

Comprehensive HIV Service Development at Primary Care Clinics

The experience from Khayelitsha



Activity Update

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Médecins Sans Frontières

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Introduction

In February 2000 Médecins Sans Frontières (MSF) and the Western Cape Department of Health initiated a comprehensive service for persons infected with HIV in Khayelitsha. The aim of this project was to show the effectiveness, feasibility and acceptability of treating persons infected with HIV, including the provision of antiretroviral therapy (ART), in a primary care setting.

By the end of 2004, the Khayelitsha programme had been integrated into the Provincial antiretroviral (ARV) roll-out plan following the announcement of a comprehensive National Treatment and Prevention Plan (approved on November 19th 2003). The national plan aims to provide universal coverage of ARV treatment in South Africa within five years.

The three existing HIV clinics initially opened by MSF are now accredited as government sites. The provincial ARV medicines' depot has taken over the supply of ARV medicines as of the end of 2004.

This report describes service developments and clinical outcomes since inception until the end of 2004.

Describing the epidemic in Khayelitsha

More than 90% of women attending antenatal services accept the routine voluntary counselling and testing (VCT) offered as part of the prevention of mother-to-child transmission (PMTCT) services. The PMTCT programme has been in place since 1999, and the proportion of HIV-infected mothers identified through the PMTCT (Figure 1) provides a good indicator of the trend in HIV seroprevalence over time. There was a rapid increase in the proportion of women testing positive in 2000 and 2001, and a more gradual increase thereafter, reaching 27% in 2004.

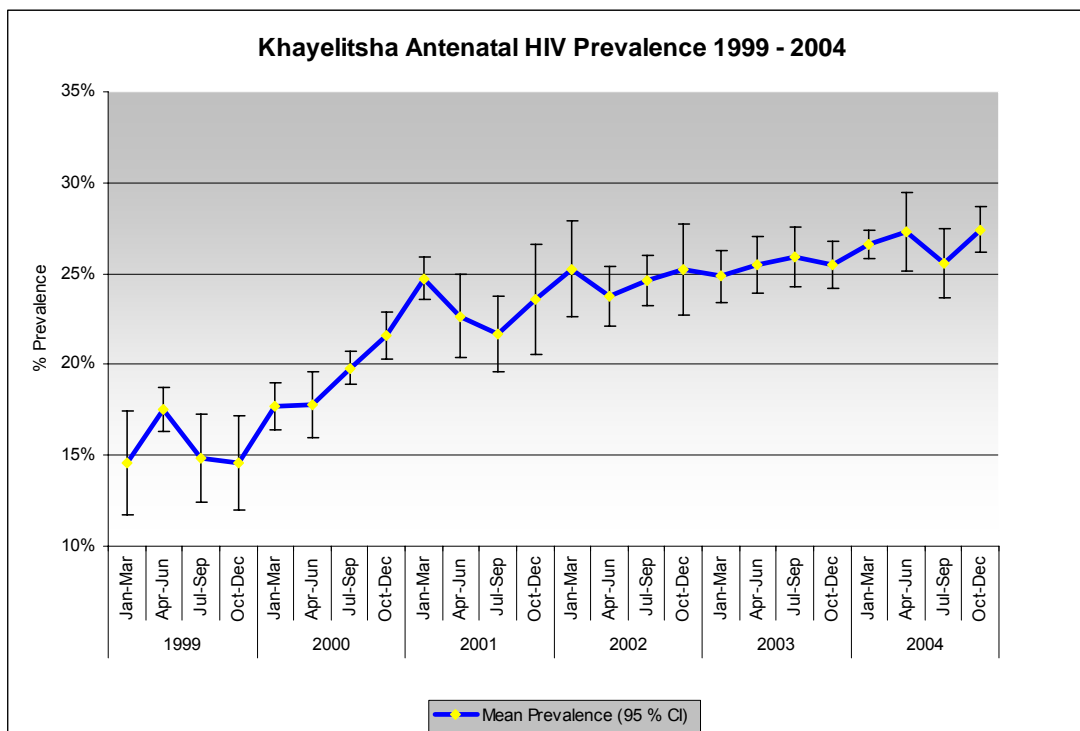


Figure 1. Evolution of the HIV epidemic in Khayelitsha

As the sero-prevalence of HIV in pregnant women in Khayelitsha is very similar to that of South Africa as a whole, we can estimate that approximately 10% of all residents of Khayelitsha are HIV-infected, based on the national modelling. The population of Khayelitsha is estimated to be 400,000, with about 40,000 being HIV-infected. Based on national modelling, as well as on the profile of CD4 cell counts of pregnant mothers, between 5,000 and 7,500 of these individuals are currently eligible for antiretroviral therapy based on CD4 cell count criteria.

Evolution of voluntary counselling and testing (VCT) services

VCT is now widely available in all antenatal clinics, obstetric units, community health centres (CHCs) and local authority clinics including the eight tuberculosis (TB) clinics and the two youth centres.

During 2004, nearly 20,000 HIV tests were performed in Khayelitsha, 25% more than in 2003 (16,024) and 20 times more than in 1998 ($\approx 1,000$). This reflects an increasing demand for HIV-testing, with approximately 10% of sexually active individuals undergoing testing in 2004. A recent community household survey showed that 41% of all adults interviewed had at some point gone for an HIV test. Nevertheless, the demand for testing is still low in the population under 24 years of age. The average HIV prevalence among people tested in different VCT centres in Khayelitsha is above 30% (Table 1), while Site B Youth Centre alone has recorded an average of 20% seropositivity.

Table 1: VCT in Khayelitsha 2004

VCT (including maternity services)	YEAR 2004												TOTAL
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	
People tested	1587	1986	1876	1285	1852	1801	1684	1664	1806	1802	1832	1401	20576
People tested HIV +	436	555	554	437	674	550	481	551	528	602	617	489	6474
% people HIV +	28%	28%	30%	34%	36%	31%	29%	33%	29%	33%	34%	35%	32%

The greatest utilisation of VCT services is not surprisingly in the maternity units. All pregnant women booking in the maternity units are offered an HIV test as part of the PMTCT programme, and the overwhelming majority (98%) accept to be tested. By contrast, only 42% of the TB patients are offered an HIV test in the TB clinics and 80% accept to be tested. This indicates the need to provide HIV testing at all services where clients have the greatest probability of being HIV-infected, such as TB and acute care services.

With the increase in the numbers accepting HIV testing, there needs to be a simultaneous increase at all services in the capacity to care for those infected in order to offer appropriate care to every infected person thereby minimising the *treatment gap* (difference in the number of people knowing their HIV-status and the number enrolling in HIV-care services). In 2004, approximately 530 new HIV-infected people were diagnosed each month, while only 225 new patients enrolled at the dedicated HIV clinics. It is estimated that a further 100 HIV-infected patients enrol in acute-care services outside of the dedicated HIV clinics at primary care level. This suggests that almost half of the newly diagnosed HIV-infected patients do not enrol in HIV care and follow-up.

Evolution of chronic care services for HIV

The total number of consultations in the three HIV/AIDS clinics in Khayelitsha continued to increase sharply in 2004 (Table 2). A total of 40,019 consultations took place during the year, an increase of 73% compared to 2003 (23,175). Of these, 2,543 consultations (6.3%) were for children under 14 years of age (1,661 in 2003). The total number of new HIV-infected patients seen in the three clinics was 2,703 in 2004, compared to 1,688 in 2003.

Table 2: HIV services activity in the 3 dedicated HIV/Aids clinics, Khayelitsha, 2004

HIV/AIDS CONSULTATIONS (OI + ART)	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	2004
Consultations (including ARV)	2229	2626	3143	2624	3039	3653	3630	3941	3967	4091	4300	2776	40019
Consultations among < 15	191	194	215	173	220	237	229	240	246	222	217	159	2543
New patients in HIV care	152	140	220	178	263	314	205	288	235	272	280	156	2703

The increased case load has been facilitated by the arrival in September 2004 of three additional and long-anticipated doctors provided by the Provincial Department of Health (PDoH) under the roll-out plan. Unfortunately no additional nurses were employed during 2004, and the service has become progressively more doctor-based as a result.

To cope with the increasing workload, the Khayelitsha HIV/AIDS task team introduced several strategies:

- An attempt was made to refer patients in WHO clinical stages I and II to other primary care services and to restrict the specialised HIV services to stages III and IV, complicated cases and ARV treatment. This has only been partially successful at one of the three community health centres (Site B), due to lack of capacity at other primary care services and/or to a lack of staff motivation.
- Two new youth-centred HIV clinics were opened as part of the existing Site B Youth Centre and the newly opened Nolungile Youth Centre. This was supported by a grant from the Urban Renewal Fund which facilitated the recruitment of additional nurses.
- Additional HIV clinical training for nurses was provided. Since 2002, formal training for nurses on HIV management has been provided twice a year. The aim was to develop HIV capacity in all community health centres and local authority clinics. Overall, close to 50 nurses from the Khayelitsha district have received HIV clinical training. Due however to shortages of staff and to the large number of vacant posts in other services, most nurses trained in HIV have not been allocated to HIV care, reducing the practical impact of the training they received. Attempts will be made once more in 2005 to address this issue.

Integration of TB and HIV services

The TB-HIV co-epidemic in Khayelitsha

TB case-finding (Figure 2, Table 3) has been rising continuously for the last 4 years. Khayelitsha accounted for 20% of the caseload for the Metropolitan Region in 2004, averaging 1471 patients started on TB treatment per 100,000 population.

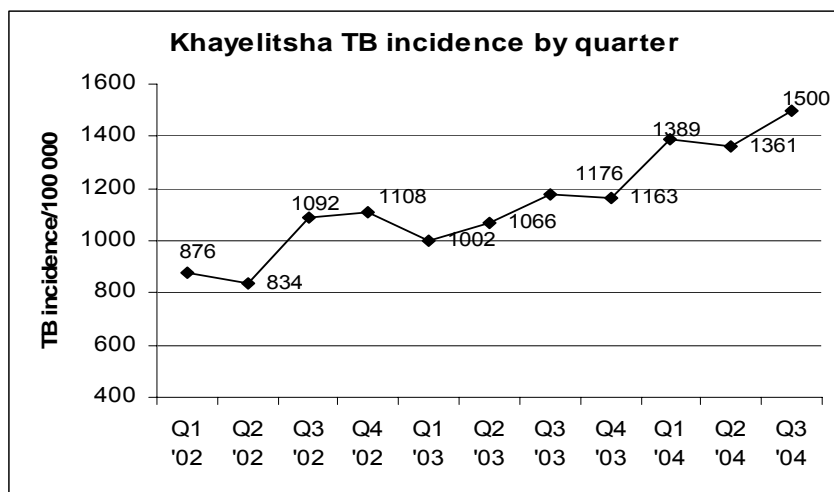


Figure 2: Evolution of TB incidence (all forms) in Khayelitsha, 2002-2004
(Source – City of Cape Town TB reporting)

Table 3: TB caseload in Khayelitsha sub-district, 2001-2004

	2001	2002	2003	2004
Total Cases	3559	3925	4566	5067
Diagnoses per 100,000 population	1031	1283	1122	1471
Extrapulmonary TB (%)	747 (21%)	926 (24%)	1159 (25%)	1141 (23%)

The rapid increase in the number of patients presenting with smear-negative pulmonary TB together with the rise in extra-pulmonary TB, highlights the need for a paradigm shift in the TB programme.

The programme is still focussing on the detection and cure of new smear-positive pulmonary TB. With approximately 65% of TB patients co-infected with HIV, new diagnostic approaches need to be identified in order to decrease the delay in the initiation of TB treatment. This delay has led to increased morbidity and mortality in co-infected patients.

The development of integrated services for TB-HIV co-infected patients, including a revised diagnostic algorithm for smear-negative TB, is a major part of the operational research currently underway in Site B (*Ubuntu*) Clinic.

Integration of TB and HIV: The pilot program

The services at Ubuntu Clinic were integrated with the following specific objectives:

- 1) To increase VCT amongst TB clients as an entry point to HIV care
- 2) To diagnose TB disease earlier in HIV-infected persons
- 3) To facilitate an integrated approach to the management of co-infected persons, creating a "one stop" service
- 4) To increase service efficiency with more rational staff deployment and increased staff motivation
- 5) To improve cure rates for both co-infected and TB patients through a more patient centred approach to adherence
- 6) To benefit from the experience of the TB programme to standardise the approach to the monitoring of ARV patients

A preliminary report on the strategies implemented and early findings for each of the above objectives is available online at www.epi.uct.ac.za or upon request (resourcec@mweb.co.za). The integration of the services has resulted in immediately tangible clinical advantages for co-infected patients. They now benefit from a one-stop service and integrated clinical care. The TB-HIV integrated clinic in Site B has become the busiest TB clinic in the Cape Peninsula (Figure 3) as well as the busiest HIV clinic, suggesting that the model is acceptable to patients. It is noteworthy that despite the heavy workload and difficulties inherent in changing accepted practices, team spirit and commitment to integration remains high.

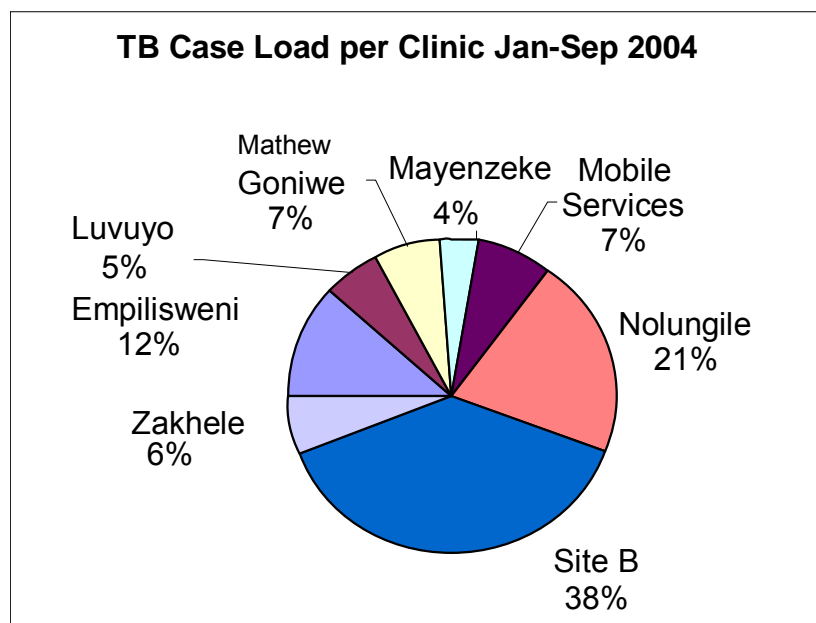


Figure 3. TB case load repartition between clinics, Khayelitsha, Jan-Sept 2004

Antiretroviral therapy (ART)

Patients' enrolment on ART

The national HIV treatment and prevention plan was approved in late 2003 in South Africa. The availability of a Global Fund grant for the Western Cape, including funds for the roll-out of ART in Khayelitsha, meant that there were less restrictions on patient enrolment onto ART. Since late 2003, enrolment of new patients increased dramatically from 30-40 per month to 100-120 (Figure 4). A total of 1170 new adult patients were started on ART in 2004, more than the cumulative total for the previous three and a half years.

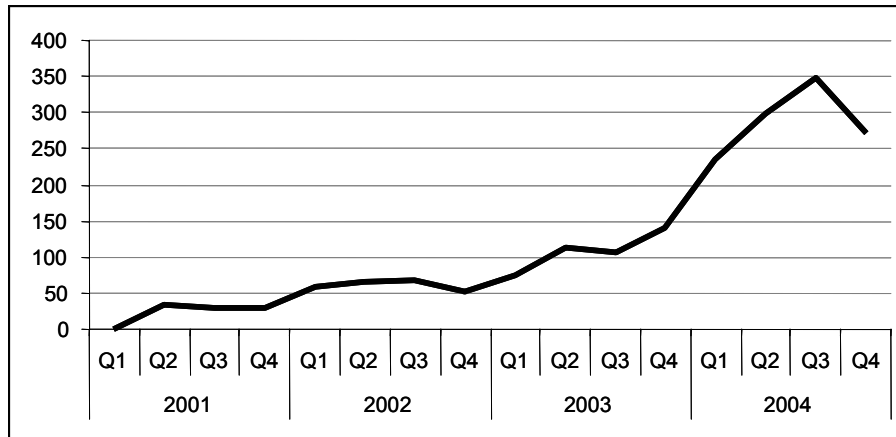


Figure 4. ARV enrolment per quarter since 2001: Khayelitsha sub-district

The CD4+ lymphocyte cell count of patients at baseline has increased from 42 cells/ μ l in 2002 to 81 cells/ μ l in 2004 (Figure 5). This can be interpreted in two ways: (1) patients are seeking care earlier and more readily; and (2) the faster enrolment is allowing the clinics to catch up with the backlog of patients waiting to start ART. In previous years patients who were very sick were more likely to be started on ART than those presenting with higher CD4 counts.

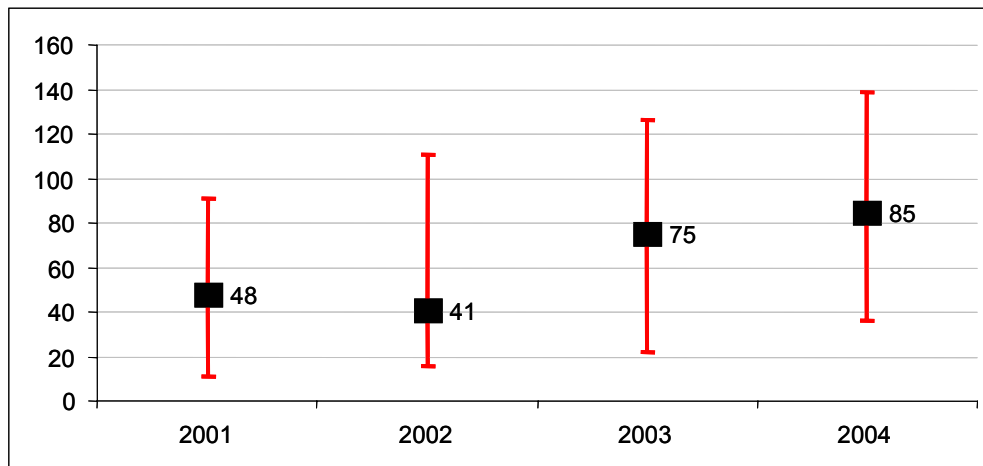


Figure 5. Evolution of CD4 count at baseline by year since ARV became available in Khayelitsha

The provision of ART in other parts of the Western Cape has resulted in fewer patients from elsewhere in the province seeking HIV care in Khayelitsha. The less rigid approach to eligibility for care has however resulted in more patients arriving from other provinces to seek HIV care, especially from the Eastern Cape, where access to ART is still very limited.

Monthly activity reports show that in 2004 the backlog (patients with a CD4 count below 200 and not yet on ART) has stabilised at around 500 patients at any given time, many of whom are in preparation to start ART.

ART regimens

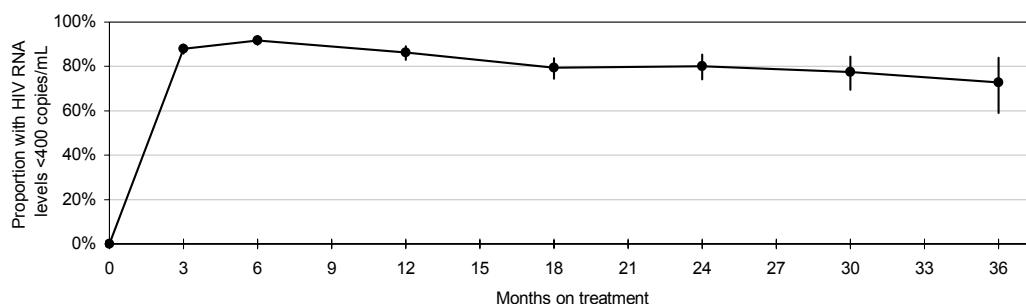
In 2004, most patients started ART on stavudine (d4T), lamivudine (3TC) and nevirapine (NVP), in line with the provincial protocol. Efavirenz (EFV) replaced NVP in the starting regimen when indicated (eg. concurrent tuberculosis), and zidovudine (AZT) replaced stavudine in pregnant women.

The preferred second line regimen was AZT, didanosine (ddi) and lopinavir/ritonavir (Kaletra®). This was used even if AZT had been used in first line regimen as expert advice suggested that the risk of major adverse-events from using d4T and ddi together would outweigh any clinical advantage of potentially less resistance to d4T.

Eight patients were started on tenofovir (TDF) due to serious adverse-events (lactic acidosis) attributed to d4T. Tenofovir is not registered yet in South Africa, and its use requires an individual section 21 authorisation from the Medicines Control Council (MCC).

Clinical response up to 36 months on ART

The following analysis is based on a review of 1731 treatment-naïve adult patients who had started ART by the end of 2004. The first patients to start ART have now been on ART for more than 3 years (36 months).



Number on treatment	1731	1265	951	544	348	225	137	61
Number with viral load results		1105	875	508	310	211	129	55
Percentage < 400 copies/mL (SL ∞ \geq 400)		88.0	91.8	86.2	79.4	80.1	77.5	72.7
95% CI		(85.9-89.8)	(89.7-93.5)	(82.9-89.1)	(74.4-83.7)	(74.1-85.3)	(69.3-84.4)	(59.0-83.9)

Figure 6. Virological responses to ART in adult treatment-naïve patients

The proportion of patients who remain virologically suppressed (viral load < 400 copies /ml) and on their first regimen at 36 months is 72.7% (95% CI 59.0-83.9 - Figure 6). Encouragingly the virological outcomes have remained stable over time in spite of the programme expansion.

Survival and patient retention

The cumulative probability of survival in care at 36 months for treatment naïve adults is now 81.5% (Figure 7, 95% CI 77.6-84.8). This analysis is conservative as it assumes that those patients whose vital status could not be determined have died (31 patients in total).

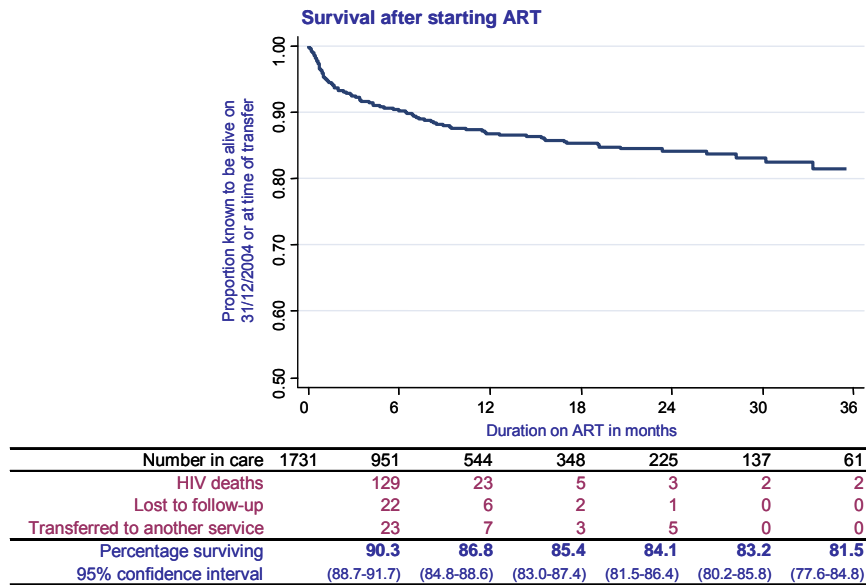


Figure 7. Survival in care of treatment-naïve adults starting ART in Khayelitsha by the end of 2004

Estimates of survival stratified by the year of initiation demonstrates that outcomes have remained consistent over time. The improved outcomes for patients starting ART in 2004 can be attributed to the improved immunological status of this group when starting therapy.

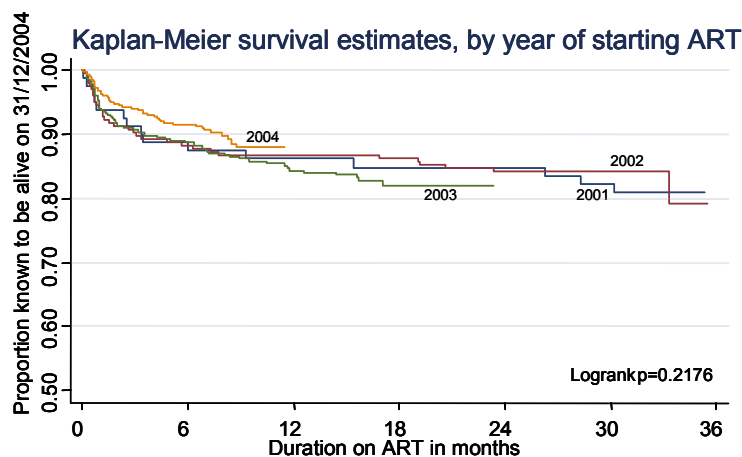


Figure 8. Survival in care by successive annual cohort of treatment naïve adults in Khayelitsha

Regimen durability

The majority of single-drug changes to the starting regimen are due to contra-indications: patient on ART diagnosed with TB and on NVP usually are switched to EFV. Patients wanting to fall pregnant or who fall pregnant on EFV switch to NVP. By three years on ART, 59% of patients remained on their starting regimen (Figure 9). Cumulatively 12% of patients had been switched to second-line regimens by three years duration on ART (all of those with three changes and some with two changes in Figure 9).

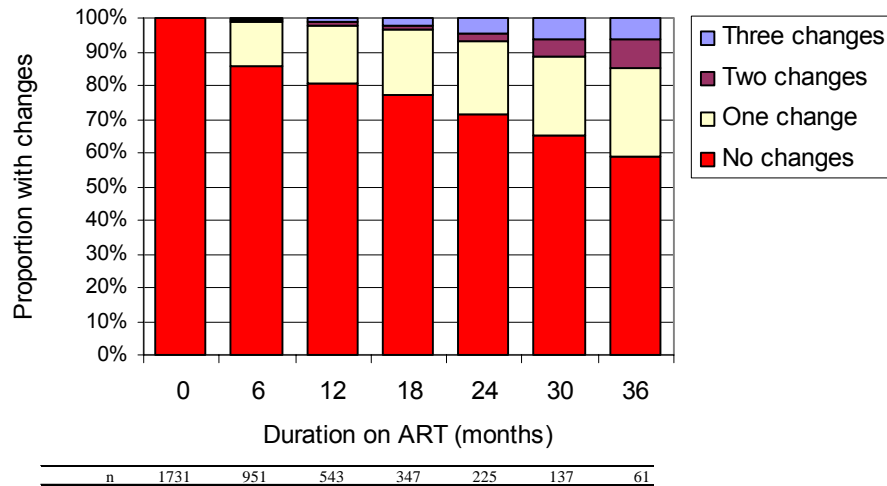


Figure 9. Durability of the starting regimen

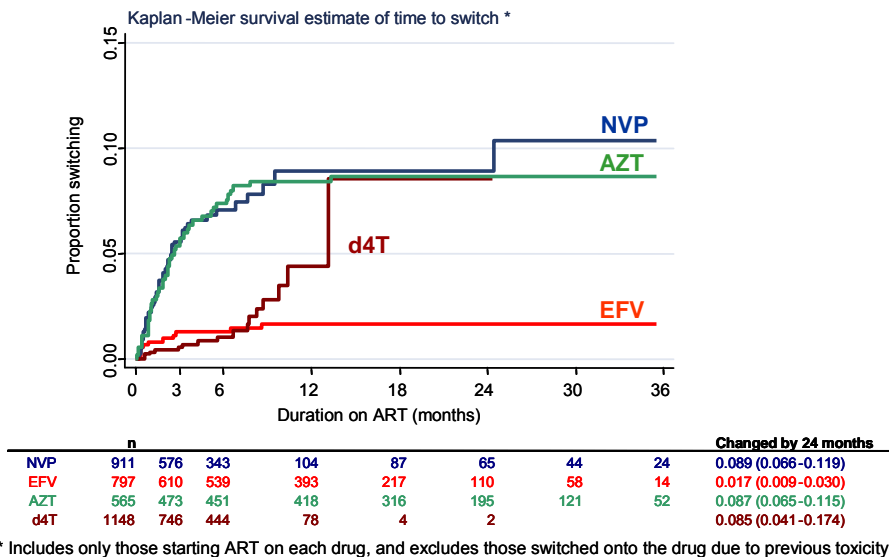


Figure 10. Drug switches due to adverse events

Toxicity-driven switches for patients on AZT or NVP are generally in the first six months, whereas d4T switches tend to occur later (Figure 10). Approximately 10% of patients on each of these three drugs have to be switched because of adverse events.

Children on ART

Enrolment of children on ART started in November 2001, and 130 children were enrolled by the end of 2004. The enrolment of children has increased very slowly during 2004 (32 children compared to 1170 adults). This is predominantly due to 2 factors:

- Fewer children are HIV-infected due to an effective PMTCT program with a transmission rate of 8.8% in 2003 (see below);
- Sick children are often referred to specialised services in tertiary hospitals, where many are started on ART and followed up at the respective hospitals instead of being referred back to primary care

While the impact of PMTCT is encouraging in preventing paediatric infections, the care of many children on ART at hospitals could have important implications over time. Parents and children are

sometimes treated at different centres, and resource constraints for carers could result in treatment interruptions. During 2005 the provincial paediatric outreach plan will refer all stable children on ART from tertiary hospitals to the community health centres closest to their homes. Mobile paediatric teams will support primary care service providers in the provision of follow-up care to these children. This shift of care is key to achieving the provincial goal of 100% ARV paediatric coverage by the end of 2005.

The treatment outcomes of children started on ART in Khayelitsha are encouraging, providing evidence of the feasibility of paediatric ARV treatment in this setting, and of the effectiveness of simplified approaches to paediatric ART, including weight-band dosing with solid formulations.

The median age of children enrolled on ART in Khayelitsha was 48 months of age. The routine implementation of PCR testing at 14 weeks of age will allow for the earlier detection and follow-up of HIV-infected children, and it is anticipated that more children

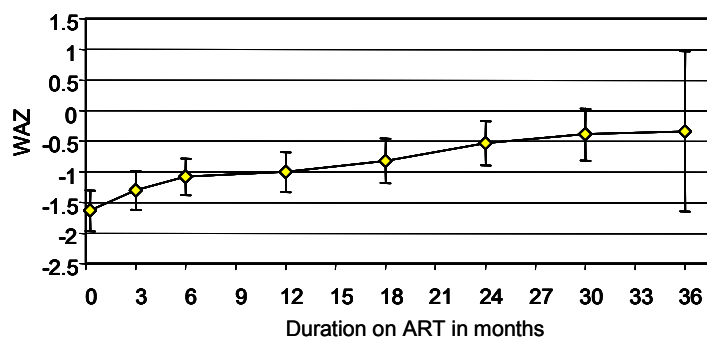


Picture 1. Children at Lizo Nobanda hospice taking their medication.

under two years of age will be started on ART in the primary care services in future.

The profile and clinical outcomes of children who had started ART by the end of 2004 (n=130) include:

- o the majority are boys (55%) a marked difference to adults where almost 70% of patients are women
- o cumulative survival at 36 months is 91% (95% CI 83.7 – 95.1)
- o four out of five children have a viral load below 400 copies/ml at 36 months comparable to adults and higher than that usually reported in the literature
- o CD4+ lymphocyte percentage increased by an average of 20% by 30 months on ART
- o Mean weight-for-age Z-scores (WAZ) increased from -1.6 when starting ART to -0.3 at 36 months on ART (Figure 11).



	130	124	108	77	57	33	21	8
Number on treatment	130	124	108	77	57	33	21	8
Number with usable weights	128	114	105	69	52	29	19	6
Mean WAZ	-1.6	-1.3	-1.1	-1.0	-0.8	-0.5	-0.4	-0.3
95% CI	(±0.3)	(±0.3)	(±0.3)	(±0.3)	(±0.4)	(±0.4)	(±0.4)	(±1.3)

Figure 11. Immunological outcomes for children started on ART in Khayelitsha

The majority of children were started on AZT/3TC/EFV or NVP regardless of their earlier exposure to an antiretroviral drug. Most of them were delivered in Khayelitsha where a short course of AZT was given to the mother when the PMTCT programme was first introduced. More recently, as part of the revised PMTCT strategy, a single dose of NVP was given to the mother and newborn as well. Given the increasing evidence for NVP resistance in infected children receiving NVP as part of

PMTCT interventions, it is likely in future that a protease inhibitor will replace NVP or EFV in the initial regimen for children who are infected despite PMTCT interventions.

Referral networks

To secondary hospitals

The creation of a specialised infectious disease referral unit at GF Jooste secondary hospital, with specific emphasis on ART patients, has led to further improvements in the referral of patients from the primary care level to higher levels of care. This clinic provides a standard range of investigations mainly on an outpatient basis with an appointment system. This has dramatically improved the quality of care for patients on ART who now have access to specialised diagnostic services within 24 hours, when needed. Telephonic advice is also available for primary care clinicians. Weekly case review and continuing education meetings are organised through this unit and bring together primary care and hospital doctors together with experts in the field. A similar arrangement is being pursued at Karl Bremmer Hospital which is the secondary hospital for parts of Khayelitsha.

To hospices for Respite Care

Respite care has improved dramatically in 2004 with the building of a new 20 bed hospice at Lizo Nobanda (Nazareth House) and the progressive medical upgrading of the 80-bed hospice run by the Sisters of Mercy.

Patients in both hospices are attended weekly by one of the Khayelitsha HIV doctors and there is a good referral system between the HIV clinics and the hospices. The role of hospices has changed and they are increasingly used for the stabilisation of patients with advanced disease and/or to initiate patients on ART where they require close supervision. As a result of this collaboration between HIV clinics and hospices, many patients that were once considered terminal and too unstable to start ART, have survived, and many are now doing well on ART.

To home based care

As a result of the availability of ART, the role of home based care (HBC) has changed dramatically. Rather than assisting very sick terminal AIDS patients at home, the HBC volunteers have become active "finders" of "terminal" cases who can be placed on ART at the clinic. They link with the health services and conduct home visits, providing social support and advising patients on referrals.

Adherence support: Strategies and outcomes

Since the beginning of ART provision in Khayelitsha, in 2001, a strong patient-centred adherence support model has been implemented. This model promotes patients' understanding and individual responsibility for their therapy. The principal elements of the model remain unchanged. Nevertheless, the dramatic increase in the number of patients on ART has required a revision of how these elements are implemented:

- **Individual support:** individual counselling visits for treatment preparedness have been structured and standardized. All patients undergo a minimum of three counselling sessions for treatment readiness prior to ART initiation. The support of a self-selected treatment assistant has been maintained.
- **Peer support:** with the growing number of patients, ensuring regular attendance at support groups has become more challenging. Understanding that patients on ART have different needs and aspirations depending on the duration on treatment, support groups were divided accordingly. Groups for patients from 0-to-3, 4-to-11, and 12-and-above months on ART were provided, and meet on different week days. Specific support group are also provided for caregivers of children.

- **Material support:** Given patients' positive perception of the value of pill-boxes, these have been maintained. Supply of pill-boxes should be taken over by Province during 2005. Treatment identification charts have been updated as regimens and formulations have changed.



Picture 2. Meeting of Positive Men United (POMU) for adherence support.

A qualitative adherence study was undertaken in 2004 to understand the factors that enhance and hinder adherence for people who have been on ART for more than 2 years. Forty-eight in-depth interviews were conducted from June to September 2004 with patients on ART. Men, women and caregivers of children on treatment were purposively selected based on their clinical history. The following themes were explored: reasons for opting for treatment, beliefs about treatment, perceptions and experiences of adherence support, adherence challenges, and experiences and perceptions of health care providers and health services.

The results showed that:

- patients who perceived themselves to have been very ill prior to commencement of treatment were more likely to be adherent than those who did not perceive themselves to be very ill, but started treatment on the doctor's recommendations.
- health care services are supportive of patient adherence.
- patients highlighted the value of self-responsibility as critical for long term adherence ("I don't know what to say, but I believe that the entire responsibility remains with the person on treatment, not with the health services"). In addition, some reported using novel techniques to remind themselves to take medication, such as cell-phone alarms, the timing of television soap operas and requesting their children to remind them.
- the main factors identified as contributing to poor adherence amongst adults were: alcohol consumption (especially amongst men), lack of social support, reported feelings of 'stress and depression', non-disclosure of HIV status, competing life priorities, and the lack of belief in treatment efficacy.

Amongst children, the main factors emerging that could potentially be linked to poor adherence included: multiple caregivers, the quantity and taste of medication formulations (syrup vs. pills), and the child's age and the age of the caregiver.

The study showed that patients who have been on ART for a longer period of time have different adherence support needs compared to those initiating treatment. The findings of this study have informed counselling and support strategies currently being implemented at the sites. Specific emphasis is being put on the needs of male patients and children on ART.

ARV drugs supply and access to generics

Since August 2004 ARV drugs have been supplied by the Provincial ARV depot. As a result, brand name products have been provided rather than generics with a few exceptions. In October 2004, a number of first and second line ARV drugs manufactured by Aspen Pharmacare became available, at the same time as Ranbaxy ARV drugs were abruptly withdrawn from the market. The possibility for effective generic competition in the ARV market in South Africa remains therefore extremely limited. The national tender for ARV drugs was only awarded in March 2005, with Aspen Pharmacare being the most successful bidder for many of the commonly used ARVs. The current price for the first line combination d4T/3TC/NVP through the public sector is low (≈R100) compared to prices available on the international market.

As the Province is now supplying the ARVs, MSF can no longer prioritise the use of generics and fixed dose combinations, limiting possibilities for advocacy and operational research on new internationally available formulations.

Prevention of mother to child transmission

Most pregnant women in Khayelitsha agree to be tested for HIV (98% in 2004) indicating that the programme is widely accepted.

The Thai PMTCT regimen protocol has been used since the initiation of the programme in 1999. In this study AZT (600mg/day) was provided from 36 weeks of gestation and during labour. However since 2001, this regimen has been adapted several times:

- in 2002 AZT was given from 34 weeks, and NVP to late bookers (for the mother and child)
- in 2003, NVP was given to all women arriving in labour (single dose) as well as one dose to newborns followed by one week of AZT syrup
- in mid-2004 PCR HIV testing was provided at 14 weeks for all babies replacing antibody testing at 9 and 18 months.
- at the end 2004 triple therapy was introduced for women presenting with CD4 cell counts of less than 200 cells/ μ l. This service is offered by a mobile team from the HIV clinics visiting the maternity units once a week.

In 2003 a PCR sero-prevalence survey was conducted to identify the rate of transmission of HIV from mother to child, including all infants over 6 weeks of age, born to HIV-infected mothers in Khayelitsha. The results from 535 mother/infant pairs showed a transmission rate of 8.8% (95% CI 6.2–11.4).

Since 2004, routine PCR data show that the transmission rate has decreased to 5.5 % and there is evidence that the addition of triple therapy for mothers with low CD4 counts will reduce transmission to less than 5%. The number of children born with HIV in Khayelitsha is estimated to have fallen from around 400 per year to less than 100. With early detection by PCR and prompt referral, universal HIV care for all HIV-infected children in Khayelitsha should be achievable.

Simelela rape survivors clinic

In September 2003, MSF in partnership with Rape Crisis and the provincial departments of social services and health opened the *Simelela* Rape Survivors Clinic in the Site B community health centre. This service includes the health services, the police, the justice system and social services, and operates as a follow-up service for patients seen in acute rape care services.

The number of patients attending *Simelela* Rape Survivor's Clinic for follow-up has increased since September 2003. All patients seen within 72 hours of being raped are counselled, tested for HIV and given post exposure prophylaxis (PEP) if they are not already HIV-infected. Most of the patients currently seen are children. All children are reported to the police and referred to the district surgeon. *Simelela* provides ongoing follow-up for all of these children.

It was hoped that the service would become a comprehensive 24 hour rape service including the provision of acute care. Not being recognised as a comprehensive service seriously limits the quality of the care provided by *Simelela*, since referrals to the only acute rape centre – *Tutuzela*, in Jooste hospital – are very problematic. Despite difficulties, *Simelela* is able to offer night services thanks to volunteer staff from social services. MSF continues to employ a forensic doctor and a nurse-co-ordinator. Province has finally committed to upgrade *Simelela* into a comprehensive service in 2005.

Youth centres and prevention strategies

In May 2004, an HIV follow-up service was initiated at the youth clinic, in Site B, for youth between 12 and 25 years of age. The diagnosis and treatment of opportunistic infections (OIs), counselling and education on HIV and AIDS and support groups complements family planning, sexually transmitted infections (STIs) and voluntary counselling and testing (VCT) for HIV.

In September 2004, a second youth centre was built with funding from MSF, alongside Nolungile Health Centre in Site C. The centre is run by the City of Cape Town with clinical support from MSF. It offers similar services to the Site B Youth Clinic, providing a youth-friendly environment with a separate private entrance, ensuring privacy from patients attending Nolungile Health Centre.

The centre employs three professional nurses, two counsellors employed by local NGOs, volunteers from the Treatment Action Campaign (TAC), peer educators trained by the Department of Health, a reception clerk and a general assistant. After four months, the average number of clients (people under 25 years of age) being seen per month is approximately 2000.

The greatest demand has been amongst young women receiving family planning services (24,000 contacts per year). These contacts provide a unique opportunity to reinforce HIV prevention messages at an early age, when adolescents initiate sexual activities.

Efforts are made to encourage young people to know their status and have an HIV test. Of those who were tested for HIV through this service, 24% were HIV-infected and were offered clinical follow-up in the same centre.

By the end of December 2004 there were 132 HIV-infected youths attending the HIV follow-up service. There is a need for education and more openness about HIV and AIDS. Efforts have been made in the youth centres to reduce stigma while increasing awareness and knowledge by offering informal teaching sessions through locally trained TAC volunteers, peer educators and groundbreakers.

Posters, pamphlets and magazines are available and youth are encouraged to take the material to their homes where the information can be discussed. Counselling sessions, psycho-social support groups, beading groups and other income generating activities are in place as well as debates and entertainment such as video afternoons, dance and sports activities.

Activities at the Youth Centre are linked to an educational programme in 16 schools conducted by peer educators. A plan to reach out-of-school youth is also being prepared.

Community mobilisation for treatment & prevention: The role of TAC

Beneficiaries of the HIV clinics are strongly encouraged by peers to engage with community responses to HIV. That response has largely been led by the Treatment Action Campaign (TAC). Between July and August 2004, the TAC Khayelitsha reorganised its structure to facilitate more widespread community mobilisation. Since September 2004 there has been a dramatic increase in TAC activities in Khayelitsha. New local leaders and educators have emerged with renewed energy, under the leadership of the district co-ordinator, Mandla Majola, and with the support of MSF.

Central to TAC's activities in Khayelitsha is a literacy programme on HIV/AIDS, treatment and prevention. TAC Khayelitsha employs a trainer (responsible for planning, coordination and follow-up



Picture 3. March against women and children abuse.

of treatment literacy activities), three treatment literacy practitioners (one per clinic; responsible for implementing treatment literacy activities at clinic level and outreach to the community served by the clinic), and a number of peer educators. Peer educators coordinate education sessions and promote involvement of participants in support groups in the PWA movement. TAC Khayelitsha has mobilised four main community sectors against HIV: People living with HIV, women, men and youth. Each of these develop activities to address their specific issues, in addition to combined activities. The TAC has strengthened its partnerships at local level with other key community players, including ward counsellors, government officials, NGOs, CBOs and the local media.

Many activities and campaigns have been developed during the last year, involving TAC members, local activists, and the Khayelitsha community. These include education about HIV, ART, HIV/TB co-infection, stigma rejection, campaigning against women and children abuse, condom and VCT promotion, and education about social grants. Specific actions include workshops, marches, street events, door-to-door campaigns, outdoor education sessions in taxi-ranks, train stations, etc.

The direction and priorities of the TAC's programme in Khayelitsha are constantly being revised relative to the context and the availability of motivated volunteers. Although there is a strong impression that these activities have impacted on community awareness about HIV and treatment, and provided cohesion to the community response to HIV, the direct impact on prevention of new infections is unknown. The strengthening of the TAC youth sector, and increasing co-ordination with activities developed in the youth centres, as well as youth programmes implemented by other local players, is being prioritised during 2005 in an attempt to reduce new infections in this group.

MSF Resource Centre

The MSF resource centre in Khayelitsha was reorganised during 2004 to provide support for community activities. As part of this role, it has developed and distributed the following materials:

- a pamphlet about HIV/AIDS medical services in Khayelitsha,
- a map of HIV/AIDS services in Khayelitsha,
- posters of people on ART to normalise ART and support adherence,
- posters to raise awareness about the overlapping epidemics of HIV and TB,
- leaflets and pamphlets to promote the *Simelela* Rape Survivors Clinic,
- posters and postcards promoting VCT amongst youth,
- ARV identification charts,
- reports related to HIV services in Khayelitsha.

The resource centre also identifies, sources and disseminates relevant material developed by different organisations. Particularly fruitful has been the collaboration with Soul City and Khomanani for the development of new education material and for the distribution of a number of education booklets in the clinics and at community centres.

Materials are disseminated at meetings, workshops, door-to-door and street campaigns, through TAC branches, clinics, NGOs and libraries. Videos and reports are available on request.

Conclusions

The rapid increase in the numbers of people testing for HIV at VCT sites in Khayelitsha suggests increasing services levels and hopefully less stigma associated with HIV. However the increasing gap between the numbers testing positive and the numbers enrolling in HIV services is disconcerting and requires further investigation.

In 2004, the Khayelitsha AIDS programme has shown that the enrolment of persons on ART can be scaled up rapidly, while still maintaining good quality care. Four years after the initiation of the ART programme the results show that there is excellent retention of patients and a high percentage of patients have suppressed viral loads. Clinical and biological parameters show a marked reduction in morbidity and mortality, including for those patients who are initiated on ART with very advanced disease. The early clinical outcomes for patients starting in recent years are the same or improved compared to the first two years of the programme in spite of the simplification in patient preparation.

Paediatric outcomes at three years on ART are encouraging, and the service anticipates a larger paediatric service load in future. The PMTCT programme continues to be adapted and improved. This programme has dramatically reduced the rate of vertical transmission in Khayelitsha.

Toxicity to antiretrovirals has been shown to be low with approximately 10% of adults on AZT, NVP or d4T being switched because of adverse events. Switches for patients on AZT or NVP are generally in the first six months, whereas d4T switches tend to occur later. Although many patients also switch due to contraindications, by three years after starting ART, 59% of patients remain on their starting regimen.

At a service management level, in 2004 the ART programme was integrated with the provincial programme and all antiretroviral drugs are now accessed through the Provincial Department of Health. Good continuity of care, with the further development of appropriate referral mechanisms between the services and secondary hospitals and between the services and respite centres, has contributed immensely to service quality.

It is estimated that at least 5000 adults in Khayelitsha should be on ART. By the end of 2004 only 2000 had been initiated on therapy. However the increase in the median CD4 cell count for patients at the initiation of ART indicates that the backlog of patients waiting to be placed on ART has been partially reduced.

The integration of HIV and TB services at Site B has resulted in a one stop service with many benefits for co-infected patients. The process of integration will be monitored closely.

The adherence counselling model implemented – based on the promotion of self-responsibility - is yielding good results even for people on treatment for more than two years. Specific attention is needed to support adherence amongst men and children.

Good communication between counselling services in the clinic and outreach education is essential to reduce stigma and increase community awareness about HIV/AIDS and treatment. Community activism continues to play an essential role in the high acceptability of the HIV programmes in Khayelitsha. The role of grassroots organisations such as the Treatment Action Campaign (TAC) is remains critical.

Challenges

Many challenges remain. An appropriate increase in the complement of clinical staff has not kept up within the increasing workload. It appears that staff “burn out” is becoming a problem in certain areas. There have been insufficient nursing personnel and this has hindered the development of the nurse-based approach that was felt to be critical to the successful roll-out of antiretrovirals.

Although the rapid increase in ART service provision has partially reduced the backlog of patients in need of ART, it is clear however that the HIV service platform needs to be rapidly expanded in order to keep up with the current and future demand for HIV care. Such an expansion will require revisiting the entire model of care for HIV in Khayelitsha as more service providers become involved. Without intervention it is clear that the three existing clinics will definitely not cope with the current demand for both HIV care and ART, let alone the anticipated demand in coming years.

At the same time as expanding the service platform, a plan for the gradual handover of the management of the Khayelitsha programme to the Western Cape Department of Health needs to be developed and implemented.

Many initiatives described above will require further energy and careful monitoring, including:

- attempts to increase paediatric HIV care in the Khayelitsha clinics coupled with further simplification of paediatric ART approaches
- the further development of the pilot TB/HIV integration project for co-infected patients at Site B Clinic

It is clear that the major challenges around HIV prevention remain. Where possible the openness created through clinical service provision and community activism should be harnessed in attempts to slow down the epidemic in this sub-district.

This programme represents one of the first attempts to integrate ART into a comprehensive government response to HIV/AIDS, in one of the most marginalised urban communities in South Africa. To date over 2000 patients have been started on ART indicating that the large scale primary care roll-out of ART can be achieved if well planned and supported, and if part of a broader co-ordinated HIV programme.

Cape Town, July 2005

