536,030	1,416,923		858,749	206,079
Nurses	68,917	231,981		100,935	40,374
Counsellors and patient advocates					
Pharmacists	172,545	335,609			206,032
Dieticians					62,456
Administrators	137,834				
Total	**987,678**	**2,140,654**	**-**	**1,115,825**	**635,172**
Economic cost (includes all posts)	**GJ**	**GG**	**HO**	**MM**	**PA**
Facility manager	72,352	156,141		156,141	120,230
Medical officers	896,720	1,416,923	160,999	858,749	412,158
Nurses	290,974	332,916	156,141	201,870	80,748
Counsellors and patient advocates	107,520	346,080	117,600	201,600	117,600
Pharmacists	172,545	335,609	34,509	-	206,032
Dieticians	-	-	-	-	62,456
Administrators	137,834	-	-	137,834	-
Total	**1,677,945**	**2,587,669**	**469,249**	**1,556,194**	**999,225**
Average patient-months on ART 2005	344	846	223	814	374
Financial cost per patient-month	239	211	-	114	141
Economic cost per patient-month	**406**	**255**	**175**	**159**	**222**

Financial costs only include the costs of posts incurred by the provincial government, whereas economic costs include the costs of all posts. Doctor salaries were the largest cost driver, explaining why Hout Bay clinic, with only one doctor working half-days, and Michael Mapongwana where nurses share clinical care, have the lowest staff costs per patient month on ART. It is hoped that laboratory and drug costs would be similar across sites and would be determined more by patient factors than service factors. Although some information was gathered on capital costs, this was incomplete and is not included in this analysis.

These costs can be put into perspective by referring to cost analyses that have calculated the full costs of ART clinic care. These analyses have indicated that ARV drugs and laboratory investigations are the most important cost drivers. If these costs are excluded, the key drivers of the cost per visit are human resource costs (approximately 50% of the cost per visit). Overhead costs, including routine running costs such as water, electricity, communications and other support staff (cleaners, security, admin clerks and data capturers), are another important cost driver, accounting for approximately 39% of the cost per visit (Cleary et al. 2005).

Patient preferences for health workers

In reply to the direct question: "In general, would you prefer to see a doctor or a nurse when you come to the clinic?", 75% of patients chose a doctor, with 16% choosing a nurse and 9% expressing no preference.

Interestingly, at Michael Mapongwana clinic, the one site where there is a large nurse-practitioner component to the clinical care, more patients (42%) expressed a preference to see a nurse than a doctor (39%). In this setting all patients would have been exposed to both.
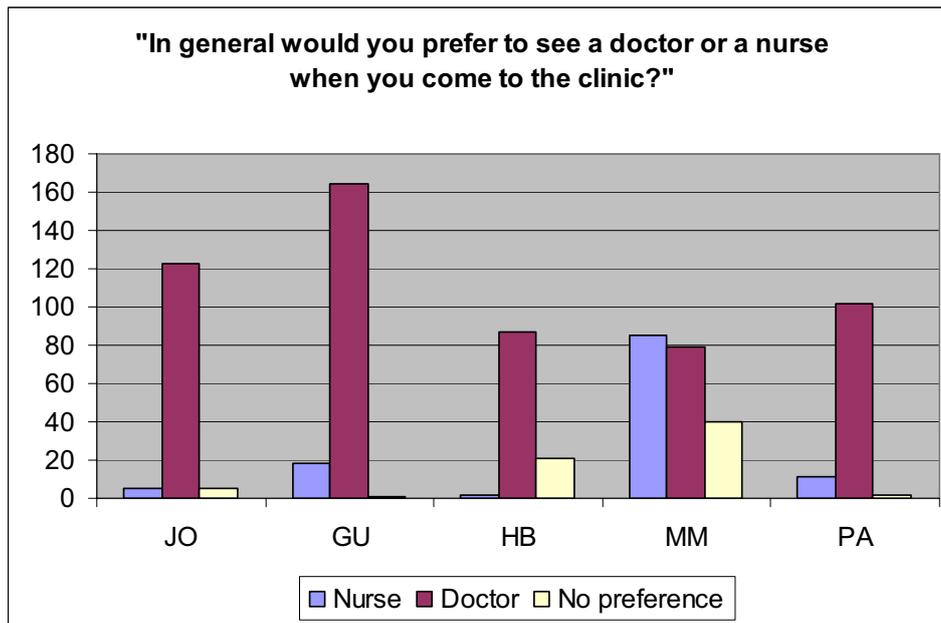
Figure 4. Patient's preference for provider by site

Some respondents reported that their preference had to do with shorter waiting times to see the nurse, since doctors tended to see more complicated patients (and thus have longer consultation lengths). Other reasons given by patients for expressing a preference of nurses over doctors included the ability to converse in their home language and the fact that nurses were perceived as more holistic.

Where patients expressed a preference for doctors, the reasons were generally more generic and were informed by patients' perceptions of doctors' skills. In general the reasons given were: "the doctor is more knowledgeable" and "the doctor is able to prescribe medication". An interesting finding with respect to stigma patients might face attending an HIV-dedicated service was, "the doctor is more confidential".

Pharmacy organization and operation

Strikingly, every clinic surveyed showed differences in the roles and responsibilities that pharmacists had. This differed from the more homogenous clinical role that doctors performed. Pharmacists' roles crossed a broad range, from stock management only to crucial adherence support to maintenance of information systems. The following summary of each pharmacist's job description might illustrate this:

Table 8. Pharmacist roles

Pharmacy	Brief description of pharmacist's roles
GF Jooste	Managed as part of hospital pharmacy, community service pharmacists rotate through the ARV service. A considerable individual adherence and initiation component is supplied by pharmacists
Guguletu	Pharmacist sees every patient to whom ARVs are dispensed and contributes a large adherence component.
Hout Bay	Stock management, database upkeep and 'program' adherence
Michael Mapongwana	No specific pharmacist. ARVs and primary care basics dispensed by clinicians. CHC pharmacy for other needs
TC Newman	Stock management, adherence, integrated with general hospital pharmacy

The table summaries are detailed further below:

G F Jooste Hospital

The ARV clinic receives medication from the hospital pharmacy, the employees of which include community service pharmacists. No pharmacist is attached to the ARV program per se but the community service pharmacists rotate through, carrying responsibility for maintaining records, ordering and collecting data of the ARV component.

All of the community service pharmacists dispense to ARV patients (in their own words, most of their day is spent dispensing. Other daily duties include 'prepping', data entering/capturing, packing shelves and delivering schedule drugs to wards). The pharmacists interviewed all spoke of an increasing workload from the ARV clinic.

To briefly describe a typical ARV clinic interaction: pharmacists receive a prescription from the ARV clinic ('25-50' scripts per day), complete it, and, if it is the first time that that patient receives ARVs, the pharmacists dispense and educate on how to take the pills and open bottles etc (at the pharmacy window). This process takes about '5-10 minutes'.

A first-time patient usually gets a 2 week 'starter pack' of ARVs, and is required to return to get their follow-up two weeks of medication. If a patient is established on ARVs, the pharmacists count pills and refer defaulters on to the counsellors. Once these activities are finished, the pharmacists file a copy in records and capture the data on an Microsoft Access™ database.

Stable patients can get scripts written up for 3 to 4 months once the doctors feel adherence is good and no medical problems are present (these patients still need to come to the clinic every month, but don't need to see a doctor. Pharmacists will do the pill counts in these instances). These long-term scripts are filed separately.

Pharmacists therefore serve as a sort of compliance check - all patient visits to the pharmacy are tracked on paper and later transferred to computer on the same day.

The people interviewed estimated that they carry about a month and a half's stock of ARVs at any given point in time. When asked about needs, they were unanimous in requesting at least one other linked computer (currently the whole pharmacy operates off one computer). It was felt that this would detect and prevent a lot of prescription errors.

Guguletu

A small pharmacy is located within the ARV clinic, which itself is a free-standing building on the site of the Guguletu CHC. The pharmacy is considered a satellite pharmacy of the CHC pharmacy. A full-time PGWC pharmacist and two recently appointed (at the time of interview) pharmacy assistants comprise the staff.

All HIV or infectious disease medication is dispensed from the 'ARV' clinic while other medication, like anti-hypertensives, were accessed from the CHC pharmacy.

The pharmacist's roles vary according to the days worked; on Tuesdays, a day for repeat medication scripts, she counts pills while patients attend an 'on-treatment counselling session'. Adherence is thus calculated and problems directed towards the counsellors. Assuming no problems, scripts for the repeat patients are then given to doctors for signing, whereupon medication is dispensed and ready for collection after the counselling session.

In terms of new patients, the pharmacist periodically attends the weekly group initiation meetings where it is decided who is to go onto treatment. This usually happens about two weeks before the patient receives the treatment, the information is passed on to the pharmacist and the ARV package is available for dispensing individually at the 'week 0' time-point. The pharmacist dispenses every new prescription personally, reinforcing adherence and demonstrating precisely how and when to take pills; thereafter the first-time patient is again referred on to the counsellors. The pharmacy assistants help with stock keeping and preparing pre-packaged ARV medication.

Although the clinic was moving towards bar-coded dispensing, at time of interview this was not operational. To determine who was missing clinic appointments it was necessary to see which pre-packed drug package hadn't been picked up.

The major complaint that the interviewed pharmacist had was the high workload related to having to see every patient individually.

Hout Bay

The NGO that placed the doctor and nurse on-site contributes a part-time pharmacist to the ARV program. The pharmacist visits once a week, for a full day, on the day of the group initiation meeting. Stock is maintained in the clinic pharmacy.

The interviewed pharmacist considers her major roles to be around stock control and database management. All patients receive individually labelled pill containers and every clinic for which the pharmacist is responsible has a separate Microsoft access database. This database is maintained by the pharmacist and kept up to date at each weekly meeting. Data that is entered includes baseline CD4 count, weight, stage, regimen ordered, pick up dates and other relevant social and medical facts. With this information the pharmacist can generate a list of 'non-attendees' and pass this information on to the patient advocates who can then make follow ups in the community.

Unlike the previous two clinics discussed the pharmacist doesn't dispense directly to patients.

The interviewed pharmacist expressed a wish for an integrated pharmacy wherein the pharmacist interacts with patients, plays a strong adherence role and is responsible for maintaining a database of all HIV+ CD4 counts, in order to track entrance into the ARV program.

Michael Mapongwana CHC

There is no pharmacist attached to the ARV program at this clinic. Instead ARVs, and certain essential drugs like analgesia and broad spectrum antibiotics are kept in a lock-up cupboard in the interconnected clinic rooms and dispensed by the doctors or nurses directly. The cupboard is restocked daily by doctors and nurses.

Certain scheduled medication however requires a prescription to the CHC pharmacy, for which the patient would have to join a separate queue.

TC Newman Hospital

The ARV pharmacy is within the general hospital pharmacy although this was expressed as an increasingly problematic issue by the pharmacist interviewed, largely because of space reasons. The program has a principal pharmacist, who had recently moved from the employ of an NGO to PGWC. At the time of interview the pharmacist was training a pharmacy assistant (for a separate program) but the assistant was helping in the running of the ARV program.

Roles again vary according to the day being worked but are split between adults and paediatrics and repeat patients and same-day clinic patients, as well as some administrative and group meetings. A difference from other pharmacies noted here is that, because of the pharmacy's situation, the pharmacist can provide a full script to all patients (for example, anti epileptics or anti hypertensives) and sometimes supplies scripts of up to 12 medications.

The pharmacist is present at the group clinic meeting where initiation is discussed and enters all potential patients onto a paper based list which is later cross-checked against new starters.

For the patient receiving their first ever ARV dispensation, only two weeks of treatment is supplied- after 2 weeks the patient returns to the clinic sister who does a pill-count, and if correct the script continues on to pharmacy for the 2nd two weeks of medication. After 28 days the patient is seen by a doctor again. Patients will get a repeat prescription once they've proved their adherence (this usually happens after being on treatment for about 3-4 months, and the repeat scripts can be for anything from 2 to 6 months). There were approximately 15-30 repeats per week (out of a total of 300 on treatment at the time)

The pharmacist does not deal directly with patients, and the patient advocates act as runners between the clinic and the pharmacy, taking scripts to the pharmacy and returning to the clinic with medication.

The pharmacist says her greatest need is a computer, which would make patient tracking easier, generate outputs/reports quicker and simplify her ordering system. Furthermore, she feels that adherence is part of her job but that she doesn't have the time and would appreciate a pharmacy assistant who could do keep up the stats and help with dispensing

Integration of paediatric with adult ART services

Although paediatrics was not the focus this study, providers were asked about their opinions with regard to delivering HIV and ARV care to children at their site.

Provider interviews reveal that primary care health care workers are not overly apprehensive about working with children, especially if they have had experience with children in their past. Interestingly, nurses and those in primary care clinics seem to express less reservation than doctors and those in hospital based programs. At the five clinics surveyed, children represent only a small proportion of the total on ARV treatment. Most providers were in agreement that children were being appropriately treated but that there was a strong reliance on specialist outreach or mentoring, with the clinically challenging cases often being 'put aside' for the weekly or bi-weekly specialist opinion.

Management structures

Disparate management structures for different categories of staff

A generalization that could serve as a useful insight is that different staff cadres tend to have different vertical management systems. For example, nurses at the clinics that are hospital-based still fall under the management of that hospital's nursing staff infrastructure. Vacation leave, off-duties and rosters, for example, benefited from nursing input from other areas of the hospital. However, in unattached clinics that held specific full-time positions for nursing staff, coping with their time off was more difficult.

Counsellors, on the other hand, tend to be managed and paid by off-site NGOs, although at certain sites an attempt to unify management is in process. Two of the larger patient education models had quite different management structures, which are detailed further in the section on adherence.

Doctors tended to 'manage themselves' as a unit, in terms of organising rosters and time-offs, with leadership generally coming from someone within the clinic structure.

A recurring theme from interviewed health care workers was their perceived lack of on-site management:

> "This need for a unit manager, a nurse unit manager, is very great actually... it would take a lot of weight off my shoulders, because then I would concentrate more on the clinical stuff. It's for example, basic things like basic supplies of blood taking tubes, of stationery of day-to-day needs. Then a step up from that... there's often something that's not there, so if someone could keep an eye on that. Then maybe a step up in terms of the kind of patient flow within the clinic, you know. So that patients come, get what needs to be done in a smooth and efficient way. That's probably the biggest task, I would say, of the unit manager and although we have kind of designated each aspect to a different person within the clinic now, it's still something which occasionally has problems, involving people arguing in groups outside your room or something like that"
>
> Principal Medical Officer

This lack of management extended to insufficient role-definition within the clinic and included the perceived absence of someone who could oversee and maintain staff roles. Doctors especially expressed their concern as to the role and management of other staff.

> "I can honestly say that it's probably one of the best managed clinics, it really is, there really aren't significant staff difficulties at all and I mean, actually no that's not true, the difficulties I am having are with the counsellors...I mean I've always been concerned about the quality of their counselling. I feel like they give the patient a lecture, they don't kind of, you know I can't

rely on them to deal with any psycho-social issue…They also don't seem to kind of 'own' the programme as much as I'd like them to… I think we should be better delineated with what the counsellors are expected to do"

<div align="right">Medical Officer</div>

"I think it's a very good thing (patient advocates) but I think, to be quite honest, I don't think they are being used effectively. If you compare them with the DOT supporters, for instance, I think we get the maximum out of the DOT supporters, whereas we don't get that out of the patient advocates. Initially I thought the difference was due to lack of supervision, and basically now, it's gone a bit better, but I still feel that they need more of supervision. I still feel that their usefulness could be improved with better management"

<div align="right">Facility Manager</div>

The problem of poorly defined role-definition was expressed by all cadres of staff and was especially evident for counsellors, patient advocates and enrolled nurses, where people were expected to be both 'task-flexible' on a daily basis and answerable to a number of different people's needs.

"It was also difficult for me to handle all the staff coming in and going out and what happened in our clinic was we had this…(situation of)… people getting into your clinic, doing bits and things - I was a bit irritated with that, thinking, not that I am going to lose control, but I think sometimes it's difficult for patients to relate to too many people…I have asked for more counsellors and things like that, but the patient advocate already sits around, there is nothing so tiring when people sit around you, and are waiting for you, and it's quite amazing how quickly they get used to sitting around and waiting for you, like 'this is my job, to come and sit in the clinic'. "

<div align="right">Medical Officer</div>

Program leadership and management

Many providers complained about lack of specific management, both at the clinic level and at the higher district level.

"What it is going to take is the actual integration of the primary care service, and it is happening at district level, and it seems to me that 11 or 12 years down the line we are still struggling to get to the district system. I can't really see it happening until the management starts working together at the primary level and that they actually demystify this whole process (ARV treatment)"

<div align="right">Medical Officer</div>

"So those first couple of months… there was absolutely no support system in place… it was not seen as a priority. And I watched the nurses burning out around me, but in the end I took the major brunt of it because I tried to, just on the ground, put in place that kind of informal support structures and tried very hard just to get the logistical stuff sorted out but with practically no support from management, and it needn't have happened. Y'know I feel very strongly, now generally the lessons have been learnt in a lot of places but I don't think the lessons in terms of staff support have been learnt."

<div align="right">Medical Officer</div>

"I think what we need in the system is better leadership, and if we look at leadership that is well focused, and what I mean by focused is better planning what is happening around us and getting more motivation for the whole system, empowering people to do things, but then also management, you know, if we change – leadership and management is two different things, I think management we definitely need more time in building systems"

<div align="right">Medical Officer</div>

Below is an example of Guguletu clinic's proposed system for tracking and monitoring patients with adherence difficulties. It is presented as an example of a complex system that would require sustained managerial input.

Case Study 3 - **Triaging for potential adherence problems in Guguletu**

All ARV patient files receive a colour coded sticker, coded as follows:

> **No Sticker** - Patients who have been on treatment for less than 16 weeks.

> **Green** - Patients who have completed over 16 weeks on treatment with their most recent viral load under 200 copies/ml.

> **Red** - Patients with an adherence percentage (at any time) of < 85% or a viral load >=200 copies/ml.

Once red alert status is assigned the following occurs:
- The patient's number is recorded and added to the red alert list for discussion at the next weekly meeting.
- If the red alert status is assigned at a doctor's visit, the doctor is expected to personally notify a counsellor that the patient needs adherence monitoring.
- If the red alert status is due to a raised viral load, the patient's counsellor is asked to recall the patient for a doctor's visit.
- The counsellor is expected to request the patient to attend the three treatment readiness sessions again.
- At the next home visit, the counsellor is expected to spend some time with the client discussing correct dosing practice and adherence issues.
- The patient's counsellor is expected to visit the patient in the week following the allocation of the red alert status and thereafter on a monthly basis.
- The patient receives individual counselling at each visit to the clinic.
- The doctor is expected to check the patient's adherence on a monthly basis until the red alert status is stopped.
- A pillbox is offered to the patient.

For patients with a viral load >=1000 copies/ml:
- The viral load is repeated 4 to 6 weeks after the red alert status has been assigned and the above procedures have been commenced.
- If the viral load falls below 50 copies, red alert status can be removed.
- If the viral load remains above 1000, the patient has failed their regimen and should be considered for Regimen 2.
- For viral loads between 200 and 1000, increased support is continued as above, with 4-monthly monitoring.

When does red alert status stop?

The red sticker is removed from a folder once the viral load is <50 copies/ml and adherence has been above 85% for two consecutive months.

Note 1: Treatment is stopped if the week 4 pill count indicates less than 70% adherence (This only applies to week 4) or a patient at any time has been without medication for longer than 1 week prior to his/her appointment. Treatment is not stopped in any other circumstances unless clinically indicated. Treatment is resumed once the patient has repeated the three treatment readiness sessions and has been assessed by a counsellor.

Note 2: Patients colour coded green may have ARVs prescribed for two-month periods. Patients with no colour code or coded red will receive ARVs on a monthly basis.

Results - Adherence support provided to patients

Overview of adherence support approaches

All the clinics surveyed share a principle of intensive patient education prior to ARV initiation. Patients are taught basics about HIV disease progression, side-effects of ARVs and the necessity for excellent adherence, over the course of a number of education sessions. Where this approach differs between clinics is whether the delivery of information is to a group of patients, or to an individual or some combination of the two approaches. Certain clinics include an assessment of the patient's home conditions prior to initiation, the idea being to identify potential barriers to adherence, like substance use problems or unsupportive household circumstances (See Table 9, page 40).

The approach of intensive education assumes that comprehension of the illness process can be used as proxy for treatment readiness and a predictor of adherence. Although this is probably not an incorrect generalization, there are almost certainly patients who have very little comprehension of their illness but who maintain excellent adherence. Similarly there were many reports of well-informed patients who understood their illness well yet could not remain adherent.

In addition, the actual process of deciding upon patient readiness should ideally take place through a multidisciplinary team approach. In all clinics surveyed, this was the approach applied. Occasionally this means that the absence of a 'home visit assessment' (or another piece of information) delays initiation of treatment. Many people interviewed considered the group decision making process to be time consuming and inefficient.

> "…in the future I can see it coming about the selection committee, if maybe we can have like a tick sheet for the counsellor, when they do their...(education sessions)... and that tick sheet they use it to check that whatever that is necessary to start with has been met so that a person don't have to go to the selection, and then whatever problem is specified there until this is resolved, because I can see it is going to go to a point whereby there is no time for selection because everybody must start so I think maybe next year or so they must use a sheet whereby maybe they just have one person in charge of that and checking everything is done properly."
>
> Nurse Practitioner

A number of providers felt that the paradigm of intensive pre-ARV education is a short term one and would need revisiting if large numbers of people were to be started on ARVs. The idea of constant, blanket reinforcement of the adherence message, rather than an initial information 'blitz' was mooted by one respondent

> "I think the further one goes into the rollout it becomes more and more important, the issue of the treatment supporter… but it's a long haul, it's the past 6 months and what are the different strategies that one is going to bring in at that point? …because different adherence issues start creeping in, the alcohol starts coming back again, the smoking comes back, they get back on their drugs, they get depressed because they haven't got the jobs that they hoped they were going to get once they were well, and I actually think a whole lot of different strategies have to be looked at for the long term, and I am not sure if we have got our heads around it yet, and the short term stuff is mickey-mouse things, little reminders on your cellphone and pop-up bottles and doing it according to Isidingo on the TV, and there are lovely things, but in the long run I don't know how it becomes as natural as waking up in the morning and going to bed at night… I am not sure but I think it has to be reinforced."
>
> Medical Officer

Once ARV treatment starts, adherence tools become more differentiated across the clinics. For example, at Michael Mapongwana, all patients receive a pill-box on the day of initiation, together with a two week supply of medication. The pillbox serves the function of a physical aid to remembering ARVs while the short prescription allows defaulters to be identified early and tends to preclude the creation of viral resistance.

Those clinics that use the home-assessment visit as a decision making tool also tended to have a system of home visits for patients after treatment starts. Here, the role of the community counsellor was both supportive and to identify problems. Providers involved in these programs were generally very supportive of them:

> "I think that is a good idea. I think what you need is a good counselling system, I think our clinic works because of the counsellors, I think if you send patients out (…"decant"…) without giving that same type of support you are going to lose people; the adherence is just going to go down; I think that is my biggest concern with sending out. I think also if you look at the model, the model is that you take – say our counsellors are HIV-positive, the vast majority of them and most of them on treatment – so you are basically taking patients and you are turning them into adherence counsellors and I think that is an excellent system. When I came at the beginning I thought 'ugh, that is very close' but it actually works very well, and I also think it's an excellent job creation scheme, you are taking people who are patients, empowering them, passing on the information, I just had a counsellor today and there was a young patient who was going to start treatment today and she was obviously quite frightened and she started crying, and the mother started crying at a certain stage, and the counsellor immediately started talking about that she was on treatment, what her CD4 was when she started treatment, what it was now, and you could see the effect it was having, it just works very very well, and I think the counsellors are quite dedicated because of that, they have been through that struggle."
>
> <div align="right">Medical Officer</div>

Some clinics made use of group support sessions, either organised by counsellors at the clinic or by patients themselves. These served the function of reinforcing education and adherence messages and providing visible support. Many clinics asked for patients to identify a treatment supporter (usually a friend, neighbour or household member) who then attended education sessions and whose role it was to remind and support the patient once ARVs had been started.

Adherence case-studies

Three case studies were chosen to exemplify the diversity of approaches to adherence support, one being a successful example of a well-managed community-based counselling model (Case Study 4 -Guguletu counselling model), one demonstrating a structured facility-based approach (Case Study 5 -Michael Mapongwana counselling model), and the final demonstrating linkages with other community health care services (Case Study 6 -Integrating adherence with existing community structures). In summary, the major axes distinguishing adherence promotion and support across the studied sites include:

- Group versus individual counselling
- Lay versus professional counselling (some sites have limited access to social workers)
- Facility versus community-based counselling and support
- Adherence aids (pill-boxes, ticksheets)
- Triage systems for adherence, identifying patients by their adherence or virological outcomes
- Integration with existing community-based health care services such as home-based care and TB supporters

Case Study 4 - **Guguletu counselling model**

A) Counselling staff

- 24 counsellors including 1 clinic-based head counsellor, 3 intermediate level counsellors (clinic based) and 19 community-based counsellors

B) Education

- The education process consists of three treatment readiness group sessions
- Each session is a module and patients must attend each module
- Module 1: HIV progression and Opportunistic infections
- Module 2: Positive living and diet
- Module 3: ARVs and their side-effects and adherence
- These modules take place on Wednesdays and Saturdays and are led by the community counsellors. There are approximately 15 to 25 patients per group
- The sessions run parallel with the clinical visits
- It usually takes 3 to 4 weeks for a patient to complete these sessions but they have been structured so that it is possible to complete them in a week
- The overall timetable and workload for these sessions is managed by the clinic counsellor supervisor

C) Adherence support

- Every community counsellor (CC) is currently responsible for about 50 people (either on ARVs or "pre" ARVs)
- Their designated role, very broadly, is a combination of education, adherence and emotional support to patients and psychosocial information gathering for clinical staff
- Each CC's patients are assigned by the clinic counsellor supervisor and are usually allocated according to the area the CC lives in
- Each patient should receive a home visit by their CC before ARVs are started. At this home visit various issues are discussed such as disclosure, alcohol problems, patient concerns about ARVs, job security and food security. This information is reported back in the forum of the interdisciplinary team meeting where it contributes to a decision to initiate or defer treatment.
- Patient's folders are 'colour-coded' as below and home visits continue at a frequency determined by that coding
- CCs determine their own timetable of home visits, working flexi-time
- CC's clinic involvement consists of the Tuesday interdisciplinary team meeting, where all must be present, and one other day per week, which varies per counsellor, for administrative work

D) Counsellor management

The counsellor management structure is as follows:

- Desmond Tutu Centre contributes a senior sister, not based on-site, who visits and oversees training and management problems and is involved in " training therapeutic counsellors throughout South Africa"
- The PMO on site has an interest in developing management systems and liaises closely with the counsellor supervisor
- The ARV site has a counsellor supervisor, based full-time at the clinic itself. She is involved in "coordinating grassroots" systems
- There are 3 senior counsellors, also full-time clinic based who have risen to this level because they are "good trainers, good coordinators" and whose work is tending towards the more administrative and managerial
- There are 19 community counsellors whose roles are described above
- All counsellors have access to a counselling psychologist who visits fortnightly

Case Study 5 - Michael Mapongwana counselling model

A) Counselling staff and roles

•	6 facility based counsellors and 1 off-site manager

B) Education

•	Counselling space in a separate prefabricated building just outside the clinic, with 5 individual rooms, a group counselling room and a toilet
•	New patients receive a group session on their first visit to the clinic just prior to seeing doctor
•	Thereafter each patient is expected to attend 4 counselling sessions (C1 to C4). Each session deals with a different topic
•	The patient is asked to bring a treatment supporter to the third counselling visit
•	The patient and treatment supporter sign a contract during the fourth counselling session whereby they confirm they understand the principles of treatment and undertake to be adherent

C) Adherence support

•	All patients get pillboxes on initiation of treatment
•	ARVs are dispensed weekly in pill-boxes for 2-3 weeks
•	The majority of counselling is prior to initiation of ARVs
•	There is no regular community follow-up after initiation of ART
•	Defaulters are telephonically contacted by counsellors, those not traceable might receive home-visits if resources allow
•	Selected patients might be identified for further counselling after initiation. This occurs on an informal referral basis from the doctor or nurse to the counsellor

D) Counsellor management

•	On-site, through head counsellor / co-ordinator
•	Counsellors record daily number of consultations and consultation types (C1 –C4 or group)
•	Counsellors report to the off-site co-ordinator weekly
•	The head counsellor reports in the same way
•	The NGO maintains a management role, which is gradually being devolved to the newly appointed facility manager

Case Study 6 - **Integrating adherence with existing community structures**

TC Newman Hospital has a support system that has arisen as a result of the hospice and home-based care organisational structures pre-dating the national roll-out. There are 2 facility-based adherence counsellors and 5 community-based patient advocates who are at the clinic on the 2 days that it runs, and a further link exists with 18 home-based carers. An NGO has added a two-hour per day stipend to the home-based carers' salary; this is geared to adherence input in the community.

Education
Patients receive individual counselling from the adherence counsellors and/or the sister (depending on language capabilities and personal preferences of the patients). Wednesdays and Thursdays are 'counselling' days and patients will be booked for their session with one of the above. Patients need to attend enough to ensure adequate comprehension of the problem and this is generally decided on in Tuesday meetings and tailored to the patient's own education and understanding. Counsellors also attend the local frail care centre and TB hospital to meet with HIV patients there. Uniquely, on Thursdays the counsellor attends outreach sessions at a peripheral HIV clinic where she will educate/counsel patients (already registered at the clinic) in an area closer to their homes. The clinic sister and the senior counsellor occasionally accompany home-based care and hospice visits to patients in their homes in order both to educate clients and elucidate problems that might impact on adherence.

Adherence support
Opportunistic sessions occur during clinic days when the physician refers patients having difficulty to the 'roving' facility based adherence counsellors. Concerns have been voiced about lack of privacy by both patients and providers. The patient advocates (PAs) work 4 hours a day, for 4 days a week, one of which is in the clinic assisting with general administrative duties like filing folders, managing patient flow, fetching scripts etc. When not at the clinic PAs are responsible for conducting home visits on selected patients and reporting findings back to the staff in order to inform decisions to treat.

Strong hospice links exist at this clinic. In part because the original two doctors involved in setting up the clinic were heavily involved in palliative care.

One of the doctors oversees a sister who manages a network of 18 home-based carers as part of an externally funded program. The 18 home-based carers have had their working hours extended by two hours a day (funded by the NGO, ARK). This is for pill check/adherence visits of patients on treatment.

Table 9. Overview of adherence support and patient preparation

	GF Jooste	Guguletu	Hout Bay	Michael M	TC Newman
Pre-ARV education	• 3 counsellor sessions on same day as medical work-up	• 3 mandatory group sessions (15-20 people) • Each session covers 2 topics • Over same time period but not necessarily on same days as medical work-up • Home visit	• 2 to 4 adherence sessions depending on the patient's understanding • Dietician and social worker available • Encouraged to attend group counselling and bring a treatment assistant to sessions. • PA home assessment	• Structured counselling sessions delivered individually • Mandatory nomination of a treatment assistant who must attend one counselling session	• No standardized 'work-up.' • Ideally, 6 individualized counselling sessions more usually sessions tailored to patient's comprehension and motivation • Counsellor attends 'outreach' clinics • PA's available
Decision to initiate	• Meetings held end of each working day • Consensus between medical and counselling staff	• Inter-disciplinary meetings on Tuesdays • Consensus between medical, counselling and other staff	• Once a week on Mondays • Consensus between medical staff, counsellors, patient advocates and dietician and social worker	• Twice a month on Tuesdays • Consensus decision between medical and counselling staff	• Tuesday morning meeting • Consensus decision
On ARV adherence support	• Hospital-based only • Identified adherence issues are referred to counsellors for 'booster' sessions	• PA visits, theoretically daily for a week, then bi-weekly, eventually monthly • Focus of home visits changing to identified problems only, not everyone	• PA home-visits variable • Identified adherence issues are referred to counsellors for 'booster' sessions	• All new starters get a pillbox • Only 2 week supply of ARVs initially • Identified adherence issues receive targeted 'booster' sessions • counsellors occasionally visit clinic non-attendees	• Identified adherence issues receive targeted 'booster' sessions at clinic • Network of PAs and home-based carers provide community outreach and problem identification

Community and facility-based adherence support

Overall, the adherence-related treatment education that patients receive at the different sites varies in terms of the degree of individually-focused education (versus group education). Similarly the methods for adherence support vary across the sites in the degree to which these are clinic-based or community-based. For instance, some clinics tailor their education process individually (the number of sessions and the duration of sessions) to the patient's perceived level of understanding, while others adopt a more general 'protocolised' approach with a significant group education component. In some instances almost all patient education takes a group format.

In terms of adherence, some clinics only have the opportunity to interact with patients at the clinic whereas others have an extensive and prolonged outreach component. For the details of these processes consult the relevant sections in the individual clinic overviews or see the table on page 40.

An impression that has been garnered from discussion with providers is that it is not so much the 'adherence model' per se that impacts on adherence, but how well it is organised and managed. Respondents in general believed that the adherence systems that operate at, for instance Guguletu and Michael Mapongwana, work because there is strong management of the processes, strong interest from the clinicians in having the process work and good physician-adherence counsellor links (see the case studies on pages 37 & 38).

The Guguletu system is designed for community contact, with patients receiving a visit from a designated adherence supporter prior to initiation of ART and a 'tailing-off' series of visits after initiation but which remains flexible to individual needs. To this end the principal medical officer on site has been designing, in conjunction with the head counsellor, a colour-coded system which dictates visit frequency (See the case study on page 34).

Two things become clear however from discussions with providers: 1) These systems require a lot of management input, and 2) It is felt there is little point in having an outreach component if there is no consistent forum to convey findings which could impact on decision making. To this end some providers expressed concern about the time-consuming nature of the interdisciplinary meetings and the need for consultative decision-making. These concerns from providers were generally in response to perceived time pressures.

The Michael Mapongwana adherence system is predominantly facility-based and includes the use of tools like pillboxes with every patient. Here, during their visits to the clinic, patients receive ongoing counselling that is appropriate to their duration of treatment. Furthermore, the facility management has ensured that counselling time is protected. For instance, the appointment of clerks prevents counsellors having to perform administrative tasks for clinicians. Also, counselling space is protected by the physical layout of the clinic since it operates from a separate and dedicated building.

The relative costs of the two adherence models are provided as additional case studies based on secondary data (pages 42 and 43). The costing methodologies are not identical, but are provided nonetheless as they are illustrative of the general cost structures of these counselling services.

Case Study 7 - **The Costs of Running a Community-Orientated Adherence Program**

The Sizophila adherence program is based at the Hannan Crusaid Treatment Centre in Guguletu Day Hospital. It has been running since 2002 and provides clinic-based counselling, HIV-related pre-treatment education and ongoing community-based adherence support through home visits. These home visits are resource-intensive, and as a result the program employs approximately one counsellor for every 50 patients enrolled at the centre. 60% of the total cost of the program in 2004 was therefore due to the cost of counsellor salaries.

The program is managed by a sister who currently devotes around a third of her time to it. Her salary accounts for 12% of the program cost. Administration, building rental and overheads account for 10% of the program's costs and training for new employees a further 3%. The final 15% of costs arose from the creation and use of a cell phone-based reporting system for pill counts and other communication. This included the cost of the phones, airtime and product development.

In 2004, when 520 patients had been screened at the centre, the adherence program cost R90 per client-month at the site. By the end of 2005, when 1,767 had been screened, this figure had fallen to R54. This reduction was due to many of the costs, particularly management and administration, being fixed rather than depending on the size of the program. Such costs are likely to continue to fall on a per-client basis if the program is further scaled-up. Although the cell-phone communication system may offer benefits to the program, it is not integral to it, and might be removed from a streamlined national program.

The majority of the cost of this project, however, is due to the cost of counselling staff, and this figure would not decline at a per-client level if the program were to be scaled-up. The benefit of a community-orientated program may be better responsiveness to adherence and other patient problems, but is likely to continue to cost more than a clinic-based system alone.

Table 10. Annual, per visit and per patient cost of Sizophila Counselling Programme

	2004-05		2005-06	
	R	%	R	%
Management	48,454	12.4	49,249	7.9
Counsellor Salaries	234,527	60.0	463,953	74.2
Counsellor Training	11,400	2.9	11,878	1.9
Administration	28,351	7.3	29,542	4.7
Patient Education	9,291	2.4	9,681	1.5
Cell-Life Communications	58,650	15.0	60,561	9.7
Total Cost	390,674		624,864	
Number of patients-months	4,321		11,569	
Cost per patient-month	**90.42**		**54.01**	
Number of patient-visits	3,177		10,137	
Cost per visit	**122.97**		**61.64**	

Lifetime assumptions: 2004 building 10 years; 2005 building 30 years;
Fixtures & fittings 5 years; Electronic hardware 3 years. Real discount rate: 3%.
Inflation rate mid-year 2005: 4.2%

Data provided courtesy of Guy Harling and the Desmond Tutu HIV Centre

Case Study 8 - The Costs of Counselling at the Khayelitsha Clinics

The Michael Mapongwana counselling programme has been running since 2000. This costing exercise was conducted using staffing, activity levels and prices appropriate to the January to December 2005 period. Given that the programme was 4-5 years old by this point, the costs should reflect any economies of scale that might be achieved by a more mature programme. Staff included six counsellors and one counselling coordinator – the coordinator was also responsible for supporting counsellors at the Site B and Nolungile ARV clinics, implying that about one-third of her time would be spent coordinating Michael Mapongwana counsellors. The counsellors spent 80% of their time working with ARV clients and the remainder with non-ARV clients. Lifeline, a local NGO, was responsible for training and supervision.

Table 11 shows total counselling costs for the ARV programme in 2005 (taking into account the percentage of time spent by the coordinator and the counsellors on ARV counselling), the cost per patient-month and the cost per visit. Supervision and coordination accounted for about 17% of the costs of the programme, while counsellor salaries were the largest cost drivers, at 64% of total costs.

Table 11. Cost of the counselling programme in Michael Mapongwana clinic

Counselling costs (2005 prices)

	R	%
Supervision (Lifeline) and coordination	42,845.36	19.9
Counsellors' salaries	134,407.14	62.4
Training and facilitation	5,548.32	2.6
Overheads	32,596.38	15.1
Total cost	**215,397.20**	100.0
Number of patient-months in 2005	9,773.00	
Cost per patient-month	**22.04**	
Number of ARV visits in 2005	17,354.00	
Cost per visit	**12.41**	

Data provided courtesy of Susan Cleary and the Health Economics Unit, UCT

Adherence measures- Patient outcomes

Self-reported adherence

For this measure a patient's reply to a 3-day recall question is used as a measure of adherence. The fieldworker took each individual ARV container, recorded it's name and asked the patient, for that particular medication, whether they had missed any pills "yesterday". The answer was recorded and the question was repeated for "the day before yesterday" and repeated again for "three days ago". The entire process was then repeated for each individual ARV. A patient who replied "yes" to any one of these (up to nine) questions was then considered to have less than optimal adherence in analysis.

This tool is recognized to have limitations, yet it is nevertheless thought to be valuable, especially when considered in the light of the routinely collected data. One caveat is that this form of questioning would not necessarily distinguish the patients who had been medically advised to withhold medication from those who were non-adherent.

Despite differences between clinics in self-reported three-day pill taking, adherence remains good across all clinics (Table 12).

Table 12. Adherence - Self-reported missed doses arranged by clinics

	All N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Any missed dose in previous 3 days?	6%	3%	7%	3%	14%	5%
Excluding the previous 3 days, any missed dose in previous month? (amongst those on for >1m)	17%	19%	18%	10%	25%	15%

Although GF Jooste is the only clinic to return an adherence rate (defined here as any missed dose resulting in less than 95% of required doses being taken) of less than 90%, it must be remembered that this is a clinic that deals with complicated cases who might have stopped treatment for medical reasons. This subtlety was not picked up by the directed question.

No strongly discernable pattern is evident relating time on treatment to degree of adherence (Table 13, Table 16), although it appeared as though patients on ART for between three and six months were the least likely to miss doses.

Table 13. Adherence - Self-reported missed doses arranged by ART duration

Months on treatment	Number reporting complete adherence	Number who've missed any ARVs in last 3 days	Percentage of patients who've missed	Total
0-1mo	74	8	9.8 %	82
1-3mo	123	9	6.8 %	132
3-6mo	114	5	4.2 %	119
6-9mo	74	1	1.3 %	75
9-12mo	110	9	7.6 %	119
12-15mo	59	1	1.7 %	60
15-18mo	47	5	9.6 %	52
18-21mo	17	1	5.6 %	18
21-24mo	18	1	5.3 %	19
>24mo	57	8	12.3 %	65
Totals	693	48	6.9 %	741

Patients were asked, from a list of options, for possible reasons why they might have missed their tablets:

Reasons for non-adherence

When asked to give reasons for missing pills, apart from 'being out of town', which confirms the migratory nature of the population, the other reasons that have a frequency of 5% or more are 'forgetfulness', 'change of daily routine' and 'busy', all of which indicate the need for a pervasive reminder system extrinsic to the clinic.

Most common reasons given by patients for missing pills
- Just forgot: 11%
- Change of daily routine: 7%
- Out of town: 5%
- Busy: 5%
- Slept through: 4%
- Felt sick or ill: 2%
- Side effects: <1%

Adherence aids

Patients were asked to spontaneously name (not pick from a list) the things that they considered most important in helping them to remember to take their pills.

Most important things that help patients to remember ARVs
- Alarm/phone/clock: 51%
- Myself/just remember/routine: 16%
- Family member: 13%
- Radio, TV: 10%
- Non-family member: 3%
- Calendar: 1%

In terms of what reminds people to take their pills, the majority mention alarms (usually cellphones, also watches and clocks), thereafter, in order, the most frequent reminders were the patients themselves or their family members. Media reminders (TV or radio) only constitute a reminder for 10% of people on ARVs.

Most valuable forms of adherence support as rated by patients

According to patients who used them, pillboxes were considered the highest ranking adherence tool (94% of users considered them 'very important' as an adherence tool), thereafter, in order, were: a clinic-based support group, a community-based support group, a patient-chosen treatment supporter and a home visit by a clinic counsellor (Table 14).

Table 14. Patients' rating of adherence support tools

	Total N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Percent using: Used **pillbox** ever (past or present)	36%	2%	100%	13%	23%	3%
Rate <u>very important</u>	94%	100%	95%	91%	81%	100%
Percent using: **Clinic-based support group**	38%	47%	68%	35%	16%	8%
Rate very important	92%	88%	92%	98%	81%	100%
Percent using: **Community-based support group**	14%	7%	10%	22%	9%	21%
Rate <u>very important</u>	91%	100%	75%	100%	75%	96%
Percent using: Self-selected **treatment supporter**	81%	61%	99%	85%	68%	78%
Rate <u>very important</u>	83%	97%	62%	97%	86%	97%
Percent using: Counsellor **home visit** since initiation	36%	40%	2%	94%	0%	43%
Rate <u>very important</u>	69%	95%	100%	62%	--	68%

It should be noted from the table above that for four of the clinics, a treatment supporter was the self-reported adherence tool that received the backing of the majority of patients. The exception was Michael Mapongwana where most patients considered pillboxes their most valuable adherence tool.

Patient's choice of most important person who helps them remember to take pills

Patients were asked to list the clinic person they considered most important in helping them to remember to take their pills. Forty-two percent of the 749 sampled considered the clinic counsellor the most important in this regard (Table 15). However doctors were considered to be the most important by 32% of people, and were ranked first in three of the clinics Pharmacists were not mentioned because they were not included on the original questionnaire.

Table 15. Patient rating of service provider adherence support
(shaded area indicates highest ranking in each individual clinic)

	Total N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Question: Most important people in helping to remember to take pills						
Clinic-based counsellor	42%	42%	64%	33%	43%	17%
Doctors	32%	46%	12%	27%	45%	51%
Community-based counsellor	10%	1%	1%	25%	5%	11%
Support group	9%	9%	12%	11%	2%	7%
Nurse	7%	1%	11%	4%	5%	13%

In Hout Bay, the doctor and facility-based counsellors received the highest rating in terms of adherence support in a context where community-based adherence supporters are present. A similar pattern was evident in Guguletu, although more respondents in this setting valued the role of the community-based counsellors the most. At Michael Mapongwana, clinicians as a whole were not as highly rated in terms of adherence support as the counsellors.

Issues related to knowledge of HIV and ART

A separate question asked who had helped the most in conveying information about HIV more generally. In response to this question, a clear majority (61%) of respondents felt that their counsellor helped them the most in learning about HIV, with doctors a distant second (18%). The only other choice in this category that went over the 5% mark was the media (8% of respondents).

In response to a further question, 49% of patients consider the practicalities of drug knowledge (side effects, necessity of adherence) to be the most important thing they learnt in their education about HIV. Twenty-one percent said general knowledge of the HIV disease process was important to them, whilst 12% considered coping skills and self-support tools to be the most important. These answers might well reflect different emphases at the different clinics in their HIV education process,

Patient's knowledge of what a CD4 count constitutes correlates well with their schooling level (R^2=0.7869). A surprisingly high 70% of patients knew the names of all of their ARV drugs, although this average statistic hides inter-clinic differences. The two clinics where 90% or more of patients knew their drug names are the two biggest ones (Guguletu and Michael Mapongwana), both of which employ an educational process involving repeated visits and group education.

Determinants of self-reported adherence

Looking at determinants of adherence through a multivariate logistic regression model (Table 16), few predictors emerge. The site with the highest odds of patients having missed a dose in the previous three days was GF Jooste Hospital, where the reason for the missed doses could be related to medical indications.

Table 16. Logistic regression model for determinants of missed doses on 3-day recall

	OR	95% CI	p-value
Per year increase in age	0.98	0.94 - 1.03	0.413
Male sex	0.97	0.46 - 2.05	0.931
Highest school grade attained, per additional grade	0.95	0.84 - 1.07	0.398
Asset index quintile, per unit increase in quintile	1.11	0.92 - 1.33	0.286
Site			
Hout Bay	1.00	-	
Michael Mapongwana	2.29	0.62 - 8.40	0.212
Gugulethu	1.13	0.27 - 4.74	0.864
GF Jooste	*5.39*	*1.51 - 19.30*	*0.010*
Paarl	1.94	0.46 - 8.27	0.369
Duration on ART			
0 - 3 months on ART	1.00	-	
3 - 6 months on ART	0.38	0.12 - 1.18	0.093
6 - 12 months on ART	0.61	0.27 - 1.38	0.235
12 - 24 months on ART	0.60	0.25 - 1.44	0.255
>24 months on ART	1.53	0.58 - 3.98	0.388

Missed appointments

A question related to adherence concerned missed appointments. Patients attending the two large community health centres (Guguletu and Michael Mapongwana) were more likely to have missed an appointment (Table 17). It is probable that a combination of long queues and easy access on alternative non-appointed days contribute to this.

Table 17. Missed appointments

	Total N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Missed at least 1 appointment since starting ART	25%	16%	30%	33%	21%	17%

Counsellor diaries- analysis of daily routines

Counsellors were asked to keep diaries of their activities in three of the sites in order to gain a better appreciation of the task mix and patient throughput. The validity was checked on a sub-sample by field workers in each instance. Although quite heterogeneous, the results of the diaries are summarised below (Table 19).

Guguletu

Eight community counsellors were asked to keep diaries for a week. Three of these were tracked by field-workers for the purposes of verification; the field-worker and counsellor diaries showed a close correlation.

Twenty-seven visit sessions were analysed, yielding the following information:
- Median time spent visiting (in hours): 3.5 (range 1-8, IQR 2.5-5)
- Median number of homes visited: 6 (range 2-28, IQR 4-12)

Note: not every home visit was successful (ie: not every home visit resulted in contact with a patient). For certain community counsellors this constituted a high proportion of their visits.

In 18 of the 27, visiting began before noon, with the remainder occurring after midday, usually between 12h00 and 15h30. One visit schedule that incorporated 28 visits was also the longest in duration, 8 hours.

Counsellors spent one or two days of their week at the clinic and were asked to record their activities there too. These included individual counselling of patients, leading of group education sessions, filing (and other administrative type work, like making appointments), translating, taking weights and temperatures and doing pill-counts.

Michael Mapongwana

The Michael Mapongwana counsellors are responsible for delivering pre-ARV education and for giving post-ARV adherence support on an 'as needed' basis. Pre-ARV counselling follows a fairly rigid protocol of four sessions, each covering a specific set of topics. These sessions are labelled C1 to C4 and a treatment supporter, nominated by the patient, must attend at least one of them. Counsellors are also responsible for running adherence support groups on certain days of the week.

Routine records kept by three counsellors over three weeks were reviewed, totalling 39 working days. Over that time-period, 153 pre-ARV counselling sessions (C1 to C4 sessions) were recorded, averaging 4 sessions per counsellor per day. 69 adherence sessions were recorded, averaging and additional 1.8 sessions per counsellor per day. In the approximately 8 working weeks recorded by these three counsellors, 5 group sessions were recorded, averaging 21 patients per group.

Hout Bay

Five patient advocates (PA's) kept diaries for a week, 2 were verified by fieldworkers

PA's are paid for a 4-hour per day working week. Every morning they sign-in at 8h30 then they move out into the community for the morning unless it is their one designated 'clinic morning' of the week. Generally they visit pre-ARV patients, recently started patients and documented non-attenders (the pharmacist gives a list to the PA's of those who've missed drug pick-ups).

Diaries document that 96 successful visits (visits where the patient was at home) occurred in a one week period, averaging 4.8 visits per PA per 4 hour shift. Occasional group sessions are documented with the number attending varying from 2 to 7.

On clinic days a PA will assist in general running of the clinic through pill-counting, filing, translating and providing individual patient feedback at the once-weekly interdisciplinary meeting. An impression from some of the records and interviews was that there might be undue emphasis on the act of pill-counting and less on support and advice. One view was that PA's see their role as 'pill-police' more than promoting and maintaining adherence support. In Hout Bay it was possible from records to determine how often home visits were successful (Table 18), with patients being found at home 72% of the time.

Table 18. Proportion of successful home visits in Hout Bay

PA	Recorded number of home visits in a week	Recorded number of times client was at home
1	25	5
2	17	12
3	16	15
4	35	35
5	41	29
TOTALS	**134**	**96 (72%)**

Using the above data, the Hout Bay PA, when not working at the clinic, conducts on average, 6.7 home visits per day in the community and makes contact with 4.8 patients per shift

Two clinic based counsellors kept diaries for a week. Some administrative work is recorded in their diaries: filing, translating, meeting attendance. Otherwise, mostly voluntary counselling and testing (VCT) pre- and post test counselling sessions are recorded.

Between two counsellors 35 such VCT session are recorded in a week, averaging about 4 per counsellor per day. Ten adherence sessions are recorded for 2 counsellors for the week. Speaking to the doctor and facility manager on-site, a lack of clarity emerges as to who, between the community and facility based counsellors, is responsible for certain types of counselling. This is corroborated by the facility counsellors who believe adherence sessions to be the responsibility of the PA's.

An attempt was made to summarise the workload carried by the counsellors participating in this diary exercise (Table 19), although it should be interpreted with caution given the differences in the types of patient contacts between clinics and counsellors.

Table 19. Counselling activities reported in counsellor diaries

	Guguletu CB	MM FB	HB CB	HB FB
Number monitored	8	3	5	2
Hours worked	20	40	16	40
Hours dedicated to counselling	15	32	12	
Pre-ART sessions		17		
ART sessions		7.5		10
VCT		0		17.5
Home visit	21	0	16	
Support Groups		1		
Clinic support		?		
Contact/week	21	22.5	16	27.5
Contacts/hour dedicated	1.4	0.77	1.0	0.69

CB – community-based   FB – facility-based   HB- Hout Bay Clinic   MM – Michael Mapongwana Clinic

Stigma, discrimination and disclosure

Across the spectrum of providers there is agreement that disclosure is a vitally important adherence tool.

> What makes a person adherent … the first thing I would say is disclosure. If you have disclosed you don't have a problem, even it it's one person, and then you will take your meds properly, that person you have disclosed to or the treatment partner inside the house is going to remind them 'time to take your meds' or ' I noticed you were not taking it but just as a reminder', you've got the overwhelming support inside the house and you are stress- free, but if you did not disclose it is eating you inside, you are sensitive and if people suspect what you have, and then one other day you will take your meds and one another day, when people are here, you won't take your meds, and the stress will make you forget, whether I have taken my meds or not, and then the stress leads to depression and then you won't adhere, so disclosure is number 1, people who have disclosed they don't have a problem, people who live openly with their status they don't have a problem
>
> Counsellor

Counsellors felt especially strongly that secrecy and stigma were contributing to the ongoing inability to control the HIV epidemic, and were interfering with patient adherence.

Probing the issue of stigma slightly further, patients were asked if they felt stigmatised at all as a result of attending an explicit ART service (Table 20), with 16% reporting that they felt stigmatised.

Table 20. Stigma associated with attending a dedicated ART service*

	Total N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Perceive stigma	16%	24%	26%	8%	10%	13%

* Exact question: "Do you feel that people in the community look upon you differently because you attend this clinic?"

Looking for determinants of patients feeling stigmatised (Table 21), men were less likely to feel stigmatised by their community than women, as were patients from Guguletu, Jooste and Paarl less likely to feel stigmatised then those from Hout Bay.

Table 21. Logistic regression model of possible associations with feeling stigmatised

	OR	95% CI	p-value
Per year increase in age	1.01	0.98 - 1.04	0.395
Male sex	*0.34*	*0.18 - 0.65*	*0.001*
Highest school grade attained, per additional grade	1.00	0.92 - 1.10	0.933
Asset index qunitile, per unit increase in quintile	1.03	0.91 - 1.16	0.686
Site			
Hout Bay	1.00	-	
Michael Mapongwana	0.97	0.55 - 1.72	0.928
Gugulethu	*0.22*	*0.11 - 0.47*	*<0.001*
GF Jooste	*0.32*	*0.15 - 0.68*	*0.003*
Paarl	*0.38*	*0.18 - 0.79*	*0.010*
Duration on ART			
0 - 3 months on ART	1.00	-	
3 - 6 months on ART	0.86	0.45 - 1.61	0.632
6 - 12 months on ART	1.05	0.61 - 1.83	0.855
12 - 24 months on ART	0.75	0.40 - 1.40	0.366
>24 months on ART	0.81	0.36 - 1.83	0.615

Results - Integration with other health services

Providers' attitudes towards integration

Western Cape health care and South African health care more generally, is faced with serious human resource constraints and a legacy of inequity in services between sites. In part to address these problems, there is a perceived need to integrate existing services and to re-orientate service delivery towards chronic care. It is recognised that this would however require intensive systems design.

Provider attitudes towards integration were explored in interviews and the following themes emerged:

Most respondents agree with the concept of integration of services in principle. Integration was perceived as a solution to the problems of communication that were affecting TB management, which were referred to commonly:

> "Very interesting. I think it (Integration) is a very good idea. The problem is at (this clinic) you refer not to one TB clinic. You know most other ARV clinics you have one TB clinic you refer to so you build up a rapport with the one TB clinic and inevitably they will trust your judgement, which is a good set-up, and inevitably that clinic is also physically close to where you are, not more than 2 or 3 kms from where you are based, but at (this clinic) we refer to at least 6 TB clinics in the area so that can be logistically difficult... So integration is the answer. I am happy that it is happening but I would like to see it work.
>
> I think it (Integration) is a very good idea, and patient follow-up and management will probably be better, because now you don't need to refer, because what we encounter a lot is we refer patients with AFB-negative TB to be started on TB treatment, then we have to call them back the following day to make sure that they have been started, and on many occasions we have to contact the TB clinic and speak to the sister"
>
> *Medical officer*

Some respondents however had specific reasons for disagreeing with the idea of integration:

> "Integration? I think we need to be vertical and we need to integrate later on because if you don't do it vertically nothing happens. I have been in the services for 10 years, you need to somehow start something and then see how you can integrate it...you must be a very good manager to be able to zoom into all of these different things, otherwise you just are handling crises, and I feel the facility managers are just handling crises"
>
> *Principal Medical Officer*

> "Ja, I don't think that's (Non-integration of TB) a major problem. I think that the way that TB is diagnosed is a problem, but that's across the board, at a primary care level. The sort of reliance on pre-HIV era diagnostic criteria, relying on micro-biological proof before starting somebody, you know having AFBs rather than just introducing this approach to tuberculosis, I think that's a major pitfall and you end up with huge delays in the time to come to a diagnosis, I think that's the major problem. I don't think that, I think TB treatment should be administered at a primary care level with specialised TB clinic, I don't think it would be the right place to start running a separate TB medicine service at this clinic"
>
> *Consultant*

Respondents differed as to how 'integrated' they felt the integration should be, whether it should be cluster management of only TB, HIV and STI's or whether all acute and chronic primary care diseases should be managed at one site.

Some people felt that non-integration potentially allows better quality of care, due to diminished time constraints.

> "I know there is pressure to amalgamate the services, but my feeling is that because we have the time to provide quality service and the ability to call patients back for example, if the sputum result comes positive, we can send a counsellor to their home and tell them to come back, and we're able to make a good referral with a phone call if necessary to the TB clinic. I don't think we're short changing the TB patients except of course, ja maybe, they've got 2 clinics to visit now"
>
> *Principal Medical Officer*

On site (clinic level) and district level management, as well as programmatic vision, are seen by providers as the necessary driving force behind the integration process. In the one example where integration has been reasonably successful, it has been due to fairly intensive and sustained training and personal input from both the attending physician and clinic manager:

> "The TB doctor would come in twice a week and so at the beginning I was very much involved only with the ARV patients, with people who's CD4s were less than 200 and that doctor was doing all the TB stuff. But quite clearly there was such an overlap in patients, and often because I wasn't that busy initially, you know, I'd kind of run out of HIV patients by half past 11, 12 and then I'd come and pick up a few TB patients and they noticed, oh, that this person's also got oesophageal thrush and whatever, so we need to get them in the system. And then when that doctor went on leave in, so we were kind of always talking and, talking about the integration of TB and HIV programmes, the ARV and TB programmes together. Then once she went on leave then that became a reality because I was the only doctor there … So we're hoping to try and help with that integration by swapping staff for a while, so I'll send one of the nurses doing TB work in my clinic to go and do the TB child care local authority stuff while it sort of integrates and get one of the Province staff to get familiar with the programme, develop relationships with the staff and so we're trying to do that, and I'm really keen to push that, because I mean, we need to."
>
> *Medical officer*

In clinics where TB and HIV services are separated (Figure 5, Table 22), complaints of delays in TB diagnosis and treatment are common. A specific problem that was mentioned on many occasions was the reluctance of nurses to deviate from the "sputum-positive protocol", that is, nurses not initiating TB treatment, despite a physician referral letter requesting it, unless the patient had sputum positive TB. It was felt that these delays were creating 'bottleneck' situations in the decision making process around ARV initiation.

A significant body of opinion believes that ARV treatment needs rapid demystification to mid-level health workers and district-wide normalisation. It was felt that a good point of introduction would be via an existing TB program.

It was thought by some that the health system needs to avoid a 'referral' mindset wherein ARV treatment becomes 'another' clinic's problem. Respondents believed that there needs to be widespread acceptance on behalf of the primary care workforce that HIV, on both an individual and health systems level, is a chronic, common problem and that every health care worker needs a working knowledge of HIV management including antiretrovirals.

The table on page 55 (Table 22) summarises some of the non-ARV services offered at each of the clinics studied. A case study on the successful integration of HIV and TB care in Hout Bay is also included in this section.

Case Study 9 - TB/HIV integration at Hout Bay

Prior to the ARV service, Hout Bay clinic offered primary care treatment by professional nurses for hypertension, diabetes and other chronic conditions, as well as antenatal care, STI management and TB treatment.

Initially, the ARV program only shared physical space with the clinic since it was inserted as a separate program with its own staff, funding and patients. However the clinic nurse manager and the ARV doctor had a personal interest in integrating services, in two senses of the word. Firstly, they wanted to offer patients same-day complete care, and secondly, they sought to share the roles of providers within the clinic

According to the clinic manager, integration of ARV patients with other clinic services, and specifically TB services "took a long time and lots of convincing" The ARV doctor mentions that the process was hastened by the part-time TB doctor being unavailable due to vacation leave. At that point, out of necessity, the 'ARV' doctor had to start seeing TB patients who were housed in the room next door to the ARV consulting room. The process of educating nursing staff and changing record-keeping systems was intensive and required sustained personal on-site training from the doctor and manager.

"…but has now reached the point where there is no separation of queues on a patient's presentation to the clinic. Folders enter a common pile where the (ARV) patient's folder goes into the fast track and if it's only for repeat, all of us (nurses) issue repeats. Okay, if there are bloods to be taken, it will be done by us (nurses), we've got a list of when the bloods should be taken. Say it's not the patient's appointment day today, we'll look at them, but if they're sick, what the nurses can't manage goes to the Doctor"

"We're trying to get away from doctor putting the program aside – we're trying to integrate the program into the clinic"

The clinic manager feels that part of the reason for the relative ease with which integration occurred is that the "staff's committed to adapting, we usually say, you know, okay let's give it a try, there's no harm in trying, let's give it a try, and that's how we've basically attacked all problems. Start, suggest, give it a try, if it works – we continue"

"It's working very well I would say, I think its working very well, patients then feel that they also get done quicker, because they had to wait long for the doctor sometimes"

Key-points:
-Personal interest from the main drivers
-Necessity can be a powerful motivator
-Good working relations between manager, doctor and nurses
-Pre-existing culture of adaptability
-Constant on-site motivation and support
-Nurses working to protocols
-Patient-centred process

Table 22. Integration of ART and other health services at participating facilities

	Hout Bay	Michael M	Guguletu	GF Jooste	TC Newman
Tuberculosis	• Diagnosed and treated on site • CNPs carry the bulk of the patient load and F/U visits	• Diagnosed on site • TB clinics in the region are area-based • One is being opened in CHC adjacent to ARV clinic but theoretically only serves ARV patients who would have drained to the (now closed) Macassar site	• Diagnosed on site • Refer to local TB clinic (issues of difficulty in acceptance of diagnosis by TB clinic)	• Diagnosed on site • Managed on an ad hoc week to week basis if it is felt that clinical condition warrants it • Refer to local TB clinic once stable or, if patient is relatively uncomplicated, at diagnosis	• Diagnosed on site • Can dispense for a week at a time • Refer to local TB clinic (issue of acceptance of diagnosis by clinic)
Family Planning	• Condoms available • Injectable contraceptives available • PAP smears by CNPs	• Condoms available • refer to FP clinic in the CHC	• Condoms available • Injectable contraception dispensed • Refer to local FP clinic	• Condoms available • Injectable contraception not dispensed • Refer to local FP clinic	• Condoms available • Injectable contraception not dispensed • Refer to local FP clinic
Sexually transmitted infections	• Managed syndromically on site	• Managed syndromically on site	• Managed syndromically on site	• Managed syndromically on site	• Managed syndromically on site
Paediatrics	• Accepts 'down' referrals from tertiary institution • Beginning to initiate uncomplicated paediatric cases	• Accepts 'down' referrals from tertiary institution • Beginning to initiate uncomplicated paediatric cases • No paediatric service in adjoining day hospital	• Accepts 'down' referrals from tertiary institution • Beginning to initiate uncomplicated paediatric cases	• Not managed	• A separate parallel service runs from the paediatric ward of the hospital • some doctor overlap due to 'locum' nature of some posts

Health seeking behaviour beyond the HIV service

As mentioned in earlier sections, problems with accessing HIV services included the time-cost of travel, constrained opening hours and shortages of staff. In this light, patients were asked about other health-seeking experiences in the previous 6 months.

Data from patient exit interviews on use of private sector services

Patients responded about visits to other health providers in past 6 months, reporting visits to the following services:
- Private general practitioners: 13% (mostly for incidental complaints and minor ailments: aches, flu, chest complaints)
- Traditional healer: 2% (range of reasons - health, spiritual)
- Retail pharmacy: 11% (mostly to buy vitamins or analgesics, some minor ailments)

Overall only a small proportion of patients accessed other (non public sector) services. However it appears as if the problems that led them to other points of care could have generally been managed at a primary care clinic.

Use of other public sector services

Patients were also asked about their experiences of other public sector services while in ARV care (Table 23).

Overall the patient interviews gave a picture of STIs and condoms/safe sex information being adequate at the ARV sites (Table 24), while access to TB management (Table 25, Figure 5) remains a problem to patients and ARV clinician alike. Similarly, most women appear inconvenienced by the unavailability of a full range of family planning options at their ARV site.

Table 23. Services accessed in the public service since starting ARVs

Services	Accessed at ARV facility	Accessed at another clinic
STI	19%	10%
Contraception (% among females)	16%	39%
Condoms/safe sex information	60%	34%
TB treatment	15%	33%
Other	--	3% (mostly referrals to hospital)

Table 24. Female reproductive services accessed since starting ARVs

Among women	Total N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Accessed contraception at <u>this</u> site since starting ARVs	16%	63%	5%	12%	6%	13%
Accessed contraception at <u>another</u> site since starting ARVs	39%	0%	25%	79%	36%	39%

Table 25. Tuberculosis treatment accessed since starting ARVs

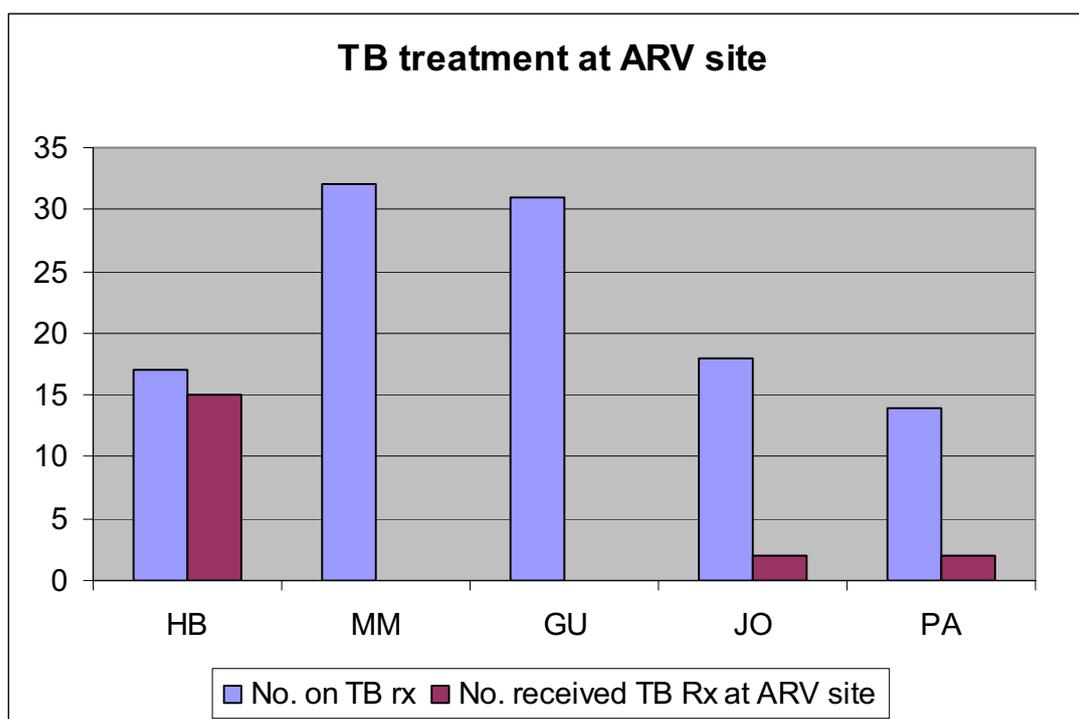| Tuberculosis	Total N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Among those currently being treated for TB, have accessed TB treatment at <u>this</u> site since starting ARVs	17%	88%	0%	0%	11%	14%

Figure 5. Use of TB services at HIV services in co-infected patients

Barriers to communication between health care service points

One problem identified by many respondents was the lack of a clearly expressed communication channel between the referring clinic and the referral site. This often meant there was no specific respondent on the other end of the line to whom problems could be addressed. Similarly, communication back to the referring clinic was also identified as problematic, with many patients returning to the primary site without clinical information.

Record keeping
Of note, there is little momentum in the system to ensure completeness of patient records, especially the patient-retained card which could prove vital when patients present unexpectedly at services to which they are not known. Although 91% of patients had their card on them (Table 26), only 31% of these had the most recent CD4 count recorded, and 18% the most recent regimen. Some sites clearly stress the importance of maintaining the patient-held card – at Hout Bay for example completeness of CD4 and regimen data was around 80%.

Table 26. Patient-retained records

	Total N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Patients have patient cards with them	91%	56%	99%	93%	99%	94%
Of those with cards						
Patient cards have current visit entered	90%	100%	99%	72%	96%	89%
Patient cards have last CD4 count entered	31%	84%	20%	56%	14%	1%
Patient cards have ARV regimen entered	18%	79%	5%	29%	2%	6%

Transport
Patient transport is clearly a problem, specifically with regard to investigations that cannot be done on site like x-rays and ultrasounds. This inability to attend off-site but necessary diagnostic investigations leads to delays in the clinical team's decision-making.

Social services
Many providers expressed a desire for better communication with the Department of Social Services and for greater clarity on the indications and long term sustainability of social welfare grants for patients with HIV. The need for greater input from social services was corroborated by patient interviews, with patients expressing a wish for waiting room food and for financial and skills assistance.

Furthermore, approximately half of the interviewed sample was on a disability grant. The most common response to an open-ended question about further needs was a request for clarity on who qualifies for a disability grant.

Results- needs expressed by providers and patients

Providers

Patients were asked for suggestions for improvement at their clinic and for any special needs they might have. Providers were asked how they would individually choose to spend an incremental amount of money (R1000, R10 000 and more than R100 000) to improve service delivery at their clinic.

At the lower financial level are requests for minor administrative needs to be kept up to date (sufficient blood tubes, adequate laboratory forms, working telephones, functional clinic equipment). That this is seen as a problem is perhaps a further indicator of confusion over roles, in that, in certain clinics, no-one has specifically been delegated the responsibility of dealing with these things and as a result maintenance and administration proceeds on an 'ad hoc' basis.

A lot of providers asked for pillboxes to be supplied to their clinics and this is supported by patient's assessment of pillboxes as an adherence tool.

Patient transport is clearly a problem, specifically with regard to investigations that cannot be done on site like x-rays and ultrasounds, and assistance with patient transport featured prominently amongst requests.

More than one provider made mention of the need for staff morale-boosting exercises as a means of averting burnout, requesting assistance with team-building and staff management.

With the hypothetical latitude to inject greater new resources, providers felt the need for more counsellors and better skills training for existing counsellors. This probably indicates two things, firstly, the value which providers place on effective counselling and secondly, the fact that counsellors tend to receive not only patients with adherence problems, but also any patient with any non-medical problem (for example: alcoholism, relationship difficulties, depression). Since these counsellors are often lay people on ARVs themselves it must be understood that they might not necessarily have the requisite training to cope with the demands made of them.

Many providers furthermore mentioned the need for nutritional support for patients, referring not only to those with low body mass indices, but often simply hungry people in the waiting room. This resonates with patient's needs, in that many requested some form of 'soup kitchen' type facility at their clinic, citing that they queue from before 5am in the morning. This suggestion might be best considered with respect to its potential for clinic attendance adherence.

Clinic and district level leadership and direct facility management was a further shortcoming often voiced by providers. Coupled with this was the desire for active district level intervention in overseeing integration of services. All providers interviewed mentioned that they had 'heard about it' (integration) but very few had yet to see the benefits thereof.

Working space was almost unanimously mentioned as a constraint by all clinics, and all spoke of the problem becoming more severe in the recent past. If resources were available, many would chose to create more consulting and clinic space.

An interesting suggestion was that of implementing a clinical training program for nurses, in order that they might have a more direct hand in patient management and ARV initiation and in so doing potentially relieve some of the current physician 'bottleneck'.

Patients

Interviews with patients revealed that their most frequently mentioned need revolved around access to services and was generally for more convenient opening hours and shorter waiting times. Second on the list of patient needs was for food assistance, either through receiving food at the facility itself or assistance with food parcels. Other needs included, access to an expanded range of reproductive health services, the desire to be treated with dignity by staff, and very commonly, a request for clarity on who qualifies for disability grant application.

Patient perceptions of quality of care

When asked to compare the "quality" of services at the facility in question to other primary care facilities they have attended (Table 27)
- o 33% said services were the same
- o 63% said the services were better
- o 4% said the services were worse

Table 27. Perceived quality of ART services compared to others

	Total N=749	HO N=110	MM N=207	GG N=183	JO N=133	PA N=116
Quality of services are better than other public health facilities	64%	32%*	53%	83%	73%	72%
Clinic hours are convenient	82%	81%	94%	87%	86%	47%

* note that in most instances this is because patients were explicitly claiming that they had no point of reference, i.e. had never attended another clinic therefore couldn't claim HB was 'better'

Discussion and recommendations

The initial rationale for this work arose out of specific questions being asked about the optimal design of a larger routine ARV service in the future. This discussion attempts to integrate the results of the research in answer to these questions, including:

- the level of care at which ART should be provided
- the composition of the clinical team, and specifically the role of nurses in providing clinical care
- the design of adherence support systems, balancing facility and community-based approaches
- the optimal axis along which to integrate ART care with other services

Before considering these issues, it is instructive to reflect on some of the general findings about the programmes, particularly the patient profiles and issues around service access. Although the project was designed to contrast sites, a number of themes have emerged that are common to all the sites, and the discussion will attempt to draw these out. Finally, we will reflect on the particular challenges of scaling up and service constraints as the most pressing of these common themes.

Are there any surprises in what we have learnt about the patient population?

We know from the routine cohort reports that the majority of patients accessing ART are women. The finding in this sample of 77% women is slightly higher than the 71% emerging from the cohort reports. It is possible that there was a slight gender bias as to which respondents participated in the research. The over-representation of women in the treated population is common to most programmes in sub-Saharan Africa. We know that the proportion of men in the private sector programmes is higher, and that according to the demographic modelling, there should be a slight excess of women requiring ART (of the order of 55% vs. 45%). The difference in median age between men and women accessing ART are also broadly consistent with HIV-prevalence age differences reported in the recent survey by the HSRC (Shisana O et al. 2005).

The comparison of the asset index to a representative sample from the Demographic and Household Survey reveals that the patients accessing ART are more likely to be impoverished than the general population in their communities. Unfortunately we are unable to compare those accessing ART to those who are HIV-infected, since there is no data set available reflecting similar parameters for HIV-infected South Africans in general. It is important to note that if the patients accessing ART in the Western Cape are compared to all South Africans, they appear to be better off. This is an artefact of the parameters in the index such as access to services which are generally higher in urban areas than in rural areas. The comparison to an urban population is probably justified. The indication that the ARV patients are more impoverished than their communities in general is corroborated by the extremely high levels of unemployment reported in this study (77% using a strict definition, and 89% using a more relaxed definition).   Linked to this issue is the high penetration of disability social assistance. Issues around access to disability grants is a recurring theme from multiple angles in this research. More than half the patients on ART rely on a disability grant as their sole source of income, and this must have implications in terms of ongoing costs to the State. Alternatively, should these grants not be renewed a renewed cycle of livelihood struggle, with possible implications for adherence, might ensue for patients on ART.

The transport costs incurred by patients in order to access treatment are lower than we expected, probably reflecting that most of those in this sample who travel are travelling within district, due to the sites being primary care sites.

The short lag between diagnosis and accessing ART is a reflection of a programme in which most of those accessing treatment have not known their HIV status for long, and are being tested for HIV when symptomatic. It may prove to be a useful metric to monitor this lag over time (together with the median baseline CD4 count) as a barometer of how much of the backlog in care has been addressed. There should come a time when a larger proportion of patients are individuals who have known their HIV status for some years and have qualified for treatment on the basis of their most recent CD4 count.

The indication for testing reflects the major entry points into HIV care and more specifically ART. Many programmes report tuberculosis services and acute care services being the major entry point to ART, largely because less than one in five pregnant women who test HIV-positive meet the clinical criteria for ART, whereas the proportion of symptomatic patients who require ART within TB services and hospitals is higher.

Are there differences in outcomes that we can pin onto the models of care?

The outcomes at six months reflected in the routine reporting are not sufficiently differentiated to point to systematic strengths or weaknesses of the service delivery models. Although this study was undertaken at a time when it was felt that reasonable maturity existed in the models, it may well be that the sites have yet to face some of the larger challenges that could differentiate approaches to care. It is reassuring though that the programme is performing similarly across a range of sites. Larger differences in patients' outcomes are likely to be observed for patients who have been on ART for longer. It must be explicitly stressed that programmatic success will be determined by excellent long-term adherence yet this research does not examine adherence beyond the short-term.

Are there sufficient differences in the models of care that could explain differences in patient outcomes?

At a macro level, the programme is surprisingly uniform. Although we will talk to the role of nurse clinicians, ART in the five selected sites is largely a doctor run service, tightly following a provincial clinical protocol. Adherence support interventions are more varied, but are all premised on a process of structured patient preparation, patient empowerment, and one-on-one relationships between a cadre of lay health workers and patients. Larger differences emerge in reflecting on the detail of how these are implemented. It is at this level that there is a lot of confounding that makes it difficult to pinpoint inherent strengths (or weaknesses).

Can we answer the big questions: level of care, role of nurses, the model of adherence support, and integration?

Level of care

The first question is perhaps the simplest. This research when all components are considered together is an extremely powerful endorsement of a primary care approach to ART provision. Although not many would argue against providing ART at a primary care level, considering these findings, there is a strong argument to be made to pro-actively facilitate the provision of care at this level where the converse exists.

The programme in the Cape Town metropolitan area is already largely primary care based. Even the one hospital site included in this study operates more as a primary care site than a

routine hospital outpatient department. There are however some contrasting findings between the two hospital sites and the three clinics. Before considering these, it is worth reviewing the aspects of this study that reflect on the level of care:

- Patient access is reasonably good.
    - There are almost no reports of user fees, and transport costs are remarkably low
    - A significant proportion of patients are able to walk to the clinics, over 80% in one instance, with travel times averaging half an hour.

- Adherence levels appear to be good
    - Virological suppression to below 400 copies / ml exceeds or approaches 90% at six months at all sites
    - Self-reported adherence at the time of interview (median duration on ART of 7 months) is good (94% report missing no doses in three days which is equivalent to more than 95% adherence, the generally accepted bench mark for good adherence)
    - Patient retention in care is good, with fewer than 5% of patients being lost to follow-up within the primary care sites

It is difficult to have a benchmark for what an acceptable level of loss to follow-up is. In the routine cohort reports, the definition of loss to follow-up is 90 days or more without a clinical visit. This is a very conservative definition chosen partly because it facilitates ascertainment within 3 months allowing for earlier reporting of outcomes. A substantial proportion of these patients do in fact return to care in the future. In rich countries a window of 12 months is used as patients only visit hospitals every six months and 12 months constitutes two missed appointments.

There are some indications from contrasting the programme at GF Jooste Hospital with the other sites that point to an advantage to delivering the service at a primary care level, including:
- The staff costs appear higher
- Even though there are problems with the routine data from the hospital site, a higher proportion of patients appear to be lost to follow-up (18%) at six months
- Although modest, travel times and costs are higher for patients
- The referral level clinicians themselves have a nuanced understanding of their ART-initiation service, seeing it as filling a gap for particular categories of patients
- The primary care providers express an appreciation of the role that the secondary level service plays in terms of supporting primary care service provision rather than carrying a large patient load of stable patients

Accepting the importance of delivering ART at a primary care level provides the opportunity to invest in the secondary level in a manner that appropriately supports a much larger number of service delivery sites. Primary care providers were glowing in their praise of the referral service offered, and investing appropriately in this level with a view to supporting a large primary care service is a key enabler of success.

One of the potential concerns of a primary care approach is that multiple small service delivery units, each with their own cadre of dedicated staff, could prove more costly than large high throughput hospital sites. It is quite possible that the early adoption of a primary care model could partially explain the higher costs of the service in the Western Cape compared to some of the other Provinces. At around R3000 a patient-year (average of R250 per month in this study) just for clinical care, before drugs or administration staff costs, the human resource costs of delivering ART are considerable. It is not surprising that the referral

hospital service is more expensive given the highly qualified staff available and the greater morbidity in the patient population that they see. The staff costs at TC Newman Hospital are similar to those in Guguletu. There appears to be some support from the costing for shared care with nurses, with the two sites in which care is shared having lower staff costs per patient-month.

Reflecting once more on issues of access, there is increasing evidence that limited access to care has a major impact on outcomes – in a recent collaborative analysis of developing country programmes, access to free care was one of the major predictors of survival (Braitstein et al. 2006). This can most likely be extrapolated to other factors that impact on access to care, which are minimised when care is provided at the primary-care level.

Role of nurses

Where nurse-based care is provided in this sample, factors reflecting positively on it include:
- It appears to be an efficient use of resources if appropriate triage is instituted as reflected in the Michael Mapongwana case study. The throughput for uncomplicated patients seen by nurses is greater
- The costs of clinical care in the two services where nurses provided clinical care were lower
- Patients at Michael Mapongwana rated the nurses highly

A few of the features that facilitated this model included the constant clinical interaction between doctors and nurses and mentoring relationships, the importance of an appropriate physical layout of the consulting rooms allowing for this interaction, and adequate training. In this context it was also suggested that visit schedules should ensure at least annual consultations with a doctor.

Role of community-based adherence support

Where community-based supporters were available, their role was valued by clinical providers. There were contrasting findings from patients – those in Guguletu were more likely to rate the community-based supporter as the most important compared to in Hout Bay. The measure is however crude and limiting the response to the most helpful provider probably masks a lot of detail in how patients experience different providers.

Clinical providers expressed a lot of reservation about the management of the community adherence supporters, and it appears that where the linkages with the clinical team are stronger, there is more trust in their role. In Guguletu for example, the champions of the clinical service are the same as those of the community-based adherence support model, and the strong linkages are evident in the case study reflecting how patients with adherence problems are flagged for extra support.

This "triage" of patients for adherence support, coupled with the concerns expressed about unsuccessful visits, and "pill-policing" may provide valuable insights into the optimal use of community-based support. Below we reflect on the emerging challenges of further and rapid programme expansion, and in all adherence models, it is unlikely that a uniform package can be sustained for all patients, irrespective of demonstrated adherence, at the level required to address the needs of those patients with identified adherence difficulties.

Two models are described, one facility-based and one community-based. In these, the counselling has been well structured, is tailored to different categories of patients, and appears well managed. Both models are under pressure with the ever-increasing numbers of patients, and the challenge in both instances is to identify patients who require additional support, rather than expending huge resources on a uniform follow-up package for everyone.

Irrespective of the model of adherence support, strong linkages with the clinical programme, clear role definition, adequate space, and coherent management are all vital to the success of the lay health worker programme.

Whether or not it adds value to systematically visit all patients at home regularly and with decreasing frequency as treatment progresses, is a question that this study is unable to address based on the data that has been gathered.

The differentiation of patient requirements based on triage creates the space however to embrace both models – there will be some patients for whom follow-up at home and the relationship with a community-based supporter are likely to provide opportunities for adherence promotion that are not available at the facility, and similarly some patients who require, at the facility, additional counselling. Some form of community-based capacity is definitely required. Even in the Michael Mapongwana example, although the facility did not have community-based counsellors linked to the facility, the district had a nurse who together with counsellors conducted home visits for specific patients when indicated.

In terms of resource requirements, the lower per month cost in the costed facility-based counselling model could reflect the low level of input received by the majority of patients who are stable on treatment. The upper bound of the per month adherence counselling costs of around R50 per patient per month approaches one third to one quarter of the total per-visit cost reported in total care costing (Cleary, Okorafor, Chita, Boulle, & Jikwana 2005).

Finally, when considering the facility-based adherence support, pharmacists in this study fulfilled diverse roles, and are key members of the clinical team with respect to adherence promotion.

Integration

Although integration with care for chronic illnesses such as diabetes is theoretically a goal, there was a remarkable absence of discourse around this. The services studied are by and large not integrated, and it is not surprising therefore that this form of integration is not high on the list of issues for providers in these services. What came through very strongly are the issues around TB and HIV. Although there were mixed opinions around whether or not formal integration with TB services should be sought, clinical and service issues around TB were definitely prominent in the concerns expressed by HIV care providers. There seems to be a much greater natural affinity between TB and HIV than between HIV and chronic illnesses such as diabetes and hypertension, due to the hugely overlapping morbidities.

Some of the concerns such as diagnostic dilemmas are clinical, and responses to them need not involve service integration, although service integration can facilitate greater clinical interchange and communication. In the Hout Bay case study, we have an example of an integration process that drew on this affinity to enable the use of existing resources to provide a rational and integrated service. The remaining facilities are not integrated along either axis, and this research is unable to reflect on the strengths or weaknesses of integrated care beyond the Hout Bay example.

Linking to the previous discussion, none of the sites had linked the community-based adherence support for HIV to the TB treatment supporters. The successful linkages in Paarl with home-based carers provides an example of how existing community-based resources could be built on in order to support HIV patients, especially in areas of lower overall HIV service burden.

Common themes

Some of the issues raised by providers apply across the board. Those who were vocal about management issues expressed a concern about the lack of management support at a district level, frequently linked to concerns about burnout. If the responses can be summarised, there is a persistent concern about the burden of care becoming unmanageable, that the solution to the ever increasing numbers is not evident, that providers are carrying constant stress about what is going to happen in six months time. The absence of clearly articulated service expansion plans could be contributing to the stress carried by doctors and nurses. The issue of down-referral of patients leads to a tension for providers, desperate on the one hand to find a solution to the patient numbers, and reluctant on the other to let go of their patients to a model that is untested. The issues of **district-level management**, and **concerns around capacity being reached** are closely linked.

As expressed above, the **clinical issues related to TB/HIV** are very prominent for doctors, probably the most persistent clinical concern that they carry.

In terms of local service organisation, even in these relatively well-established clinics, **role-definition** remains a problem, with widely disparate roles between sites for the same category of staff. This is evidenced by the varying roles played by pharmacists and by clerks.

A further common theme is the lack of oversight around **clinical record-keeping**. The paucity of data (with one notable exception) on patient retained records is an example of this. One of the original planned components of this study was to try and audit clinical records with a view to looking at quality of care across sites. The pilot study for this component revealed such varying standards of clinical record keeping that valid comparisons would have been very difficult to make. There is a broader **information systems** issue relating to "down-referral", with one of the concerns expressed being the perceived inability to keep track of patients who are referred out.

As mentioned above in the section on demographics, the issue of **disability grants** and the criteria for continuation was mentioned repeatedly by patients, doctors and counsellors as a concern.

Is there anything from this study which can inform the process of down or out-referral?

The concerns around capacity being reached were ever present, but the sites had not at the time of the research implemented schemes to expand their service to other sites with more circumscribed responsibilities. This study cannot therefore reflect on the down-referral process. Some of the above findings are however relevant.

The location of ARV care at a primary care level appears to be viable and optimal. This supports in principle the idea of expanding the service to more primary care sites.

The involvement of nurses in clinical care is also viable in the examples in this study. The enabling feature of the nurse-based models may provide insight into how the expansion could happen, including the reflections on clinical mentorship between doctors and nurses, training, triage and internal referral, and the design of physical space.

The lack of information systems to support constant movement of patients between two levels of care even if they are both in the primary care setting is also a concern expressed here which is likely to recur in discussion about down or out-referral of patients.

In order to give some texture to two of the points raised here, namely the issues around capacity limits impacting on staff morale, and the rationale for further primary care expansion, it is useful to consider the implications of programme expansion on the clinics studied as part of this exercise.

Extrapolating from the numbers described in the introduction (Table 1, page 9), assuming that 80,000 patients will be on ART by mid-way through 2011, and applying these to the relative proportion of the current patient load carried by each clinic (Figure 6), the projected number of patients on ART at each of the five clinics assuming no further service expansion are reflected in Figure 7.
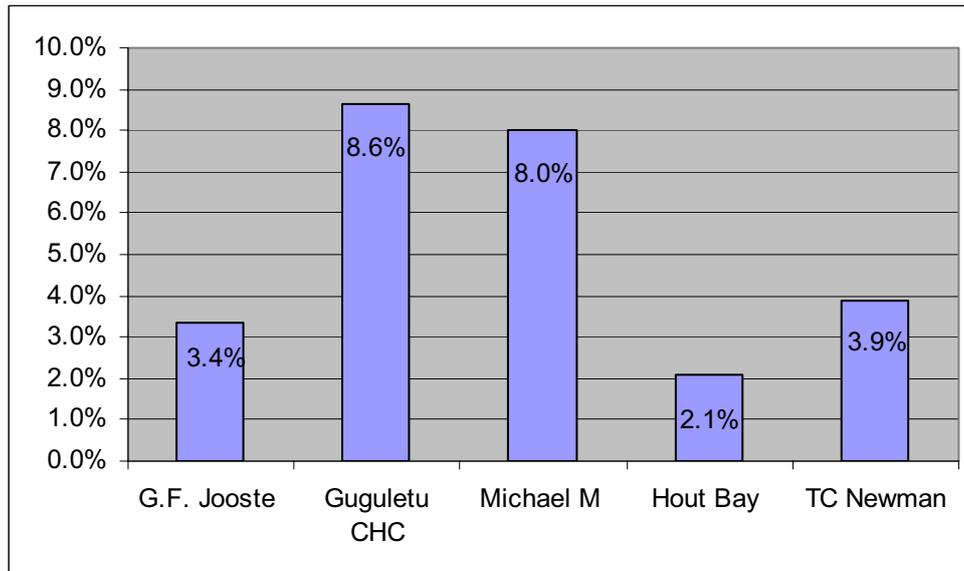
Figure 6. Proportion of provincial ART patients treated by the five studied clinics (Oct. 2005)
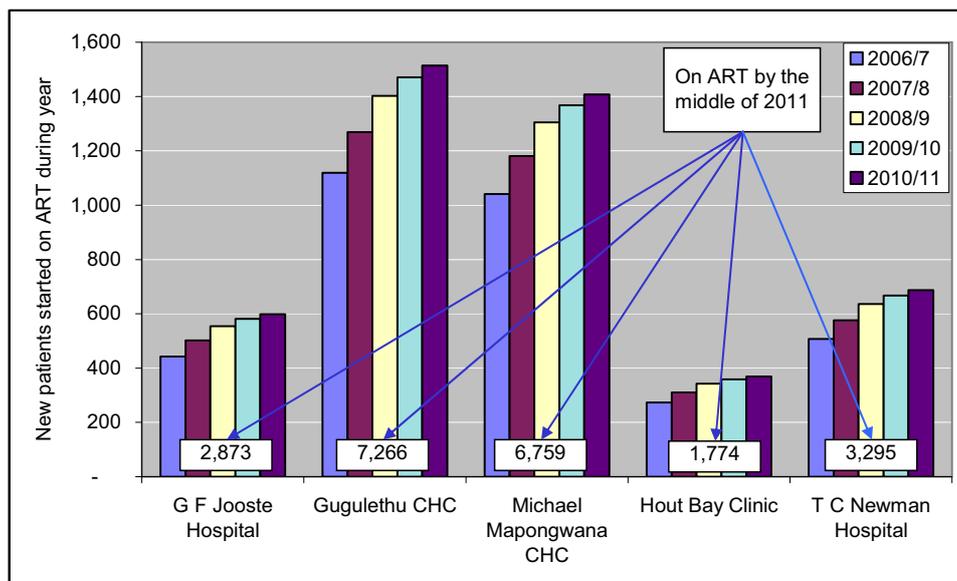
Figure 7. Projected ART patient load in mid 2011 assuming no new sites
Each bar indicates the number of new patients who would have to be started on ART in a given year

For example, Michael Mapongwana and Guguletu, both currently treating around 1,000 patients, would have in excess of 5,000 patients on ART by the middle of 2011 if the province were seeking to maintain or reduce current levels of HIV-related morbidity and mortality. Articulating to providers a year-by-year service plan in their districts that can support the projected patient numbers would help enormously in addressing the current concerns.

Conclusions and recommendations

Data collected from patients has demonstrated that those accessing ART are not privileged relative to the provincial population, and confirms the predominance of women in the patient population, who are on average younger than male patients.

Routine outcomes at six months duration on ART do not obviously differentiate the sites studied, with the outcomes in terms of virological suppression, self-reported adherence and patient retention all being good compared to international benchmarks. These data validate the functioning of the service as a primary care intervention, supported by data showing patient acceptance, and relatively low costs to patients in accessing care. Comparisons at longer durations on ART may be more appropriate as a measure of programme success in future studies.

The varying roles of nurses in providing clinical care in this study suggest that, if appropriately managed, care models in which nurses deliver a substantial proportion of clinical care are feasible, potentially more affordable, and acceptable to patients.

Well-functioning models of adherence support were described, both facility-based and community-based. Key to their success is effective and sustained management and integration with clinical care, rather than specific details of the adherence support model. The debate about whether or not the community-based adherence model is desirable and affordable is likely to be offset by the huge challenge of numbers requiring treatment. In seeking to make maximum use of limited resources, it is plausible to consider a model of targeted support that is directed towards individuals that clinic tracking systems have identified as having adherence difficulties. Such a system could utilise facility or community-based adherence supporters depending on individual circumstances and requirements. This presupposes effective identification of those having adherence difficulties, which is in turn a reflection of efficient site management, well-directed transit through the care process and dependable record keeping and information systems.

The dominant theme around service integration is around TB/HIV services due to the overlapping burdens and clinical challenges, with most providers favouring it in principle, but with varying concerns about the impact it could have on vertical services which currently function well. Integration with other chronic care services, while theoretically desirable, was not prominent in the discussions with providers.

Common themes across the sites not pertaining to differences in the model of care include the desire for more visible district level management, particularly to allay concerns about burgeoning patient loads, which was implicated as contributing to staff burnout. An ancillary concern raised through this study is the variability of clinical record keeping evidenced by numerous incompletely maintained patient-retained records. Patients, counsellors and doctors alike raised the issue of uncertainty around qualification for disability grants, and its possible future impact on adherence.

The service configuration at the time of the study did not allow for the evaluation of any attempts at outward referral of stable patients, but the general findings around primary care and nurse-involvement support the notion of an expanded primary care antiretroviral service in which care is shared by clinical teams, rather than a two-tier doctor-nurse service. The future burden that each of the districts included in this study are likely to face (at over 5,000 patients per clinic in two of the larger clinics in 2011) makes such expansion virtually unavoidable, unless an alternative "super-clinic" model (single, resource-intensive clinic designed to initiate and maintain thousands of patients on treatment) is anticipated.

Either way, an active process of planning for service expansion will both allay the fears of health workers and help prepare the Provincial Department of Health for the foreseeable quadrupling of the antiretroviral patient load over the next five years.

References

Actuarial Society of South Africa. ASSA2003 Aids and Demographic Model, Provincial version. http://www.assa.org.za . 2005. 1-9-2005.

Bekker, L. G., Orrell, C., Reader, L., Matoti, K., Cohen, K., Martell, R., Abdullah, F., & Wood, R. 2003, "Antiretroviral therapy in a community clinic--early lessons from a pilot project", *S.Afr.Med.J.*, vol. 93, no. 6, pp. 458-462.

Braitstein, P., Brinkhof, M. W., Dabis, F., Schechter, M., Boulle, A., Miotti, P., Wood, R., Laurent, C., Sprinz, E., Seyler, C., Bangsberg, D. R., Balestre, E., Sterne, J. A., May, M., & Egger, M. 2006, "Mortality of HIV-1-infected patients in the first year of antiretroviral therapy: comparison between low-income and high-income countries", *Lancet*, vol. 367, no. 9513, pp. 817-824.

Cleary, S., Okorafor, O., Chita, W., Boulle, A., & Jikwana, S. 2005, "Financing Antiretroviral Treatment and Primary Health Care Services," in *South African Health Review 2005*, Health Systems Trust, Durban.

Coetzee, D., Boulle, A., Hildebrand, K., Asselman, V., Van Cutsem, G., & Goemaere, E. 2004a, "Promoting adherence to antiretroviral therapy: the experience from a primary care setting in Khayelitsha, South Africa", *AIDS*, vol. 18 Suppl 3, p. S27-S31.

Coetzee, D., Hildebrand, K., Boulle, A., Maartens, G., Louis, F., Labatala, V., Reuter, H., Ntwana, N., & Goemaere, E. 2004b, "Outcomes after two years of providing antiretroviral treatment in Khayelitsha, South Africa", *AIDS*, vol. 18, no. 6, pp. 887-895.

Coetzee, D., Hilderbrand, K., Goemaere, E., Matthys, F., & Boelaert, M. 2004c, "Integrating tuberculosis and HIV care in the primary care setting in South Africa", *Trop.Med.Int Health*, vol. 9, no. 6, p. A11-A15.

Corbett, E. L., Marston, B., Churchyard, G. J., & De Cock, K. M. 2006, "Tuberculosis in sub-Saharan Africa: opportunities, challenges, and change in the era of antiretroviral treatment", *Lancet*, vol. 367, no. 9514, pp. 926-937.

Lawn, S. D., Myer, L., Orrell, C., Bekker, L. G., & Wood, R. 2005, "Early mortality among adults accessing a community-based antiretroviral service in South Africa: implications for programme design", *AIDS*, vol. 19, no. 18, pp. 2141-2148.

Orrell, C., Bekker, L. G., & Wood, R. 2001, "Adherence to antiretroviral therapy--achievable in the South African context?", *S.Afr.Med.J.*, vol. 91, no. 6, pp. 483-484.

Shisana O, Rehle T, Simbayi LC, Parker W, Zuma K, Bhana A, Connolly C, Jooste S, & Pillay V 2005, *South African National HIV Prevalence, HIV incidence, Behaviour and Communication Survey, 2005*, HSRC Press, Cape Town.

South African National Department of Health 2003, *Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for SA*, South African National Department of Health.

Annexure A. Overview of clinics studied

GF Jooste ARV clinic

Situation: In a dedicated space in the out-patients wing of a secondary level hospital

Inception: As an infectious disease clinic it predates the roll-out, but as an ARV site since early 2003

Opening hours: The ARV clinic per se is open three days a week: Mondays, Thursdays and Fridays from 8h00 to 16h00

Distinguishing features

This clinic is arguably an "academic" clinic with the senior staff including 3 consultants. It has probably the best access to tertiary level investigative services and offers a separate HIV referral unit. The clinic staff are directly involved in continuing medical education around HIV/AIDS and conduct a weekly teaching forum on the hospital premises. Two foreign-funded studies are currently attached (long term) to the clinic and one contributes directly to the staffing of the clinic and is integrated into daily patient management.

This is also the only clinic where the counsellors have no community outreach capacity.

The staff involved (apart from DOT-HAART study staff) all fall under the Infectious Disease unit of the department of Medicine, and as well as the 3 consultants, includes 3 medical officers.

The consultants have established an HIV referral unit in the same space as from which the ARV clinic operates. The referral unit has also negotiated 8 'virtual beds' from the department of medicine that are filled wherever a bed space becomes available in the hospital. The referral unit accepts complicated patients from the surrounding drainage area and includes such cases as diagnostic difficulties for further investigation, drug side effect problems and immune reconstitution illness. Cases can usually be seen on a 'same day' or 'next day' referral basis. Most are discharged back after the consultation with advice and/or treatment but the capacity for admission to one of the 'virtual beds' exists. This referral clinic operates largely on Tuesdays and Wednesdays but also has space and a medical officer allocated to it on the ARV clinic days, where it runs concurrently.

The GF Jooste clinic is looking to position itself as a centre of clinical excellence for HIV and as a training unit for building up medical HIV capacity in the province.

Drainage and entry points
- GF Jooste in-patients
- Local VCT clinics, General Practitioners and occupational health clinics
- Partners/relatives/friend of clients on treatment

Work-up and initiation of treatment
- Seen by medical doctors on first booked visit, worked up as individual case warrants
- Barring problems, usually seen for 3 medical consultations before initiation, over a 4-6 week period, not necessarily by same doctor
- Counsellors see patients on same day as clinical visits
- Should be seen 3 times by counsellor prior to initiation (one of those times being day of initiation)
- Counsellors and doctors confer in daily after-clinic meeting re: patient's eligibility for treatment

Counselling model

<u>Counselling staff and roles</u>
- 2 clinic counsellors employed by lifeline
- 2 study counsellors employed by NIH
- The clinic counsellors also attend to in-patient VCT needs and the senior counsellor visits Carnation ward (hospice) on Fridays

<u>Education process</u>
- Patients require 2 counselling sessions and a third on day of initiation
- Pharmacists reinforce teaching when drugs are dispensed

<u>Adherence support</u>
- Wholly clinic based
- Up to 5 counsellor sessions while on ARVs (quick, 'corridor' booster sessions and pill counts)
- Adherence difficulties referred to counsellors on an ad hoc basis

<u>Counsellor management</u>
- Through lifeline via a system of record keeping
- Alternatively, through NIH

Guguletu CHC

Situation: A freestanding, recently built, dedicated clinic, within the grounds of a regional CHC

Inception: September 2002. The clinic was originally NGO-staffed but clinical staff is now employed by PGWC and counselling staff employed by a separate, but linked, NGO.

Opening hours: 5 days a week, 8h00 to 16h00

Distinguishing features
This clinic has by far the largest number of counsellors of the clinics studied, and these counsellors have extensive reach into the community, with every patient getting a home visit prior to ARV initiation . The counsellors are arranged in a hierarchical management system with 1 head counsellor, 4 senior counsellors and 20 community counsellors. All patients undergo a semi-formalized training and education program consisting of 3 training sessions, detailed below.

The clinic accepts referrals of patients already eligible for ARVS. Patients drain from 8 HIV clinics in the Nyanga district and arrive at the clinic with a pro-forma completed by the referring clinic. No telephonic booking needs occur for this visit.

All patients, unless just picking up repeat medicines, are seen by doctors on clinical visits.

Drainage and entry points
- From 8 peripheral HIV clinics in the Nyanga district
- In turn fed by CHCs, TB clinics, VCT clinics, STI clinics and MOUs

Work-up and initiation of treatment
- Arrive with the pro-forma referral, receives brief assessment by PMO as to urgency of case
- If not urgent then patient registered and given an appointment to see a medical officer, usually within the next 3-5 weeks
- From the first booked appointment a formal 'countdown' process begins, the initial visit serving as the 'week minus four' visit (ie expected to start ARVs in 4 weeks time)
- Follows with two more medical consultations and a parallel education program detailed below

Counselling model
Counselling staff and roles
- 1 on-site head counsellor, 3 on-site senior counsellors, 21 community based counsellors
Patient education
- Three mandatory treatment readiness group sessions
- Modules take place on Wednesdays and Saturdays and are led by the community counsellors. There are approximately 15 to 25 patients per group
- The sessions run parallel with the clinical visits
- It usually takes 3 to 4 weeks for a patient to complete these sessions but theoretically possible to complete them in a week
- The overall timetable and workload for these sessions is managed by the clinic counsellor supervisor

Adherence support
- Every community counsellor (CC) is currently responsible for about 50 people (either on ARVs or "pre" ARVs)
- Their designated role, very broadly, is a combination of education, adherence and emotional support to patients and psychosocial information gathering for clinical staff
- Each CC's patients are assigned by the clinic counsellor supervisor and are usually allocated according to the area the CC lives in
- Each patient receives a home visit by their CC before ARVs are started. At this home visit various issues are discussed such as disclosure, alcohol problems, patient concerns about ARVs, job security and food security. This information is reported back in the forum of the Tuesday interdisciplinary team meeting where it contributes to a decision to initiate or defer treatment.
- Patient's folders are 'colour-coded' and home visits continue at a frequency determined by that coding
- CCs determine their own timetable of home visits, working flexi-time
- CC's clinic involvement consists of the Tuesday interdisciplinary team meeting, where all must be present, and one other day per week, which varies per counsellor, for administrative work

Counsellor management
- The Desmond Tutu Foundation contributes a senior sister, not based on-site, who visits and oversees training and management problems and is involved in " training therapeutic counsellors throughout South Africa"
- The PMO on site has an interest in developing management systems and liaises closely with the head counsellor
- The ARV site has a head counsellor, based full-time at the clinic, involved in "coordinating grassroots" systems
- 3 senior counsellors, also full-time clinic based who have risen to this level because they are "good trainers, good coordinators" and whose work is tending towards the more administrative
- All counsellors have access to a counselling psychologist who visits fortnightly
- This clinic is participating in an experimental cellphone/sms adherence monitoring tool

Hout Bay clinic

Situation: 2 rooms within a local authority (City of Cape Town) clinic and a pre-fabricated 2-roomed counselling building just outside the clinic

Inception: In January 2004 the ARV program was instituted with an NGO funding a doctor, nurse, part-time pharmacist, 3 community counsellors (now increased to 5) and medication

Opening hours: 5 days a week, half-days

Distinguishing features
The ARV service is situated in a LA clinic offering TB and STI management, a VCT service, family planning, antenatal care and walk-in consultations to adults and children. The rest of the LA clinic staffing structure is unchanged since the advent of the ARV program. The doctor and unit-manager have been actively involved in trying to integrate the on-site TB and HIV services and in encouraging the nursing staff to see HIV/ARV patients as a clinic responsibility and not a 'program' responsibility. As such, CNPs employed there are comfortable seeing ARV patients in the afternoons when the program staff is absent. These consultations are however limited to managing inter-current problems and dispensing ARV medication to those already on treatment and do not include assessing eligibility for treatment initiation. Patient advocates on-site provide community outreach.

Drainage and entry points
- Mostly from the surrounding community and nearby harbour fishing village
- The majority of patients undergo VCT for HIV at the clinic itself, usually secondary to attending TB, STI or antenatal consultations
- A few referred from Wynberg and Constantia areas and by Victoria Hospital, most of these referrals pre-date the provision of ARVs elsewhere and patients have elected to stay with the clinic

Work-up and initiation of treatment
- After being diagnosed HIV positive at VCT, a patient is advised to return for further counselling sessions
- Sessions range from 2 to 4 in number depending on the patient's perceived understanding
- At the first of these visits they will be counselled, staged (in a separate consultation room) by a CNP, will receive a PAP smear if female, and have CD4 blood tests taken.
- They will also be put into contact with a dietician and social worker
- Encouraged to attend a group counselling session as well as bring a treatment assistant to those sessions.
- By the time patients have their first consultation with the doctor (for clinical assessment and routine safety bloods) they might well have completed all of the foregoing.
- Patients will usually be assigned to the PA who is working at the clinic on the day of their first doctor's clinical visit.
- By the next doctor's visit, and in consultation with the rest of the team at the Monday interdisciplinary meeting, the doctor is usually able to give patients an expected start date within a month of first seeing them.

Counselling model

Counselling staff and roles
- 2 facility-based counsellors funded by Leadership South
- 5 community-based counsellors (called patient advocates) funded by ARK

Education
- A variable number (2 to 4) of one-on-one education sessions are given from clinic-based counsellors in a room just off-site from the clinic.
- Patients are encouraged (although it is not imperative) to bring a treatment assistant to these sessions.
- Patients are also encouraged to attend at least one group support session.
- A patient could theoretically have all the requisite education sessions completed by the time they first see the doctor
- The doctor, program nurse, pharmacist, 5 patient advocates, 2 clinic-based counsellors as well as a visiting social worker and dietician meet once a week on Mondays to discuss treatment readiness of patients. Issues including disclosure, comprehension, social habits, motivation and such-like are discussed and a decision to start or defer treatment is taken.

Adherence support
- 5 patient advocates spend 4 days a week in the community and one day a week (separately) in the clinic
- If a new person to the clinic has not been assigned a PA they will be assigned the person working on the day of their first medical consultation
- PA's are supposed to visit their patients at home prior to the initiation of ARVs and complete a home assessment form that helps in feedback at the Monday meetings
- After a patient has started ARVs their PA is supposed to visit them: daily for the first week, then 2-3 times/week for the next three weeks, then approximately weekly until eventually tapering down to a monthly 'catch-up' or 'spot-check' visit of pill counts.
- These visits are intended to be supportive, advisory and precautionary (looking out for drug side-effects).
- It is unclear (and probably highly variable) what proportion of patients get this support at the frequency at which it is intended.

Counsellor management
- The on-site counsellors are managed by a local NGO, Leadership South
- The 5 PA's were initially managed by an international NGO, ARK
- The management of the PA's has been transferred onto the organization responsible for TB-DOTS support in the area.
- The facility manager mentions the possibility of the full-time TB nurse at the clinic also taking on more day-to-day micromanagement of the PA's.
- PA's need to sign-in daily in a clinic-based register.
- On their individual clinic days the PA's are involved in organizing and maintaining patient flow, occasionally weighing and taking temperatures, checking with patients that future bookings have been made and invariably counting pills.

Michael Mapongwana CHC

<u>Situation</u>: This clinic is housed within the superstructure of the local CHC. It has dedicated clinical and administrative space within the CHC with counselling space in a prefabricated structure just outside the clinic

<u>Inception</u>: As an HIV clinic since May 2000, as an ARV site since May 2001

<u>Opening hours</u>: 5 days a week, 8h00 to 16h00

<u>Distinguishing features</u>
This clinic has the highest number of monthly patient consultations of the clinics studied. It was initially instituted by an NGO and retains some of the counsellor management and other systems instituted at the time. Three other key features of this clinic are: a) the use of clinical nurse practitioners to handle a high proportion of the patient visits, b) a dedicated administrative clerk who oversees a computer based booking and data capturing system and c) it is the only clinic where patients starting ARVs routinely get pillboxes

Prior to the introduction of ARVs to the province, the clinic was an HIV management clinic and retains some HIV (non-ARV) patients on their register from the pre roll-out period. Currently however it only accepts those who qualify for ARVs

The medical, nursing and management staff is largely PGWC employed and the counsellors NGO employed. CNPs tend to see uncomplicated cases and triage patients for doctor consultations but no patient begins ARVs without at least one consultation by a doctor.

This clinic has very minimal counsellor 'reach' into the community.

<u>Drainage and entry points</u>
- Adjoining day hospital VCT
- Local primary care clinics, TB clinics and GPs
- Currently accepting only those who qualify for ARVs
- Retain some HIV (non-ARV) patients on their register from pre roll-out period

<u>Work-up and initiation of treatment</u>
- Must be seen by a doctor at least once before initiation
- Need to attend 4 counselling sessions and nominate a treatment assistant before being eligible for ARVs
- Discussion meeting twice a month on Tuesdays, doctors, nurses, counsellors inform decision to start treatment
- On start day all patients get pillboxes

<u>Counselling model</u>

<u>Counselling staff and roles</u>
- 6 facility based counsellors including 1 head counsellor

<u>Education</u>
- Counselling space in a separate prefabricated building just outside from the clinic, with 5 individual rooms, a group counselling room and a toilet

- New patients receive a group session on their first visit to the clinic just prior to seeing doctor
- Thereafter must attend 4 counselling sessions (C1 to C4). Each session deals with a different topic
- On third counselling visit must bring a treatment supporter
- On fourth counselling visit signs a contract to take pills adherently

Adherence support
- All patients get pillboxes on initiation of treatment
- ARVs dispensed weekly in pill-boxes for 2-3 weeks
- Majority of counselling is prior to initiation of ARVs
- No regular community follow-up after initiation exists
- Defaulters are telephonically contacted by counsellors, those not traceable might receive home-visits if resources allow
- Selected case might need further counselling after initiation. This occurs on an informal referral basis from doctor/CNP to counsellor

Counsellor management
- On-site, through head counsellor
- Counsellors record daily number of consultations and stage (C1 –C4 or group)
- Report to site B coordinator weekly
- Head counsellor reports to same
- NGO maintains a management role, gradually being devolved to facility manager

TC Newman Hospital

Situation: The clinic operates from a 'rural' district level secondary hospital. The entire clinic occupies the specialist outpatients department of the hospital for two days a week but does not have dedicated space. (The space is used by other specialty clinics, for example, orthopaedics and ophthalmology on other days of the week.). There is no dedicated counselling space.

Inception: First ARVs dispensed in February 2004

Opening hours: Two days a week, Tuesdays lunch-time till end, Fridays 8h00 till end

Distinguishing features
This clinic has strong historical and personal links with local hospice organizations. It also has, according to the staff, arguably the most heterogeneous population on treatment. Consequently the initiation and education processes of patients entering this service are more flexible and more tailored to individual patient requirements than in other models

A parallel paediatric service is offered at this facility, running on different days and operating from the paediatric ward outpatient's department. Because of the 'locum' nature of some of the medical staff there is occasionally doctor 'overlap' between these two clinics.

The medical staff is a mix of PGWC and NGO-employed and the counselling staff NGO employed. Community outreach exists in the form of Patient Advocates.

Drainage and entry points
- Telephonic referral from peripheral HIV clinics
- Out-patient departments in the CHC send patients suspected to be HIV positive to on-site NGO (AGAPE) VCT area, if they test positive, sister there informs ARV clinic staff
- The senior adherence counsellor has worked as a counsellor for 6-7 years, and ex-clients of hers contact her now that they are becoming ill
- Patients on ARVs might introduce family members from as far afield as the Eastern Cape
- Retain some HIV (non-ARV) patients on their register from pre roll-out period
- Mixed entry points therefore a heterogeneous group in care, ranging from stage 1 patients with high CD4's to pre-terminal bed-bound patients being cared for by home-based carers.
- Lately, due to workload constraints, the clinic has tended to accept only those referrals who qualify for ARVs
- Patients attending the clinic for the first time are entered onto a register

Work-up and initiation of treatment
- Difficult to define a standardized 'work-up.'
- In the idealized situation of a patient, known to qualify for ARVs, presenting to the clinic for the first time it is presumed that they will begin ARVs within 4-6 weeks (assuming they are not critically ill)
- The physician, after examining them, will introduce them to the clinic-based counsellor on the same day and will give them a repeat physician appointment in about 4 weeks

- Counsellor arranges for, ideally, 6 individualized counselling sessions before treatment initiation.
- This idealized system is probably the exception and not the norm, with the majority of clients having their counselling sessions tailored to their comprehension and motivation
- Treatment readiness is discussed as a group in a Tuesday morning meeting

Counselling model

Counselling staff and roles
- 2 facility-based adherence counsellors; 5 community-based patient advocates
- 18 home-based carers with a two hour per day adherence input

Education
- Patients receive individual counselling from the adherence counsellors and/or the sister (depending on language capabilities and personal preferences of the patients)
- Wednesdays and Thursdays are 'counselling' days and patients will be booked for their session with one of the above
- Counsellors also attend local frail care centre and TB hospital
- A unique feature of this clinic is that on Thursdays the counsellor attends outreach sessions at a peripheral HIV clinic where she will educate/counsel patients (already registered at the clinic) in an area closer to their homes
- The sister and the senior counsellor occasionally accompany home-based care and hospice visits to patients in their homes in order both to educate clients and elucidate problems that might impact on adherence.

Adherence support
- Opportunistic sessions during clinic days when the physician refers patients having difficulty to the 'roving' facility based adherence counsellors. Concerns have been voiced about lack of privacy
- PAs work 4 hours a day, 4 days a week, one of which is in the clinic assisting with general administrative duties, filing folders, managing patient flow, fetching scripts etc.
- When not at the clinic PAs are responsible for conducting home visits on selected patients and reporting findings back to the staff in order to inform decisions to treat.
- Strong hospice links exist at this clinic. In part because the original two doctors involved in setting up the clinic were heavily involved in palliative care.
- One of the doctors oversees a sister who manages network of 18 home-based carers. This program is externally funded
- The 18 home based carers have had their working hours extended by two hours a day (funded by ARK) and this is for pill check/adherence visits

Counsellor management
- The patient advocates were initially introduced through ARK but now report to Sister in charge of AGAPE, an on-site VCT service
- Also report to Sister in charge of Mbekweni clinic where off-site counselling occurs
Facility-based counsellors managed through the NGO AGAPE

Annexure B. Patient exit interview

Questionnaire for exit interviews with individuals attending ART services

#	Item	Responses
1	Interviewer initials	
2	Date of interview	DD-MM-YYYY
3	Site [2 digit code]	
4	Informed consent for interview provided by participant?	Yes=…1 No=…0
5	Informed consent for record review provided by participant?	Yes=…1 No=…0
6	Participant ID number	[4 digit code]
	Background	
7	Sex	Female=…1 Male=…2
8	Date of birth? DD-MM-YYYY (record age if DOB not known)	
9	Where were you born? Specify town and province or, if not born in SA specify country	
10	If you were born outside of the Western Cape, in what year did you come to the Western Cape? Enter year	
11	Are you planning to leave the Western Cape permanently, to live somewhere else, within the next year?	Yes=…1 No=…0
12	Have you traveled away from home (where you are living at present) for more than 1 week in the past year?	Yes=…1 No=…0
13	If yes, approximately how many weeks have you spent away from home in the past year?	Enter number of weeks, rounded down

	Education and income	
14	What is the highest level of schooling/education that you have completed? (If completed more than matric, enter 'tertiary')	Specify: Grade or standard
15	Have you worked in the last two weeks?	Yes=…1 No=…0
16	If you are working, how would you best describe the work that you do?	Full time =…………………………………1 Self-employed=………………………2 Casual =……………………………………3 Unemployed=…………………………………4
17	Are you on a disability grant currently?	Yes=…1 No=…0
18	If you are a disability grant, how long have you been on it?	
19	If you are not on a disability grant, have you applied for one?	Yes=…1 No=…0
	Clinic attendance costs	
20	Did you miss work to get here today?	Yes=…1 No=…0
21	How long did it take you to come to the clinic today? [enter number of minutes/hours; state 'min' or 'hours']	
22	How did you get here?	Foot=……………………………………………1 Taxi=……………………………………………2 Bicycle=…………………………………………3 Own car=…………………………………………4 Train=……………………………………………5 Other=……………………………………………6 Specify other:
23	How much did it cost you to get here? Enter amount in rand	

24	Did you lose pay from work in order to get here today?	Yes=…1 No=…0
25	Did you pay to attend this facility today?	Yes=…1 No=…0 If yes, record amount in rand
26	Have you ever had to pay to attend this clinic?	Yes=…1 No=…0

	Socioeconomic indicators	
27	What is the main source of drinking water for members of your household?	Piped water in dwelling=…………1 Piped water in site/yard=………2 Public tap=…………………………………3 Water carrier/tanker=………………4 Borehole/well=……………………………5 Dam/river/stream/spring=…………6 Rain-water tank=………………………7 Bottled water=……………………………8 Other=…………………………………………9
28	What type of toilet facility does your household use?	Flush toilet (own) =…………………1 Flush toilet (shared) =……………2 Bucket latrine=…………………………3 Pit latrine =………………………………4 No facility/bush/field=……………5 Other=…………………………………………6

29	Does your household have?		
		YES	NO
	Electricity?	Electricity? ....1...................0	
	A radio?	A radio? ....1...................0	
	A television?	A television? ....1...................0	
	A cellphone?	A cellphone? ....1...................0	
	A landline?	A landline? ....1...................0	
	A refrigerator?	A refrigerator? ....1...................0	
	A personal computer (PC)?	A PC? ....1...................0	
	A washing machine?	A washing machine?...1...................0	
30	What kind of home do you live in?	Shack/informal dwelling=.........1	
		Formal house=...2	
		Flat/council home=..........................3	
		Hostel =...4	
		Other=...5	
		Specify other:..............	
31	What is the main material of your house's floor?	Earth/sand/dung..................................1	
		Bare wood planks...............................2	
		Cement...3	
		Vinyl..4	
		Carpet...5	
		Ceramic tiles..6	
		Parquet or polished wood.........7	
		Other...8	

32	What is the main material of your house's walls?	Plastic/cardboard...............................1
		Mud...2
		Mud and cement...3
		Corrugated iron/zinc........................4
		Prefab...5
		Bare brick/cement block.............6
		Plaster/finished...................................7
		Wood...8
		Other...9

33	Does any member of your household own:		YES	NO
	A bicycle?	A bicycle? ....1...............0
	A motorbike?	A motorbike? ....1................0
	A car?	A car? ....1..............0
	A donkey or horse?	A donkey or horse? ......1................0
	Sheep or cattle?	Sheep or cattle? ....1................0

| | **Home environment** | |

| 34 | Including yourself, how many adults and children live in your household? | Number of children............................... |
| | | Number of adults..................................... |

35	What language do you speak at home?	isiXhosa=..1
		isiZulu=...2
		isiSotho =...3
		Afrikaans=..4
		English=..5
		Other=..6
		Specify other:

36	If you are in a relationship, how would you describe the relationship?	Married=…………………………………………………1 Not married, living together=…2 Not living together=…………………………3 Not in a relationship=…………………4 Other=…………………………………………………5 Specify other:
37	In what year did you test HIV positive for the first time? Enter YYYY	
38	In what town or city did you test HIV positive for the first time? Enter town or city AND province	
39	Did you have an HIV test because you were advised to by a health worker (doctor, nurse, counsellor) or did you decide to have the test by yourself? **(NOTE: If you have circled '1', ask question 40 and skip question 41. If you have circled '2', skip question 40 and ask question 41)**	Health worker……………………………………1 Decided myself…………………………………2
40	If you had the HIV test because you were advised by a health worker, was it for any of the following reasons?	You were pregnant…………………………1 You had TB………………………………………2 You were hospitalised………………3 You attended an STI clinic…………4 Other (specify)……………………………5
41	If you decided on your own to have an HIV test, did you do so for any of the following reasons?	Because of a TV ad………………………1 Because of a newspaper ad……………2 Because of a billboard ad……………3 Because my partner disclosed …4 A friend advised me to…………………5 Other (specify)……………………………6

	ART therapy	
42	For how long have you been taking antiretroviral drugs?	Enter date of initiation (DD-MM-YYYY) or number of months on ART
43	Are you currently pregnant?	Yes=…1 No=…0
44	Are you currently receiving TB treatment?	Yes=…1 No=…0
45	Have you been treated for TB before?	Yes=…1 No=…0
46	Have you visited a private doctor within the last 6 months? If yes, please explain the problem that led to your visit ……………………………………………………	Yes=…1 No=…0
47	Have you visited a traditional healer within the last 6 months? If yes, please explain the problem that led to your visit ……………………………………………………	Yes=…1 No=…0
48	Have you visited a private pharmacy/chemist within the last 6 months? If yes, please explain the problem that led to your visit ……………………………………………………	Yes=…1 No=…0

Can you show me the ARVs you are receiving from this clinic?

INTERVIEWER: You need to check the correct drug names. Please ask to see the drug containers and record the name of the <u>FIRST</u> drug for the next 3 questions. The next three questions are all about ONE drug only, the <u>FIRST</u> drug.

49	DRUG NUMBER ONE: Name	Does the patient know this drug's name	Yes=1 No=0
50	DRUG NUMBER ONE: Name	How many times a day does the patient Rate they take this drug?	
51	DRUG NUMBER ONE: Name	How many of this drug does the patient Rate they take in one day?	

INTERVIEWER: You need to check the correct drug names. Please ask to see the drug containers and record the name of the <u>SECOND</u> drug for the next 3 questions. The next three questions are all about ONE drug only, the <u>SECOND</u> drug

52	DRUG NUMBER TWO: Name	Does the patient know this drug's name?	Yes=1 No=0
53	DRUG NUMBER TWO: Name	How many times a day does the patient Rate they take this drug?	
54	DRUG NUMBER TWO: Name	How many of this drug does the patient Rate they take in one day?	

INTERVIEWER: You need to check the correct drug names. Please ask to see the drug containers and record the name of the <u>THIRD</u> drug for the next 3 questions. The next three questions are all about ONE drug only, the <u>THIRD</u> drug

55	DRUG NUMBER THREE: Name	Does the patient know this drug's name	Yes=1 No=0
56	DRUG NUMBER THREE: Name	How many times a day does the patient Rate they take this drug?	
57	DRUG NUMBER THREE: Name	How many of this drug does the patient Rate they take in one day?	

People may miss taking their ARVs for various reasons. Have you <u>ever</u> missed taking your ARVs for the following reasons: [Interviewer: read each]

58	You were out of town?	Yes=…1 No=…0
59	You were busy with other things?	Yes=…1 No=…0
60	You simply forgot?	Yes=…1 No=…0
61	You had too many pills to take?	Yes=…1 No=…0
62	You wanted to avoid side effects?	Yes=…1 No=…0
63	You did not want others to notice you taking your antiretrovirals?	Yes=…1 No=…0
64	You had a change in your daily routine?	Yes=…1 No=…0
65	You felt like the drugs were toxic/harmful?	Yes=…1 No=…0
66	You fell asleep or slept through dose time?	Yes=…1 No=…0
67	You felt sick or ill?	Yes=…1 No=…0
68	You felt depressed or overwhelmed?	Yes=…1 No=…0
69	You had problems taking pills at specified times?	Yes=…1 No=…0
70	You ran out of pills or you missed a clinic visit?	Yes=…1 No=…0
71	You felt good?	Yes=…1 No=…0
72	The clinic had no stock of ARV drugs?	Yes=…1 No=…0
73	You were drunk?	Yes=…1 No=…0
74	Other that these reasons, have you <u>ever</u> missed taking your ARVs for a different reason?	Yes=…1 No=…0 If yes, specify:

	Recent adherence	
	For each of your drugs, can you tell me how many pills you missed (did not take) **yesterday**?	
75	#1: Number missed yesterday	Number
76	#2: Number missed yesterday	Number
77	#3: Number missed yesterday	Number
	For each of these drugs, can you tell me how many pills you missed (did not take) **the day before yesterday**?	
78	#1: Number missed day before yesterday	Number
79	#2: Number missed day before yesterday	Number
80	#3: Number missed day before yesterday	Number
	For each of these drugs, can you tell me how many pills you missed (did not take) **3 days ago**?	
81	#1: Number missed 3 days ago	Number
82	#2: Number missed 3 days ago	Number
83	#3: Number missed 3 days ago	Number
84	If you didn't miss any tablets in the last three days, when was the last time you missed any of your anti-retroviral medications?	Within the past week=……………………1 1-2 weeks ago=…………………………………2 2-4 weeks ago=…………………………………3 1-3 months ago=………………………………4 More than 3 months ago=………………5 Never missed=………………………………………6
85	If you have ever missed your ARV medications, tell me what happened to make you miss your tablets?	

	HIV appointments and blood tests	
86	Can you explain in your own words what a CD4 count is? _____ _____ _____ _____ _____ _____ _____	
87	When was your most recent CD4 count?	Enter date of test (or number of months ago)
88	Do you know the result of your most recent CD4 count?	Enter CD4 count if known Don't know=..0
89	When are you due for your next CD4 check?	Today=...9 In 1 month=..1 In 2 months=....................................2 In 3 months=....................................3 In 4 months=....................................4 In 5 months=....................................5 In 6 months=....................................6 Don't know=..0
90	Do you have your patient held card with you?	Yes=…1 No=…0
91	INTERVIEWER: Is the current appointment recorded on the card?	Yes=…1 No=…0
92	INTERVIEWER: Is the next appointment given on the card?	Yes=…1 No=…0
93	INTERVIEWER: Is the last CD4 recorded? **IF YES, PLEASE RECORD CD4**	Yes=…1 No=…0

| 94 | INTERVIEWER: Is the ARV drug regimen recorded? | Yes=…1 No=…0 | | | |

Adherence support

	When you remember to take your medications, what are the most important things that help you to remember?	[Open-ended: probe to make sure **ALL** reasons are noted]			
95	(A) Specify:				
96	(B) Specify:				
97	(C) Specify:				
98	Of the different things that you have listed, which is the most important one in helping you remember to take your pills?	[enter A-C]			
99	Have you ever used a pillbox to carry your pills? [Show sample]	Yes=…1 No=…0			
100	If you have used a pillbox before, do you still use a pillbox?	Yes=…1 No=…0			
101	Do you feel that the pillbox helps you take your pills?	Very much	Somewhat / moderate	Not much	None
102	Have you ever attended a support group for people who are HIV-positive? (Ask questions 103 to 105 only if the answer to this question is 'Yes', if the answer to this question is 'No', skip to question 107	Yes=…1 No=…0			
103	If you attend a support group for HIV, is that support group clinic based or community based?	Clinic =1 Community =2			
104	How many support group sessions have you attended in the last 2 months?	Enter number			

105	Do you feel that the attending the support group helps you take your pills? (If yes, please explain how the support group helps you)	Yes=…1 No=…0			
106	If you attend a support group, how does it help you with taking your pills?				
107	Has someone from the clinic ever visited you at home to talk to you about taking your pills?	Yes=…1 No=…0			
108	If someone from the clinic has visited you at home to talk about you taking your pills, did they visit you:	Before you started ARVs…………………1 After you started ARVs……………………2 Before and after starting ARVs……………………………………………………3			
109	How many times in the last 3 months has this person visited you at home?	Enter number			
110	Do you feel that this person helps you remember to take your pills?	Very much	Somewhat / moderate	Not much	None
111	Have you identified somebody (who you chose yourself) who can help you take your pills?	Yes=…1 No=…0			
112	Does this person live with you in the same house for most of the year?	Yes=…1 No=…0			
113	Does this person know that you are living with HIV?	Yes=…1 No=…0			
114	Has this person visited your HIV clinic with you to learn about ARV therapy?	Yes=…1 No=…0			
115	Do you feel that this person helps you remember to take your pills?	Very much	Somewhat / moderate	Not much	None
	Retention in care				
116	Have you ever missed an appointment at this clinic for your ARV therapy? **INTERVIEWER: If the reply to this question is 'NO', skip the next 3 questions and start again at Q120**	Yes=…1 No=…0			
117	How many times have you missed in the last 6 months?	Number			

118	What happened the last time you missed an appointment? Tell me about it.	
	_____ _____	
119	If you have ever missed an appointment, did someone from the clinic come to tell you that you missed your appointment?	Yes=…1 No=…0
120	When you have an appointment at the clinic, what are the most important things that help you to remember to come to the clinic? [Open-ended: probe] (A) Specify: _____ _____	

Quality of care

121	Are the hours of this clinic convenient for you? If no, explain: _____	Yes=…1 No=…0
122	Did you have to miss school or work to attend the clinic today?	Yes, school=…………………………………2 Yes, work=……………………………………1 No=………………………………………………0
123	Do you feel that people in the community look upon you differently because you attend this clinic? If yes, explain: _____	Yes=…1 No=…0
124	In general, would you prefer to see a doctor or a nurse when you come to the clinic? Why? _____	Nurse=1 Doctor=2

125	From whom did you learn about HIV and ARVs? (INTERVIEWER: you can circle more than one response)	Nurse=..1 Counsellor=...2 Doctor=...3 A friend=..4 Things I read=..................................5 Other=..6 (Specify other)
126	Of the people in the above question, who do you think helped you the most to learn about HIV and ARVs?	(Choose from above)
127	What do you think is the most important thing this person taught you about HIV and ARVs?	
128	Overall, how would you compare your experiences attending this clinic to your other experiences with other public health facilities—is this clinic about the same, or better, or worse? (If your experiences are better or worse than other facilities, could you please explain why)	Same=..0 Better=...1 Worse=...2

	Integration of services						

129	If you have accessed any of these services at this site please state whether you accessed them during the same consultation as your HIV/ARV consultation **or** if you accessed them either in another area of this facility or at another time If yes, which ones:	Have you ever accessed this service at this site?		Was this service accessed in the same consulting room and at the same time as your HIV/ARV visit?		Was this service accessed at a different time (or day) or in a different area from your HIV/ARV visit?	
		Y	N	Y	N	Y	N
	a. Sexually Transmitted Diseases screening &						

treatment...							
b. Contraception (females only)...							
c. Condoms and/or information about sex...							
d. Tuberculosis treatment..							
e. Other health complaints that you may have: Specify:							

130	Since you stated taking antiretroviral therapy, have you accessed any of the following health services **at another site**?		
	a. Sexually Transmitted Diseases screening & treatment	Yes=…1	No=…0
	b. Contraception (females only)	Yes=…1	No=…0
	c. Condoms and/or information about sex	Yes=…1	No=…0
	d. Tuberculosis treatment	Yes=…1	No=…0
	e. Other health complaints that you may have: Specify:	Yes=…1	No=…0
131	Is there anything that we have not discussed that you would like to talk about, regarding the services at the clinic, or anything else? _____	Yes=…1	No=…0

Thank you for your time

Annexure C. Counsellor Diary

COUNSELLOR DIARY

DAY OF WEEK:

DATE:

CLINIC:

Client number of the day/ or type of work done eg: filing, pill count, translating for doctors, etc.…	Time started	Time ended	If counselling was done, where was client seen? Home = (1) Clinic = (2) (If client was not seen at home or in the clinic please indicate where they were seen)	Is client on ARVs yet? On ARVs = (1) Pre-ARVs =(2)	Did you do any group counselling sessions today? If yes, please indicate how many people were in the group and how long the session was