

Evaluation of interventions to increase the proportion of people living with HIV who are diagnosed, initiated on, adhering to and retained in HIV treatment and care in South Africa

## Formative Qualitative Research: Phase 1 Report



November 2014



**WORLD BANK GROUP**  
Health, Nutrition & Population



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Department:  
Health  
**REPUBLIC OF SOUTH AFRICA**



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1818 H Street NW, Washington DC 20433  
Internet: [www.worldbank.org](http://www.worldbank.org); Telephone: 202 473 1000

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## Acronyms and abbreviations

aHR	Adjusted hazard ratio
ANC	Antenatal care
aOR	Adjusted odds ratio
ART	Antiretroviral therapy
ARV	Antiretroviral
BP	Blood pressure
BMI	Body Mass Index
CBO	Community-based organisation
CD4	Cluster of differentiation 4 (protein found on the surface of immune cells)
CCG	Community caregiver
CCW	Community Care Worker
CHW	Community healthcare worker
CI	Confidence interval
CKD	Chronic Kidney Disease
DCSP	District Clinical Specialist Team
DG	Disability Grant
DOH	Department of Health
DOT	Directly Observed Therapy
DR-TB	Drug-resistant tuberculosis
ELISA	Enzyme-linked immunosorbent assay
FDA	Food and Drug Administration
FDC	Fixed-dose combination drugs
FGD	Focus group discussion
GNI	Gross National Income
GPP	Good Pharmacy Practice

HAT	Harmonised Assessment Tool
HbA1c	Glycated haemoglobin
HCT	HIV counselling and testing
HCW	Health care worker
HE <sup>2</sup> RO	The Health Economics and Epidemiology Research Office (division of the Wits Health Consortium of the University of the Witwatersrand)
HR	Hazard ratio
ICDM	Integrated Chronic Diseases Management
I ACT	Integrated Access to Care and Treatment Program
IPT	Isoniazid preventive therapy
ISHP	Integrated school health programme
iTEACH	Integration of TB in Education and Care for HIV/AIDS
KP	Khethimp'ilo (model)
LMIC	Low-and middle-income countries
LTFU	Lost to follow-up
M2M2B	Mother-to-mother-to-be programme
m-DOT	Modified Directly Observed Therapy
MDR-TB	Multi-drug resistant tuberculosis
MEDUNSA	Medical University of South Africa
mHealth	Mobile Health
MSF	Médecins Sans Frontières
NASTAD	National Alliance of State and Territorial Directors
NCD	Non-communicable diseases
NDOH	National Department of Health
NHI	National Health Insurance
NHLS	National Health Laboratory Service
NICD	National Institute for Communicable Diseases
NIMART	Nurse-initiated and managed antiretroviral treatment

NNRTI	Non- nucleoside reverse transcriptase inhibitors
OR	Odds ratio
PA	Patient advocate
PCR	Polymerase chain reaction
PEPFAR	President's Emergency Plan for AIDS Relief
PHC	Primary health care
PICT	Provider initiated counselling and testing
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
POC	Point of care
RR	Risk ratio
SASSA	South Africa Social Security Agency
SOP	Standard operating procedures
STI	Sexually transmitted infections
TasP	Treatment as prevention
TB	Tuberculosis
THP	Traditional Health Practitioner
TIER.net	Three Integrated Electronic Registers system
UNICEF	The United Nations Children's Fund
USD	United States dollar
VL	Viral load
WBOT	Ward-based outreach team
WHO	World Health Organization
XDR-TB	Extensive drug-resistant tuberculosis

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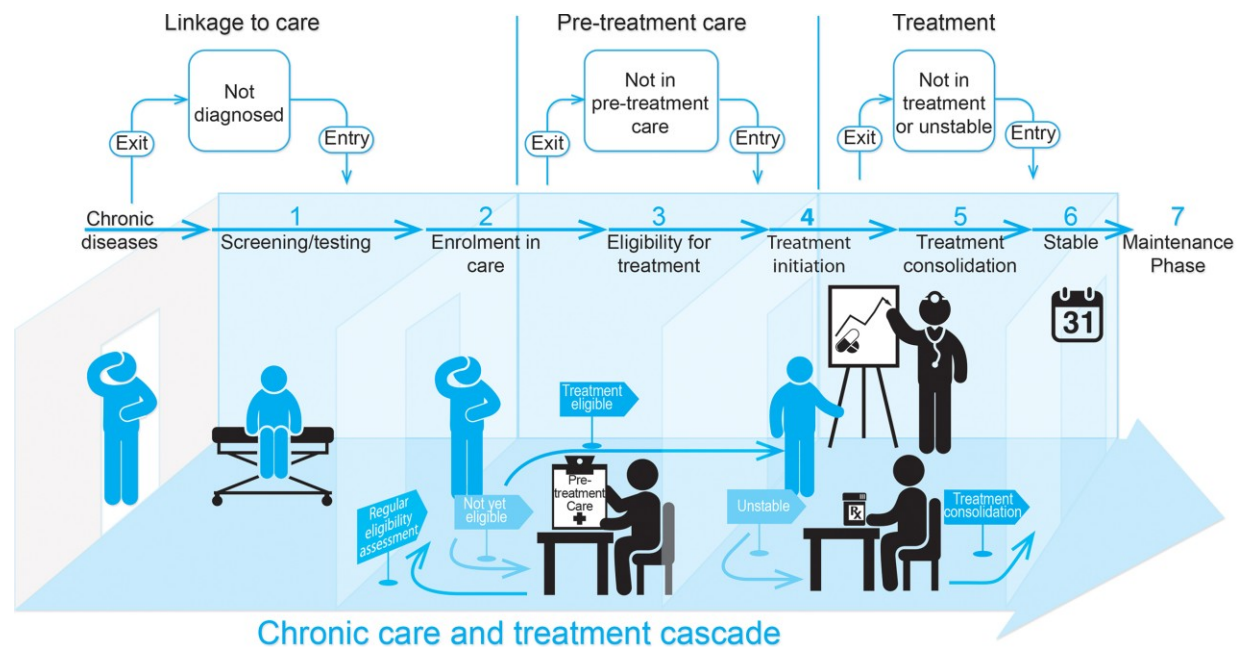
# Executive summary

## Context and rationale

It is reported from many country contexts and types of chronic diseases that non-adherence to prescription medication and monitoring schedules is widespread and costly<sup>1</sup>. It is also evident that the problem of non-adherence is multifactorial, with clients, caregivers, clinicians and the health care system as a whole playing a part. Effective interventions to improve adherence therefore need to adopt various approaches, involving several proven strategies that are tailored to clients' circumstances and support needs. While there is no universal formula to improve adherence and retention in all settings, several ingredients have been found to be essential for any well-designed intervention to improve medication adherence and retention in care, aptly described by Zullig and colleagues<sup>2</sup>. These include improving clients' understanding of their treatment, providing counselling and nurturing accountability, ensuring that there are tools and strategies to assist client self-monitoring, and reducing financial barriers to treatment.

With the advent of antiretroviral treatment (ART) and increased longevity of people living with HIV (PLHIV), HIV/AIDS is now considered a chronic condition. South Africa has seen an over ten-fold increase in the number of ART clients over the last decade, from just below 207,000 in 2005 to about 2.4 million people enrolled in the ART programme today. It is estimated that 52% of clients with a CD4 count of  $<350$  cells/mm<sup>3</sup> have been initiated on ART. In parallel with the expansion of the ART programme, more healthy people are being enrolled, ART clinics have dramatically increased ART client loads, and ART adherence has gradually declined. The continuum of HIV care happens across several stages of diagnosis and treatment provision, with the final stage being the management of the infection in a long-term ART maintenance phase (HIV care cascade). At each stage of the cascade, people may default due to a multitude of reasons; specific interventions can prevent this from happening, however. Likewise, re-entry into the continuum of care can be facilitated by specific measures (Figure 1).

Figure 1. Chronic care and treatment cascade



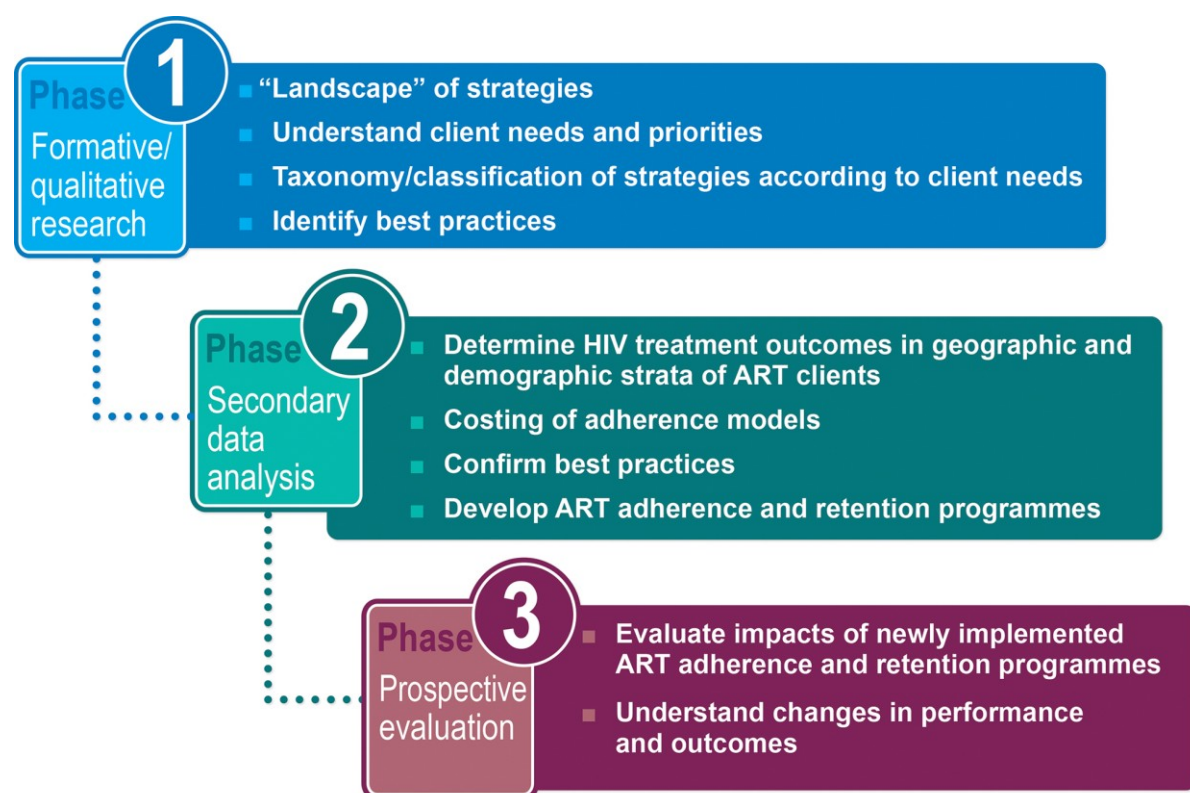
Source: Authors' own based on Kranzer et al. (2012)<sup>3</sup> and the South Africa draft adherence strategy.<sup>4</sup>

Note: Although TB is considered a chronic disease, it does not have a maintenance phase.

Retention rates among South African adults are declining over time, from an estimated 83% at 12 months to 68% at 48 months<sup>5</sup>. There is also evidence of a comparatively high mortality during the ART consolidation phase in South Africa compared to North America and Europe<sup>6</sup>. With further ambitious ART programme scale-up planned (which will also chiefly contribute to prevention of HIV transmission), the Government of South Africa is focusing on systematically addressing the leakages across the HIV care cascade, in the context of its broader adherence strategy for chronic diseases and its national primary health care (PHC) re-engineering policy (which aims to decentralise and decongest health facilities through ward-based PHC outreach teams, clinical specialist teams at the district level, and other measures).

This report presents the findings of the first phase of the “evaluation of interventions to increase the proportion of people living with HIV who are diagnosed, initiated on, adhering to and retained in HIV treatment and care in South Africa”, a collaborative effort between the National Department of Health of South Africa, the National Health Laboratory Service (NHLS) with the National Institute for Communicable Diseases (NICD), academic institutions and the World Bank. The evaluation seeks to answer which mechanisms, strategies and delivery models work best in different settings in South Africa to improve enrolment in ART after HIV diagnosis, adherence to ART and long-term retention in care. The evaluation is guided by a Steering Committee that is chaired by the National Department of Health. The evaluation design foresees three interlinked phases (Figure 2).

Figure 2. The phased design of the evaluation



Source: Concept note: Phase 1 of the South Africa evaluation of interventions to increase the proportion of people living with HIV who are diagnosed, initiated on, adhering to and retained in HIV treatment and care.

Phase 1 was implemented from July to September 2014. It consisted of: 1) a literature and data review including published and unpublished reports up to September 2014, and 2) semi-structured interviews with 177 key informants and 45 health care clients on existing ART adherence programmes, their implementation and results, different delivery models across the HIV care cascade, as well as the challenging and enabling factors for ART adherence experienced by care providers and clients. The interviews were conducted at national level and in five selected provinces (Gauteng, KwaZulu-Natal, Limpopo, North West, and Western Cape), and involved visits to 23 health facilities.

## Findings

### HIV diagnosis

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*“I got tested for HIV and for TB. I saw a counsellor and a dietician and a social worker. This was very useful.” HIV/TB client, on ART for two months, Gauteng Province*

*“Based on the high target set, counsellors will need to cater to more than 10 clients per day which could reduce the quality of counselling”. Key informant, KwaZulu-Natal Province*

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Uptake of HIV testing has increased in the general population in South Africa. However, over half of South Africans are still unaware of their HIV status. Importantly, only 38% of HIV positive men and 55% of HIV positive women know that they are living with HIV. Several supply side interventions contribute to HIV testing scale-up, boosting both first-time testing and regular testing. The most important initiatives are the decentralised, mobile and community based HIV counselling and testing (HCT) campaigns, provider-initiated counselling and testing (PICT), task-shifting (to lay counsellors), and the prevention of mother-to-child transmission (PMTCT) programme. The main limiting factors to HCT take-up are: low HCT demand from men, children and youth; poor referral and follow-up of people diagnosed positive at the community level; insufficient infrastructure to provide facility-based HCT; client-perceived quality issues such as waiting times, lack of privacy and quality of counselling; and the child consent procedure. Marketing and distribution of HIV self-test kits is currently very limited but research data suggest they are acceptable and easy to use.

Promising interventions and models are: further generalisation of the opt-out strategy at the clinic level; development of the regulatory context, marketing and easy-to-use HIV self-test kits; home-based multi-disease screening including for HIV; integration of immunisation and HIV testing for children; clinic-based multi-/chronic disease approaches which tap into the demands for TB and non-communicable diseases (NCD) diagnosis; demand creation and increasing HCT delivery capacity with lay counsellors, patient advocates, and traditional health practitioners. As already well known, any chosen HCT model must have a strong component of systematic and effective linkage to HIV care of people diagnosed HIV positive.

### Linkage to HIV care

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*“When people get tested positive for HIV they get sent to another room upstairs to do the CD4. Sometimes they see a big queue and they leave and say to themselves I will come back another day.” Key informant, KwaZulu-Natal Province*

*“You inherit a problem down the line if you don’t treat counselling properly right at the start.” Physician, Western Cape*

---

Between HIV diagnosis and the first assessment of ART eligibility, many HIV positive people are lost to the health system, with chief reasons being the secrecy around HIV diagnosis towards family and employers, geographical access to CD4 testing services, facility characteristics like long waiting times and insufficient human resources, and inability for people to take time off work and disclose their status to their employer. At this stage, the cascade experiences two significant leakages: people are lost between the positive HIV test and the CD4 count test (often 40% or more), and between the CD4 test and the return visit for the CD4 test result (loss across the two steps up to 65% in one study).

Point of care CD4 testing is promising but expensive and currently small scale. In addition, although it is associated with significant increases in getting ART eligibility assessed and in some studies also to get clients initiated on ART (if the test time is below 45 minutes



according to one study), this benefit must be outweighed by the fact that with the current climate of moving away from CD4 testing (and possibly one day to a test and treat strategy) investing in such technology may not be the most cost-effective option in the long-term. Data on point of care viral load testing suggest that this technology becomes more affordable with economy of scale and by using a higher viral load detection limit to avoid unnecessary treatment switches. Another potential strategy to scale up viral load testing is sample pooling. Overall, remedial interventions need to better link clients testing positive for HIV to care.

## Pre-ART care

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*“Tracking of patients is usually not very successful. People give wrong addresses or they move.” Key informant, Western Cape*

*“The dropout is massive. But do we have the resources to keep them? That is the big question.” Key informant, Western Cape*

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Pre-ART care (between the first assessment of ART eligibility and ART initiation) is not currently a focus in the South African public sector service provision. Poor record keeping and tracking of pre-ART clients combined with a lack of staff confidence in managing pre-ART clients are the main reported challenges. Pre-ART guidelines are integrated in other guidelines and are ‘not visible’. Weak pre-ART care is seen as a major contributor to overall ART adherence problems. However, the dynamics of pre-ART care will change with new eligibility criteria for ART in 2015, bringing ART initiation forward by on average of 2.5 years compared to the current CD4 350 threshold and therefore removing an extended pre-ART phase for many clients. In the future, if a test and treat strategy is implemented, the pre-ART phase may become obsolete, except for those who may refuse treatment.

Current promising interventions and models for pre-ART are: the Integrated Access to Care and Treatment Programme (I ACT), which is a six-module structured education and support programme for newly diagnosed PLHIV (though there is mixed feedback from clients and health care workers about its implementation); pre-ART support groups (which however appear to struggle to retain clients over time as no additional incentives can be offered); client tracking to prevent loss-to-follow-up (LTFU) and increase re-entry into pre-ART care; Isoniazid preventive therapy (IPT); and Wellness hubs, with late opening hours, which provide pregnancy screening, some family planning and have a role in the integrated management of chronic diseases.

## ART initiation

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*“There are many people who don’t want medication. They feel OK. They only come here when they are very ill.” Stable client on ART, Limpopo Province*

*“Willingness to initiate is a real marker of adherence later on.” Key informant, Western Cape*

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Scale-up of the ART programme currently translates into over 50,000 new initiations per month on average. Documented risk factors for low initiation rates or low ART uptake are

being male, young, unemployed, unmarried, and having low education levels, among others.

Elements of strategies and models with potential are: The MSF ART initiation counselling model, which is client-centred and accompanies the client post-initiation too; task-shifting and other health systems measures to increase ART initiation capacity; support initiatives for HIV positive pregnant women and mothers using mobile technology (MomConnect) and mentoring (Mother-to-Mother-to-be programme); and Cotrimoxazole provision. The announced change in treatment eligibility to a CD4 count of 500 cells/m<sup>3</sup> and lifelong ARV treatment for all HIV positive pregnant women from 2015 will lead to an accelerated growth of the ART programme.

### ART consolidation phase

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*“I used to be a cheese maker. I told my work that I was HIV positive and I got fired. We can never tell our work.” Male client on ART, Gauteng Province*

*“The viral load doesn’t lie.” Key informant, Western Cape*

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An increasing percentage of each annual ART cohort is already lost in the first six months; of the 2012/2013 treatment cohort, approximately 20% of initiated clients (or about 120,000 individuals) had dropped out of the cohort by six months. Client characteristics for non-adherence include food shortages, lack of education and alcohol abuse. System barriers include difficulties associated with long waiting times, distance to facilities, difficulties in transportation, and unsuitable opening hours for those who employed. Clients at facilities with larger client loads had increased attrition and were less likely to achieve virologic suppression. In addition, stigma around HIV is still a problem.

Elements of strategies and models with potential are: diagnosing the true reason for non-adherence and prescribing an individualised action plan; The MSF risk of treatment failure programme based on early detection of clients who are non-adherent, through a viral load measurement, and provision of tailored support, which leads to re-suppression in many clients (also run for paediatric clients); The Adherence Community Care Worker Programme providing home visits; a modified directly observed treatment approach; nutritional support for ART clients; text messaging; and the MSF counselling model designed for clients with drug-resistant TB. Fixed dose combination drugs have been shown to reduce adherence problems, and there is trial evidence that positive parenting, treatment buddies, and cash/in-kind support help ART adherence in adolescents. Effective, scalable interventions during treatment consolidation will prevent clients exiting the cascade, facilitating their re-entry, and prevent AIDS deaths.

### ART maintenance phase

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*“The clinic is opened on Saturdays, which really helps.” Stable client on ART, Limpopo Province*

*“We are taking the services to the people.” Key informant, Gauteng Province*

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Maintaining ART clients on treatment long-term is today a greater challenge than when the client load in the ART programme was small and fewer ‘healthy-feeling’ people were being initiated on treatment. The fear of disclosure and stigma of HIV infection and treatment permeates even at this phase of the HIV care cascade, with clients not wanting to be seen at clinics, not wanting to be followed-up at their homes, and providing wrong contact details. The current data systems cannot track clients as they transfer between treatment facilities due to labour migration or other personal reasons. In addition, there is a perception that remaining on treatment (thus increasing CD4 count) leads to the removal of a government grant.

Elements of strategies and models with potential: ART adherence clubs for adherent stable adults and other family members, the Khethimp'ilo Patient Advocates and Index Trailing Staff, and public-private partnerships for delivering medications to stable clients (MediPost, Pharmacy Direct, and the General Practitioner's Programme). The 3D model (decentralisation, dispersion and decongestion) is applied with decentralised HIV services (via down-referrals, for example) and the utilisation of community health workers with the aim to decongest health facilities and improve access to local care. As the TIER.net system is further rolled out, its potential, for instance to flag up those who missed their appointments or default, becomes more apparent. However, the data system's capacity is not yet matched by adequate manpower to actually trace clients in the field. Creating unique identifier numbers for ART clients and using mobile phone technology more widely at a national scale (beyond MomConnect) hold significant promise to address key challenges the ART programme is confronted with.

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*“With MomConnect women will be now be able to say, “I didn’t receive folic or I didn’t receive calcium”. They can also report if a sister was not good or was rude. So I think it will also be a part of service improvement. They will remind the sisters what they need.”*  
*Key informant, Limpopo Province*

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## Conclusions and recommendations

Conclusions and recommendations are presented according to four broad characteristics of well-designed interventions to improve adherence across all stages of the care cascade:

### AREA 1 | Improving clients’ understanding of their treatment

**Based on evidence reviewed in Phase 1, we conclude that:**

- Clients living with HIV may not have sufficient knowledge about the risks of non-adherence to ART and of delaying ART initiation once ART eligibility is confirmed.
- Nurses and counsellors often don’t have the time to comprehensively answer client questions.
- Counsellors’ training has been focused on HCT and not on ART adherence.
- It was apparent that many people are not familiar with the National AIDS Helpline.

- Client knowledge and understanding of their treatment is an essential ingredient for medication adherence in chronic diseases.
- International good practice in chronic diseases' management shows that for clients to adhere to any treatment intervention over time, it is prerequisite to determine clients' knowledge and perceptions, and to address their uncertainties. The educational content needs to be matched to the client's level of health and treatment literacy and their age group, and put into the appropriate context. Also, the education should be aligned with the client's readiness to make a behavioural change and build on the client's existing knowledge. The information should be reinforced by others in the provider team and messaging should be clear and harmonised

#### Recommendations for future treatment adherence models:

- 1 Information provided to clients must be focused on the individual needs of the client as well as on the understanding of "client typologies".
- 2 Clients must be able to access and exchange information anonymously and at convenient times and places.
- 3 Clients must obtain information on what to expect to happen from a specific scheduled appointment, and what services they have a right on.
- 4 The National AIDS Helpline can be better utilised to support client education, and could be complemented by a mobile application, which could also have a broader application to chronic diseases' management and treatment adherence.

### AREA 2 | Provide focused counselling and grow accountability

#### Based on evidence reviewed in Phase 1, we conclude that:

- Client-oriented counselling is important at all stages of the treatment and care cascade.
- Satisfied clients feel empowered from counselling sessions. Clients that do not receive the counselling support they need, specific to their circumstances, may default from treatment as a consequence.
- The timing, length, session composition and delivery characteristics of counselling sessions are perceived as important by practitioners and clients.
- When preparing ART eligible clients for ART initiation, it is beneficial to extend counselling into the ART consolidation phase to reduce delays in ART initiation.
- As the ART programme grows in scale, there is a danger that health staff-to-client ratios decrease and extended face-to-face counselling may not be feasible.
- There is an urgent need to make counselling for ART and other long-term treatment adherence as efficient as possible.

### Recommendations for future treatment adherence models:

- 5 Standardise adherence counselling approaches to have a predictable offer for clients, simplify service delivery, and facilitate quality assurance.
- 6 Revise the ART preparation counselling model based on lessons learnt, such as shifting some of the ART preparation counselling sessions to post-ART initiation (MSF ART initiation counselling model) to prevent unnecessary delays in ART initiation.
- 7 Identification of clients at risk of treatment failure early, through the use of viral load testing.
- 8 Improve data quality and systems across providers and facilities, thereby strengthening accountability.

### AREA 3 | Ensuring that there are tools and strategies to assist client self-monitoring

#### Based on evidence reviewed in Phase 1, we conclude that:

- There is much scope for increased self-monitoring by clients along the treatment and care cascade of HIV and other chronic diseases.
- Increased self-monitoring will support ART programme expansion and the scale-up of other chronic disease programmes, in which decongestion of facilities and decentralisation of care functions are regarded as essential.
- The deployment of community health workers can facilitate self-monitoring by clients, and further technical development on data carriers and shared data platforms will contribute to initiatives for increased self-monitoring.
- The concept of self-monitoring also fits with calls for empowerment of clients and makes people accountable for their health and medication-taking behaviours
- Self-monitoring is especially promising in client populations who are stable on their treatment regimen (HIV and other chronic conditions) and are treatment literate.
- The international literature regards self-monitoring as an essential tool to improve adherence and also to inform health providers about client behaviours and health needs. The collection of client data is a rapidly developing field, and encompasses several metrics of which some can be collected remotely, depending on the chronic condition of interest and availability of technology. Medication adherence data such as prescription renewal and medication diaries are promising, as are NCD indicators such as blood pressure or glucose levels.



- Data collected through self-monitoring gives clients direct feedback and it can be shared with health providers. Importantly, the data can also be reported to health care systems for client tracking and incorporation into the electronic health record.

#### Recommendations for future treatment adherence models:

- 9 Use self-monitoring approaches in a model specifically designed for the needs of “healthy feeling” people: those who are diagnosed early who are not yet eligible for ART; those initiated early on ART; those who are stable and well on ART; those with chronic conditions and who are asymptomatic such as those with hypertension, for example.
- 10 Data systems could link self-monitoring data and health service data and allow bi-directional data exchange.

### AREA 4: Reducing barriers to diagnosis, treatment and care

#### Based on evidence reviewed in Phase 1, we conclude that:

- There are barriers to access to services across the treatment and care continuum, from testing and linkage to care and treatment to the stable management of a chronic condition. Although there are clinical differences between diseases, barriers to care—such as long queues and poor education—and managing and overcoming barriers to care—such as the need to reduce client opportunity costs and to provide adherence support—for HIV and other communicable diseases are similar to non-communicable chronic diseases.
- In ART, some barriers are mounting as the programme expands in scale, for instance through increased opportunity costs of clinic visits due to waiting times.
- Models must be designed to mitigate barriers to testing, treatment and chronic care, as stigma persists and client volumes rise.
- Decentralisation, integration of HIV and chronic disease care and self-management of conditions are important measures. The Integrated Chronic Disease Model (ICDM), for example, aims to provide client-centred care in an integrated manner and promote “assisted” self-management of chronic diseases through the PHC ward-based outreach teams. It is important to bear in mind that although decentralisation of services is key to improving scale-up and coverage, decentralised services must not be disconnected from facility-based services, potentially leading to parallel services. Decentralised services (and the associated data) must be a continuum or arm of the whole service delivery package.
- Even in the well-established PMTCT programme there are barriers; late ANC booking was highlighted as a major factor in late HIV testing and ART initiation for PMTCT for pregnant women. Initiatives that promote women empowerment, such as community

dialogues, mentoring and mHealth platforms like MomConnect, seem well placed to help address barriers.

### Recommendations for future treatment adherence models:

- 11** Better ‘diagnosis’ of non-adherence and ‘prescribe’ individualised ‘treatment’ of non-adherence
- 12** HIV self-testing as a low-threshold method and an integral part of the ART scale-up model.
- 13** Point -of-care technology as a means to increase convenience of testing for clients and reduce barriers to biological monitoring. With regards to POC CD4 technology, it is important to consider that scaling up such POC CD4 technology may not be the best investment in the long term, particularly as the current climate suggests a move to universal testing and treatment may be a reality in the future, which would render CD4 testing unnecessary.

Developing models which combine elements of the above - improving clients’ understanding of their treatments, providing focused counselling and nurturing accountability, making tools available which empower clients to self-monitor, and reducing barriers across the HIV cascade—is one step towards maintaining and potentially increasing ART adherence in South Africa. Models that can provide synergistic effects across different conditions and diseases will be especially valuable for public health aims and for ART as a public good. Components of the models must be personalised to the clients’ situations—even in a very large ART programme. The intensity of resources and technology used should be scaled to meet an individual client’s needs. Some clients will require intensive, individualised in-person counselling, others may respond just as well or better with infrequent face to face contact and instead with reminders via mobile phone. Matching intervention delivery and intensity with clients’ needs is the goal for South Africa’s adherence programmes, which must be scalable and sustainable.

## Outlook: Phases 2 and 3 of the impact evaluation

### Phase 2

The second phase of the evaluation will consist of two separate analyses:

- A.** Secondary analysis of laboratory test data to determine HIV treatment outcomes in geographic and demographic strata of ART clients to guide Phase 3 focus
- B.** Micro-costing of four major adherence counselling models: I ACT model (for newly diagnosed); MSF ART initiation counselling model (ART preparation); ART adherence club model (for those who are stable and adherent); the enhanced adherence model (for non-adherence)

Phases 1 and 2 will help pinpoint which ART adherence and retention interventions should be tested in which ART facilities and demographics in Phase 3.

### Phase 3

This phase consists of prospectively evaluating adherence interventions to improve ART outcomes in specific types of clients, and to learn what works more generally in supporting medication adherence.

Preliminary discussions suggest the following interventions to be evaluated for impact in Phase 3:

- A. Prospective impact evaluation of selected strategies to improve ART adherence and retention in care** – using evidence from the Phase 2 micro-costing activity and the Phase 2 laboratory data analysis, as well as Phase 1 insights into the available adherence counselling and club options for different client categories and their specific ART support needs. It is likely to include a combination of approaches in adherence counselling and support via clubs, decentralised drug delivery, staff training for better client experiences, and availability of VL data for client monitoring and clinic management purposes.
- B. The impact of a mHealth intervention on ART adherence and retention in care of adolescents/youths who have been enrolled in the ART programme** – focusing on younger ART clients, a group known to have a problem of low ART adherence (but high levels of use of electronic media and mobile technology). This age group has generally high levels of sexual activity and partner change and makes this a priority population for improving ART adherence for treatment and prevention alike. One element of the intervention will be the communication of test results via mobile technology. The intervention would be a tailored app that allows downloading of all prior test results, as well as new results, in a format that is easy to interpret (results with date, normal values and a short explanation of what the test measures). This evaluation responds to several criteria identified in the previous section on client knowledge and understanding, targeting individualised adherence effort where it is needed, harnessing mHealth technology and strengthening bi-directional communication, and client self-monitoring and empowerment.
- C. Case study and programme evaluation to understand the Integrated Chronic Disease Management model and its scope to address and improve medication adherence** – the model has been piloted in 42 health facilities in three select districts and requires assessment. This evaluation activity involves costing and participatory review of the model, the implementation experience and what can be learnt from it for South Africa's National Adherence Strategy.

# Chapter 1. Introduction

## 1.1 Background

South Africa has the largest antiretroviral therapy (ART) programme in the world with approximately 2.4 million people living with HIV (PLHIV) enrolled in the ART programme out of a total of approximately 6.5 PLHIV in the country (See Table 1).<sup>7</sup>

Since the programme began in 2004, the exponential and rapid scale-up of ART for PLHIV is very commendable. Between 2009 and 2012 alone, the expansion of ART services resulted in a four-fold increase in the number of people receiving ART<sup>8</sup>. It is estimated that over the last five years, 79% of clients with a CD4 count less than 200 cells/mm<sup>3</sup> and 52% of those with CD4<350 cells/mm<sup>3</sup> were initiated on ART.<sup>9</sup> However, with the rapid increase in the number of people on treatment, there has also been a noticeable decline in adherence rates, and retention of clients in long-term care.

Consequently, reported client attrition rates are high, with 88% of ART clients still in care at the same facility 24 months after initiating ART<sup>10</sup>. A recently conducted systematic review by Rosen et al., (2014) reported declining retention rates among a cohort of ART clients from approximately 83% at 12 months to 68% at 48 months.<sup>5</sup> Another analysis carried out by Boulle et al., (2014) shows that in South Africa the mortality rate on ART has been comparatively high in the early phase of treatment, but then flattens and becomes comparable to rates reported in countries in North America and Europe.<sup>6</sup> While this is partly due to later ART initiation in the South African context (especially in the early years of the programme), it does suggest poor ART adherence especially in the treatment consolidation phase.

The World Health Organization (WHO) defines adherence as “the extent to which a person’s behaviour corresponds with agreed recommendations from a health care provider”<sup>1</sup>, and thus includes all stages of the care cascade from HIV diagnosis and ART initiation to adherence to drug regimens and care instructions and retention in HIV care. Alongside this definition, retention in HIV care refers to “the continuous engagement from diagnosis in a package of prevention, treatment, support and care services.”<sup>11</sup> In other words, it encompasses diagnosis and “the moment of initial engagement in care, when a person with HIV is linked successfully to services, to assessment for eligibility, initiation on ART and retention in lifelong ART care.”<sup>11</sup> As South Africa prepares to change its ART eligibility criteria for the general population (from a CD4 count of <350 cells/mm<sup>3</sup> to <500 cells/mm<sup>3</sup>), and to switch to option B+ for HIV positive pregnant women in January 2015, the ART programme is expected to expand further. Concurrently, the profile of ART clients is expected to change, as people with higher CD4 counts who are generally healthier and may not feel sick will be initiated on ART. These clients may experience side effects and start to feel sick as a result of their medication.

Because of these reasons, it is even more essential today to address the issues impacting on client adherence and retention in life-long care at every step of the cascade, in order to maximise the full benefits of ART, including the attainment of an undetectable viral load and to simultaneously reduce the risk of transmission.<sup>12,13</sup>

Table 1. Key statistics South Africa

Indicator	Value	Year	Source
<b>Socio-demographics</b>			
Population	52.98 million	2013	(1)
% urban	62%	2012	(3)
% population living below national poverty line	23%	2006	(1)
GNI per capita, current	7,190	2013	(1)
% population unemployed	25.5%	Q2/2014	(2)
Under 5 mortality rate (per 1 000 live births)	53	2010	(2)
Maternal deaths per 100 000 live births	140 (85–210)	2013	(5)
Total fertility rate	2.4	2012	(3)
Life expectancy at birth, years	59	2012	(3)
Annual number of births	1,102,300	2012	(7)
Adult risk factors			
▪ Diabetic (HbA1c>6.5%)	11.0% (F), 7.9% (M)	2012	(8)
▪ Hypertensive	10.2%	2012	(8)
▪ Hypertensive or hypertension treatment	31.8%	2012	(8)
▪ Obese (BMI 30+)	39.2% (F), 10.6% (M)	2012	(8)
▪ Daily tobacco smoking	16.2%	2012	(8)
Cellular phone subscribers per 100 population	89.2%	2011	(2)
<b>Health service</b>			
Physicians per 10 000 population	7.8	2006	(3)
Nurses/midwives per 10 000 population	49	2006	(3)
% births attended by skilled health personnel	94.3%	2009	(2)
<b>HIV and TB</b>			
HIV prevalence, adults aged 15–49	19.1% (18.1%–19.9%)	2013	(6)
Number of people living with HIV of which children aged 0–14	6,300,000 (6,000,000–6,500,000) 360,000 (320,000–390,000)	2013	(6)
AIDS-related deaths	200,000 (170,000–220,000)	2013	(6)
Number on ART			
HIV+ people screened for TB	949,800	2012	(4)
HIV+ people provided with IPT	369,747	2012	(4)

Indicator	Value	Year	Source
TB case notification	296,996 (new) 52,586 (retreatment)	2012	(4)
Laboratory-confirmed MDR-TB cases	15,419	2012	(4)
TB clients with known HIV status	84%	2012	(4)
HIV+ TB clients	65%	2012	(4)
HIV+ TB clients on ART	54%	2012	(4)

Sources: Accessed 1 October, 2014: (1) World Bank data base: [http://data.worldbank.org/country/south-africa#cp\\_wdi](http://data.worldbank.org/country/south-africa#cp_wdi); (2) Statistics South Africa: <http://beta2.statssa.gov.za/>; (3) WHO country profile: <http://www.who.int/gho/countries/zaf.pdf?ua=1>; (4) Global TB report: [http://apps.who.int/iris/bitstream/10665/91355/1/9789241564656\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/91355/1/9789241564656_eng.pdf); (5) Global health observatory, maternal mortality country profile South Africa: [http://www.who.int/gho/maternal\\_health/countries/zaf.pdf?ua=1](http://www.who.int/gho/maternal_health/countries/zaf.pdf?ua=1); (6) UNAIDS key country data: <http://www.unaids.org/en/regionscountries/countries/southafrica/>; (7) UNICEF country statistics: [http://www.unicef.org/infobycountry/southafrica\\_statistics.html](http://www.unicef.org/infobycountry/southafrica_statistics.html); (8) National Health and Nutrition Examination Survey, 2012: <http://www.hsrr.ac.za/en/research-outputs/view/6493>

## 1.2 Rationale for evaluation

The global strategy to end AIDS by 2030 by attaining HIV testing and treatment targets (90-90-90)<sup>14</sup> is highly relevant to South Africa. The country contributed key evidence to the promotion of these ambitious 2020 targets, which are thought to lead to the end of AIDS a decade later. Modelling studies on treatment expansion scenarios in South Africa suggest highest health and economic benefits when ART is available to all PLHIV<sup>15</sup>, with a potential to avert up to 3.3 million new HIV infections in South Africa through 2050 and save US\$ 30 billion. There is also evidence of the immediacy of impact if a 90-90-90 approach is pursued<sup>16</sup>. In South Africa, estimates indicate that the country would reach the break-even point within a decade after scaling up treatment to all PLHIV, regardless of their CD4 count<sup>15</sup>. Data from KwaZulu-Natal show that the HIV prevention benefits of ART are apparent at the population level. Every 1% increase in ART coverage has been found to yield a 1.1% reduction in HIV incidence<sup>17</sup>. These findings are similar to those reported in the Canadian province of British Columbia, where every 1% increase in the number of people with suppressed virus has been associated with a 1.2% reduction in estimated HIV incidence<sup>18</sup>.

### Rationale 1: South African data suggest a growing problem of retention in HIV care over time

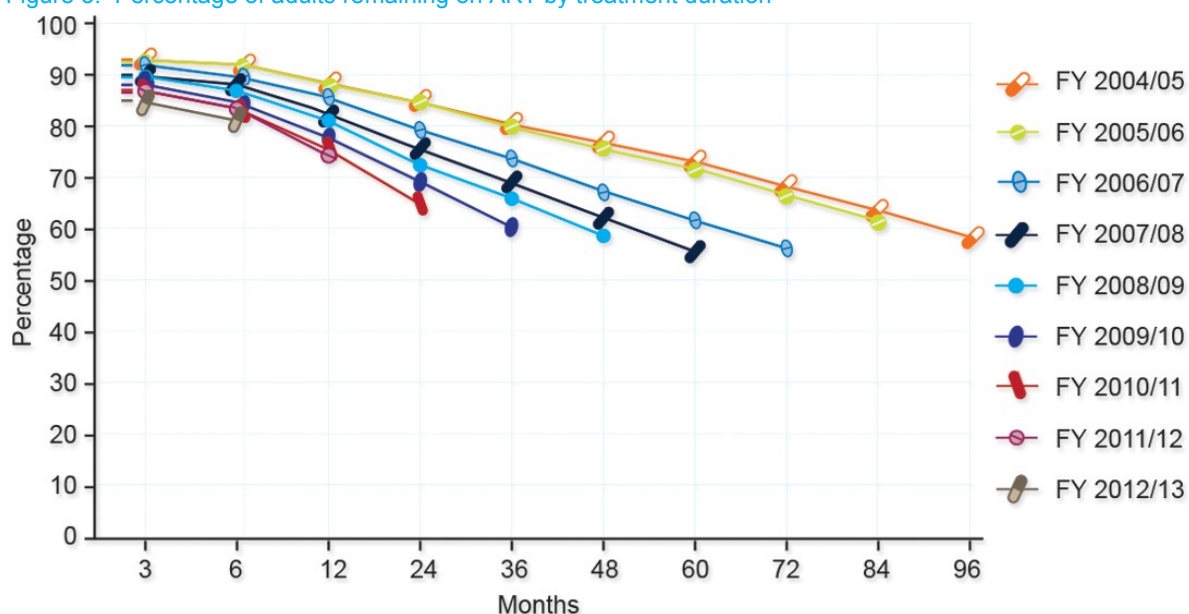
Retention rates of ART clients are reportedly deteriorating over the years with newly initiated ART clients at a higher risk of being lost than earlier cohorts of ART clients since the ART programme began about a decade ago.<sup>19,20</sup> Following the increase in the size of the cohort of clients initiated on ART, there is an observed decline in the number of HIV positive clients remaining on treatment (Figure 3). A review carried out by Rosen and Fox (2014) reported varying retention rates across the same time periods in select low-and middle-income countries (LMICs) (Figure 4)<sup>5</sup>. While some countries such as Malawi and Kenya reported relatively

poorer retention rates of  $\leq 60\%$  at three years others such as Uganda and Vietnam maintained better rates ( $\geq 70\%$ ).

One possible factor that could be contributing to South Africa's declining retention rates over time include overburdening of the healthcare system leading to congestion and longer waiting times in facilities. A study by Cornell et al., found that as facilities' client loads expanded, the number of clients lost to follow up (LTFU) increased, from 14% at 12 months to 29% at 36 months (cumulative LTFU)<sup>19</sup>. Similarly, a recent study assessing treatment outcomes over the last seven years at Johannesburg's Themba Lethu Clinic, a facility with one of the largest HIV treatment programmes in the world, reported an increase in the proportion of clients LTFU after 12 months, from 8.5% in 2004 to 12.1% in 2009 [risk ratio (RR) 1.42, 95% confidence interval (CI) 1.18–1.71; mortality rate: 16%].<sup>20</sup> However, Rosen and Fox (2014) report in a recently conducted review that increasing access to ARVs in the public health facilities (thus facilitating self-transferring), and a lack of a well-functioning electronic tracking system to keep track of clients who move around different facilities, makes it difficult to provide an accurate estimate of the number of clients who are actually defaulting on treatment and not retained in care.<sup>5</sup> The increasing number of HIV service points over the years means it's relatively easy for clients to self-transfer between facilities—to those that may be geographically closer or that offer a preferred service—particularly in the context of long bureaucratic processes in official transfer procedures. These self-transfers are usually unable to be tracked in current data systems. Therefore this may lead to an overestimate of loss to follow-up from one facility and an overestimate of new ART initiations in those facilities where clients self-transfer to.

Overall, findings from these studies confirm the challenges that the ART programme is experiencing with regards to retaining clients in lifelong care, and emphasises the need for effective interventions to improve retention rates.

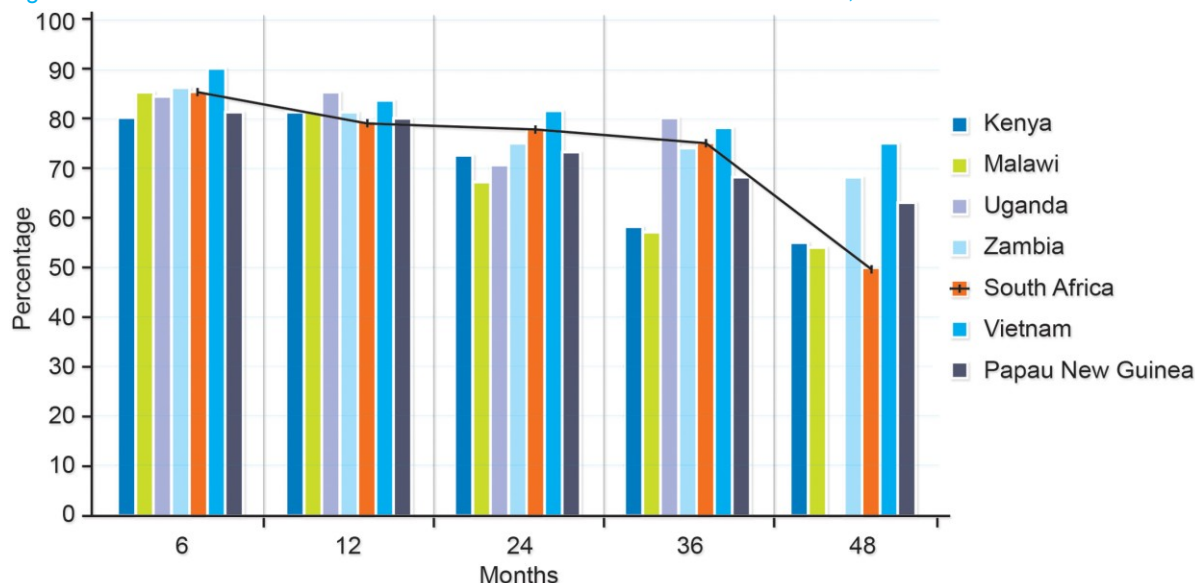
Figure 3. Percentage of adults remaining on ART by treatment duration



Source: Department of Health Government of South Africa. Directorate: Monitoring and Evaluation. Antiretroviral Health Indicators Update. Issue III<sup>10</sup>



Figure 4. Retention rates over time in seven low- and middle-income countries, 2008–13



Source: Fox and Rosen (2013)<sup>21</sup>

## Rationale 2: the cost effectiveness of HIV treatment is maximised when ART adherence is higher than 95%

The National DOH indicator update reports low rates of adherence among adults, with only around 35% virally suppressed at 48 months).<sup>10</sup> Lower adherence is reported among rural populations, those experiencing discrimination, and those with higher depression scores.<sup>22</sup> To obtain successful treatment outcomes, the current treatment for HIV/AIDS requires medication adherence levels of greater than 95%.<sup>23</sup> This level is essential to fully suppress viral replication, improve clinical outcomes, and reduce the risk of HIV transmission and the development of drug resistance. Given the importance of increasing ART adherence and retention rates in South Africa, especially at a time when plans are underway to expand treatment access and as the government is currently in the process of finalising its draft adherence and retention in care strategies for all chronic diseases (including HIV/AIDS), it becomes even more critical to prioritise the design and implementation of best practices at a national scale. The government of South Africa has thus indicated that it wishes to undertake an evaluation of different strategies through which to improve ART adherence and retention in public sector health facilities and community-based organisations (CBOs) providing ART services.

## Rationale 3: what we learn about HIV treatment initiation, adherence and retention can also apply to other chronic disease management in South Africa

In 2010, it was estimated that half of all years of life lost in South Africa are due to HIV and TB, and that this percentage follows a decreasing trend over time.<sup>24</sup> The decline in death from HIV/AIDS over the years and the increase in life expectancy warrant the need to improve services for other chronic conditions, which are associated with aging populations, including

diabetes, hypertension, and mental health disorders. It is reported that cases of co-morbidity with at least one other chronic condition continue to rise among those living with HIV.<sup>25–27</sup> In the case of TB, the most commonly occurring chronic disease in PLHIV, South Africa is reported to have the third largest case number in the world (after India and China) at 993 cases per 100,000 population<sup>28</sup>. There are an estimated 400,000 new cases of TB treated per year, out of which 15,000 are diagnosed as multi-drug resistant TB<sup>29</sup>. Among the cohort of HIV positive clients initiated on ART, more than 54% are co-infected with TB<sup>8</sup>. In addition, the major cause of the worsening TB epidemic in the country is attributed to poor adherence, and clients not being initiated on, or lost to treatment.<sup>8</sup>

Research shows that lessons learnt from the scale-up of the ART programme over the years can be extended to address other chronic client groups that present with similar needs for client-centred long-term care, including the engagements of adherence counsellors to promote optimal medication adherence, task-shifting, and support from community health workers (CHW) at the primary care level.<sup>26</sup> This can thus be seen to have influenced the government's recent decision to move towards an Integrated Chronic Diseases Management (ICDM) approach for the delivery of care to clients. The ICDM is a model of managed care that provides for integrated prevention, treatment and care of clients with chronic communicable and non-communicable diseases at the PHC level. It is designed to help with the early detection of chronic conditions and their appropriate management. The ICDM resonates with the 90-90-90 concept, which, if applied to other chronic diseases, would translate to the following:

- 90% of all people living with a chronic disease should know their status
- 90% of all those with a positive diagnosis should be on treatment
- 90% of those on treatment have high medication adherence and the desired clinical or infection benefits

If successfully implemented, such a strategy would result in almost three-quarters of people with a chronic condition (73%) to be on sustained treatment, deriving the full benefits of high medication adherence. For infectious diseases like HIV and TB, the positive externalities would come to full fruition by significantly decreasing transmission in the community. This concept highlights the importance of effective case finding, treatment monitoring and obtaining the desired treatment outcomes (viral suppression in the case of HIV treatment, negative smear in the case of TB and blood pressure within normal ranges in the case of hypertension, for example).

Underpinning the move towards the ICDM model is the government's primary health care (PHC) reengineering strategy, adopted in November 2010. The idea behind the PHC reengineering is to utilise the services of a ward-based outreach team (WBOT) as part of the primary healthcare system for the provision of better care to clients. The WBOT, consisting of professional nurses, enrolled nurses and CHWs, is complemented by the District Clinical Specialist Team (DCST), and the Integrated School Health Programme (ISHP) that together provide primary health care services in each health district. Such an approach is likened to the

provision of quality services to clients via a 3D- model: “decentralisation” of care from hospitals to clinics, “decongestion” of clinics; and dispersion” of CHWs for home-based care in the communities (see results chapters).

Findings from the Joint review of the HIV, TB, and prevention of mother to child transmission (PMTCT) programmes in South Africa shows that a functional integration of HIV, TB and PMTCT services exists, especially at the primary care level. However, diagnosis and management of non-communicable diseases (NCD) for PLHIV are still yet to be implemented in most HIV care/ART settings.<sup>28</sup> A major recommendation of the joint review is around the routine use of cascade analysis at all levels of the care cascade to pinpoint intervention points for adherence and to enforce the long term retention of chronic clients in life-long care. The cascade of care analysis has been adapted for the research conducted in Phase 1 of the evaluation and to communicate research findings reported in the results chapter.

## 1.3 The three phases of the impact evaluation

The overarching objective of this evaluation is to assess the impact of specific interventions to increase the proportion of diagnosed PLHIV who are initiated on, adhere to and are retained in HIV treatment and care in South Africa.

### 1.3.1 Impact Evaluation Question

The evaluation seeks to identify which mechanisms / methods (or combination of methods) work best in different settings to improve:

- Enrolment in ART (after HIV diagnosis)
- Adherence to ART
- Retention in care

### 1.3.2 Impact Evaluation Phases and Methods

In accordance with the identified needs, the evaluation process has been sub-divided into three phases, briefly described below.

**Phase 1:** To conduct a literature review of published and unpublished data and reports from Sub-Saharan Africa; and to interview key informants on existing adherence and retention in care programmes (and their impact) for HIV/AIDS and other chronic conditions. This review enables the development of a taxonomy of programmes, and defines best practices.

**Phase 2:** To conduct a secondary analysis of laboratory test data to determine HIV treatment outcomes in geographic and demographic strata of ART clients. In addition, micro-costing of four major adherence models—identified from this Phase 1 evaluation—will also be carried out. These four models are: I ACT model (for newly diagnosed clients); currently being evaluated); MSF ART initiation counselling model (ART preparation); ART adherence club model (for those

who are stable and adherent); and the MSF ‘enhanced adherence counselling’ model (for unstable and non-adherent clients). This costing will complement the HE2RO work on the overall costing of the proposed South Africa Adherence Strategy. Phases 1 and 2 will help pinpoint which adherence and retention interventions should be tested in Phase 3.

**Phase 3:** Once potential good practices have been defined and confirmed, a prospective study of adherence/retention programmes will be performed after adherence guidelines have been finalised and new programmes have been implemented in selected areas. Analysis of outcome data will be repeated to identify best and worst performers. The survey of facilities and communities will be repeated to determine programme implementation and other variables contributing to the observed changes. Further information is provided at the end of the report in the Outlook section.

## 1.4 Objectives of Phase 1 formative research study

The aim of Phase 1 (a formative research study that comprised of a literature review, key informant interviews and focus group discussions with clients) was to:

- Identify current and innovative best practice models of care to improve treatment initiation at appropriate CD4 counts, adherence to ART and retention in PLHIV care in South Africa, as well as information about the scope, coverage, quality and perceived impacts of such interventions
- Identify and understand the challenging and enabling factors in implementing and scaling up such models of care
- Review evidence and collect additional information about the perceptions around the quality of HIV testing, pre-ART and ART care from PLHIV, and to determine issues that, if addressed from the PLHIV client’s perspective, could improve adherence and retention.

Findings from Phase 1 are intended to help inform the development of the government’s broader adherence and retention strategy for the purpose of achieving its overarching objectives of: 1) proper linkage of clients to care upon diagnosis; 2) ensure all clients with chronic conditions, and on treatment are adhering to their treatment regimen; and 3) retention of clients in lifelong care.

## Chapter 2. Methodology

The study team conducted interviews with key informants in five provinces—Gauteng, Limpopo, Western Cape, North West and KwaZulu-Natal –, which were purposefully chosen by the Department of Health to provide a range of settings. These interviews were conducted using pre-designed interview guides (provided in the Annex), to help identify current and promising practices in client adherence support and retention. Interviews with key informants were also conducted at the National Department of Health. In total, the research team interviewed 177 key informants from a wide range of backgrounds including government representatives from the national, provincial and district departments of health, academics, public and NGO programme managers, physicians, nurses, pharmacists, counsellors, community health care workers, support group facilitators, and data capturers. The research team also had informal discussions with about 45 clients to gain a better understanding of their needs and preferences.

Concurrent to the qualitative research study, the research team conducted a literature review to help contextualise the findings and to provide supporting evidence for findings from the field. In addition to targeted searches, according to research question, the research team carried out a literature review of the published and unpublished literature and reports. The team searched the peer-reviewed literature databases - Medline (via PubMed) and Embase (via Ovid) - for articles and reviews that described, evaluated and reported the impact of different interventions or models of care on ART adherence and retention. The following key search terms were utilised: antiretroviral therapy; medication adherence; patient compliance; retention; loss to follow-up; attrition; South Africa. In order to ensure the review was time efficient (but still sensitive to identify innovative and promising approaches), primary studies were limited to those published between 2007 and 2014. The following conference websites were also searched: International Aids Society (IAS 2012) and Conference on Retroviruses and Opportunistic Infections (CROI 2014). In addition, bibliographies of relevant articles were searched. For other published articles and reports as well as unpublished (grey) literature, the team searched online websites and databases with the above key words, including the NDOH, PEPFAR, PEPFAR partners, World Bank, UNAIDS, WHO and other relevant websites and databases. Key informants were also asked if they knew of any relevant literature to help ensure a comprehensive review could be realised.

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## Chapter 3. Results: HIV diagnosis

### 3.1 Key points

- There is an increase in the uptake of HIV counselling and testing (HCT) among the general population. Nonetheless, more than half of South Africans are still unaware of their HIV status; only 38% of HIV positive men and 55% of HIV positive women know that they are living with HIV.<sup>7</sup>
- Several supply side interventions contribute to HCT scale-up, boosting both first-time testing and repeat testing. These include the decentralised/community based HCT campaigns using lay counsellors, provider-initiated HCT (PICT), and opt-out testing under the PMTCT programme.
- Limitations are the low HCT demand from men, children and youth, as well as supply-side barriers for these groups such as lack of youth or male friendly services and unsuitable clinic opening hours for these groups. Other limitations include poor referral and follow-up of people diagnosed positive at community level, insufficient infrastructure to provide facility-based HCT, client-perceived quality issues (waiting times, privacy, counselling) and the child consent procedure.
- Promising interventions and utilised models to increase HIV testing are: development of the regulatory context and marketing of HIV self-test kits; home-based multi-disease screening including HIV; clinic-based multi-/chronic disease approaches which tap into demand for TB and NCD diagnosis; demand creation and increasing HCT delivery capacity with lay counsellors, client advocates, and traditional health practitioners.
- Marketing and distribution of HIV self-test kits is currently very limited but research data suggest they are acceptable and easy to use.

Any chosen HCT model must have a strong component of systematic and effective linkage to care of people diagnosed HIV positive.

### 3.2 Uptake of HCT

The National HIV Counselling and Testing (HCT) campaign, launched in April 2010, saw more than 20 million South Africans tested for HIV over the course of 20 months with more than 2.1 million people diagnosed with HIV and 400,000 being initiated on ART<sup>30</sup>. A further 9 million South Africans tested for HIV between April 2012 and March 2013. The National HCT campaign has rolled out HCT services to more than 90% of public health facilities. By 2012, an estimated 55% of HIV positive women and 38% of HIV positive men knew their status, according to the 2012 South African National HIV Prevalence, Incidence and Behaviour



Survey.<sup>7</sup> Overall, the survey found that 92% of clients were aware of a location near their home where they could test for HIV. **The survey also showed that, in 2012, a significantly higher proportion of people have been tested for HIV in the past 12 months (66%) compared to 2008 (49%) (p<0.001).**

In January 2015, more clients will become eligible for ART as the South African government implements the 2013 WHO guidelines to initiate clients with a CD4 cell count of <500 cells/mm<sup>3</sup> on ART and maintain pregnant women on ART for life, regardless of their CD4 count (option B+).<sup>31</sup> In order to achieve the government's objectives of providing universal access to ART and HIV care for all qualifying individuals, it remains critical to further improve the uptake of regular HIV testing. To do this, both supply and demand for HIV testing need to be increased through existing and innovative approaches, including provider-initiated counselling and testing (PICT) and self-motivated HIV counselling and testing. Evidence from a systematic review, carried out by Suthar et al., and published in 2013, on the effectiveness of community-based approaches<sup>a</sup> to improve HIV testing rates, suggests that community-based approaches increase HCT uptake in participants (n= 5,832; RR= 10.65, 95% CI = 6.27–18.08), the proportion of first-time testers (RR 1.23, 95% CI = 1.06–1.42), and obtain a lower positivity rate (RR 0.59, 95% CI 0.37–0.96), relative to facility-based approaches.<sup>32</sup>

Increasing the uptake of HIV testing services provided at health facilities and in the community means more PLHIV can enter the cascade of HIV care. The current practice in South Africa with regards to provision of facility-based HCT is to make use of lay counsellors, who are employed by the DOH or by non-governmental organisations. **Barriers to testing presented during key informant interviews are well aligned with those commonly cited in existing literature, such as long waiting queues at health facilities, transportation costs, stigma-related discrimination and disclosure issues.**<sup>33</sup> Overall, testing of clients was not reported to be a major challenge in the clinics and provinces visited.

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*“Testing is not a problem here, but dealing with the result is”. Key informant, KwaZulu-Natal Province*

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However, key informants interviews carried out in the five provinces visited highlighted poor uptake of HCT services among men. Key informants reported that men usually present late to the clinics, when they are ill. This finding is in line with existing evidence showing that only 38% and 36% of HIV positive and HIV negative men are aware of their HIV status compared to 55% and 45% of HIV positive and negative females respectively (p<0.001).<sup>7</sup> In addition, key informants and clients suggested that having male staff deliver the HIV test may improve the uptake of testing among male clients.

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*“Men refuse to test. If they do test, they refuse to accept the results and shop around. They only return back in the later stage, usually when they are very sick”. Key Informant, Edendale Hospital, KwaZulu-Natal Province*

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<sup>a</sup> Community-based approaches reported to increase HCT uptake include door-to-door testing, index testing, mobile testing, self-testing, and workplace testing.

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*“When I told him I’m HIV positive, he said ‘then it means I’m also positive so I don’t need to go to the clinic’”. Focus Group Discussion (FGD) with clients from Amogelang support group, North West Province*

*“If it was a man giving the test, it will influence my decision to test, 100% yes”. Male client, FGD with clients, North West Province*

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### 3.3 Testing for Children

The requirement of a signed consent form to test children for HIV is perceived to be a major bottleneck, hindering the process of testing for children aged 2–15 years old. According to a key informant at the NDOH, this is a challenge in all nine provinces. It was reported that as children get older, their biological parents are not always readily accessible to provide consent to the test. Cited reasons for the unavailability of biological parents were diverse and include parents’ work-related commitments. As a mitigation effort, the country’s immunisation services are capitalised upon as a way of getting more children tested. However, in cases where non-biological parents (other family members or care-givers) bring in children to get immunised, the issue of the obtaining a signed consent form from a biological parent still persists. In this case, **community caregivers (CCG) are utilised to follow up in the households**. Nonetheless, the lack of a proven method of linking clients tested in the community to care still poses a huge challenge.

### 3.4 Models and interventions

As part of a concerted effort to increase the uptake of HCT services in South Africa, the government has prioritised the funding of **regular HCT campaigns** and adopted the **PICT strategy** for all clients visiting facilities, resulting in increased uptake of HIV testing. The country’s first HCT campaign, for example, saw almost 14 million individuals being tested for HIV throughout the country<sup>34</sup>. More recently, a campaign in Gauteng Province led to a six-fold increase in the number of individuals tested, from 15,000 in February 2013 to 90,000 in July 2014.<sup>b</sup> In the last quarter, KwaZulu-Natal Province also reported an increase in the number of individuals tested for HIV, with current estimates at 240,000 (72% of the province’s set target).<sup>c</sup> These results are also attributable to HCT campaigns, which were held in the 37 municipal wards. For PICT, it was reported that only 3% of clients were offered an HIV test in facilities in April 2010, which increased to 8% by June 2011<sup>34</sup>. While the research team found that clinics in South Africa were implementing PICT, nurses and physicians usually referred clients to the counsellors to conduct the HIV test. Another model used to improve HIV testing uptake in South Africa is the utilisation of lay counsellors to conduct door-to-door home testing, which is becoming more acceptable in the communities. A study carried out by Naik et al., in KwaZulu-

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<sup>b</sup> Data derived from a key informant interview in Gauteng Province.

<sup>c</sup> Data derived from a key informant interview in KwaZulu-Natal Province. The set target for the province is to test at least 90% of the population by 2015.

Natal province reported a 75% acceptance rate of home-based testing among study participants (n=6757).<sup>35</sup>

Despite these recorded achievements, some systems issues impacting on the uptake of HCT services have been raised at provinces' sub-district nerve centre meetings.<sup>d</sup> These system issues include overworking of health care workers (HCW) and long queues at facilities resulting in long waiting times, which affect the client-perceived quality of the service provided.

There are reported differences in HCT uptake between provinces, with some doing better than others. Key informants in Khayelitsha's sub-structure office, for example, suggested that uptake of HCT was not a problem in Western Cape province, as these services are offered both in the facilities and at the decentralised level, such as in the wellness hubs (see chapter 5), which provides not only HCT but also testing for TB, diabetes, and hypertension. In North West Province, on the other hand, key informants highlighted that the province was lagging behind in attaining set testing targets, including workplace testing programme targets.

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*"Based on the high target set, counsellors will need to cater to more than ten clients per day, which could reduce the quality of counselling." Key informant, KwaZulu-Natal Province*

*"We don't meet the target for HCT in the North West, we've never met it in all the four districts". Focus Group Discussions with key informants, North West Province.*

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A key district partner NGO called Broadreach is working in the North West province on a situational analysis of the lower numbers of HCT uptake and ART coverage, particularly among those aged younger than 15 years. However, as it was pointed out during focus group discussions with key informants, it is important to consider other factors that might be impacting the under-performance of the province. For instance, it was reported that with an emphasis on reporting HCT uptake among those aged 15–49 years, key populations such as pregnant women in the PMTCT programme are not included in the head count (regardless of their age) in addition to those who fall outside this age category. This means that testing numbers of such groups are not included in the statistics used in the calculation of provincial performance. Additionally, information from focus group discussions with HIV positive clients in North West province highlight the need for **improved collaborations with clients and assistance to support groups to improve uptake of HCT services in the province.**

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*"When people hear I'm HIV positive and see me in the campaigns, they will listen to me, and would like to know what I'm doing that is keeping me beautiful. The DOH should involve us in these campaigns". Female client living with HIV, Amogelang Support Group, North West Province*

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Although overall testing uptake in South Africa has increased significantly, a major gap that was reported is linkage to care post testing, with an urgent need to particularly strengthen linkage to care after community-based HIV testing. This includes improving referral systems during campaigns. Key informant interviews highlighted that it was often unclear who attended

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<sup>d</sup> Sub-district nerve centre meetings serve as a space for provinces to report on recorded successes and challenges with meeting their HCT target.

facilities (and where they attended) and who was lost to follow-up following HIV testing. The recently held Joint review on HIV, PMTCT, and TB supports these findings, reporting that clear strategies to link newly diagnosed HIV positive individuals to healthcare services were not defined.<sup>28</sup> A study assessing the quality and standardisation of training provided to lay counsellors who conduct HIV tests attributes the low rates of linkages to care post-testing to the poor quality of counselling provided to clients during testing.<sup>36</sup>

Another issue raised during focus group discussions with provincial partners in the North West Province is the extent to which the DOH is looking to implement the opt-out strategy,<sup>e</sup> which has been utilised by other countries to improve uptake of HIV testing.<sup>37</sup>

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*“With an opt-out strategy everyone is encouraged to test except those who explicitly say no. This was a strong message at the HIV/TB conference. Other countries are doing it, and it seems to be working very well”. FGDs with Provincial Partners, North West Province*

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Using an opt-out strategy it is the responsibility of the HCW to initiate HCT for their clients as part of routine care, with clients maintaining their right to refuse testing. A study assessing the impact of the opt-out strategy on the uptake of HCT for TB clients in the Eastern Cape province showed a significant positive association between the use of the opt-out strategy and HCT uptake; 20.2% of clients attending an intervention clinic (opt-out strategy) were tested for HIV compared to 6.5% of clients attending a control clinic (standard VCT) (n=754, p=0.009).<sup>38</sup> A cluster-controlled trial carried out in the Western Cape province showed that the use of the opt-out strategy for HCT among clients presenting with other sexually transmitted infections (STI) led to a significant increase in the proportion of new STI clients tested for HIV and the proportion of new STI clients offered HIV testing, as well improving consistency in the performance of clinics.<sup>39</sup> However, the study suggests that the use of the opt-out strategy, although effective, is not sufficient, and must be complemented with other operative interventions in order to attain high levels of post-test linkages into the cascade of care.<sup>38</sup>

#### 3.4.1 Community-based, decentralised HIV testing within the 3D model of service delivery

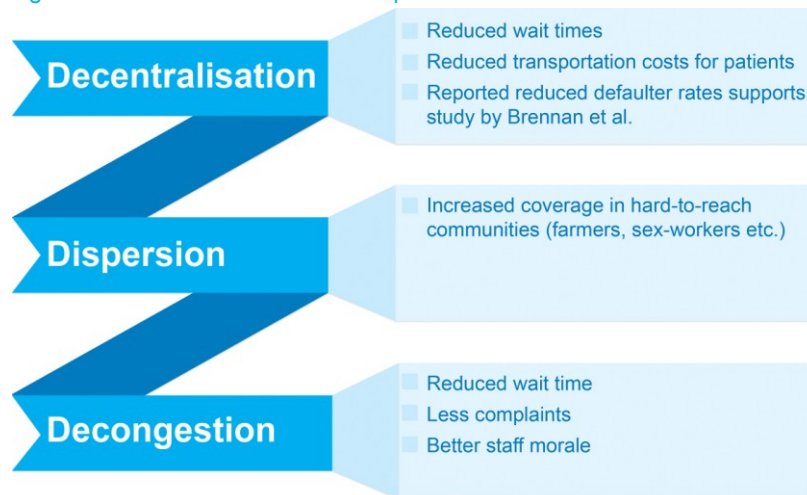
The decentralisation of HIV services via down-referrals from hospitals to clinics, and from clinics to the communities via the dispersion of CHW, is a commonly employed tactic that is being used to decongest health facilities, and improve uptake of HIV services at every step of the cascade (Figure 5). A systematic review carried out by Mwai et al (2013) reported that the use of CHWs for the delivery of HIV services helps to enhance the reach, uptake and quality of HIV services, as well as the dignity, quality of life and retention in care of PLHIV<sup>40</sup>. One approach for the utilisation of CHWs is the Philani intervention, a programme that makes use of CHWs to provide home-based HIV care within the communities. The CHWs used mobile phones for data collection and monitoring, and as a supervisory tool. A randomised control trial assessing the impact of the programme reported significantly enhanced maternal and child health among pregnant women (HIV positive and negative), including an increase in exclusive

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<sup>e</sup> According to the WHO, the term “opt-out” means that a client offered PICT must explicitly refuse an HIV test.

breastfeeding at six months compared to those receiving standard of care (odds ratio 3.59,  $p < 0.001$ ). There were no differences between the intervention group and those receiving standard of care in asking a sexual partner to test and having a baby test for HIV at six weeks, however<sup>41</sup>.

Figure 5. The 3D model for service provision



Source: Authors graph based on findings from the literature review.

As part of efforts by the government to integrate the screening and management of other chronic diseases with existing HIV services, the NDOH has set in place a new mandate to hire CHWs who report directly to the clinics on the status of clients; past practices have been to utilise the services of NGO-funded CHWs who report to the NGOs. As of July 1 2014, four out of five provinces visited (excluding the Western Cape) have rolled out this method of utilising DOH-funded CHWs as part of a decentralisation effort.



*"We are taking the services to the people. Attendance registers used to monitor CHWs works; the CHWs are now reporting directly to the nurses on the status of patients", Key informant, Gauteng Province*

Notwithstanding, there are still challenges reported about the health system's capacity for better HIV-TB management, from the point of diagnosis to retention of clients at every step of the cascade.<sup>42</sup> Key informants reported on the fragmentation in care of co-infected clients, with newly diagnosed clients having limited knowledge about where to receive these two services. Other issues reported to be impacting on HIV diagnosis are discussed below.

## Limited infrastructure

In the facilities, lack of adequate spaces for HCT commonly emerged as a major challenge with offering HCT services. In some facilities, two or more counsellors are assigned to a counselling room, which bring to light issues with client privacy and disclosure in addition to reductions in healthcare worker morale.

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*“The sisters are working in the dressing room. I have to provide my office space when there are more than 20 patients waiting”. Key informant, KwaZulu-Natal Province*

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Other methods are being adopted by the DOH to overcome space limitations and to reduce decongestion in the facilities, such as the use of gazebos in the communities. However, HIV testing in the community is also reported to face some challenges, as clients who test positive are often lost at this stage because point-of-care (POC) CD4 count is unavailable, and clients are usually referred to a facility for their result. Processing time for CD4 count results is reported to take up to a week on average, depending on the facility, and most times clients don't follow up with the referrals provided (see Chapter 4 on linkage to care).

## Quality assurance of HIV testing

The general practice for HCT is for lay counsellors to carry out HIV tests for clients, and a professionally trained NIMART nurse (trained for nurse-initiated and managed antiretroviral treatment) confirms the test results. If there is discordancy in interpretation of results, an ELISA (enzyme-linked immunosorbent assay) test is carried out. However, it was highlighted that there are some quality issues with newly procured HIV test kits, with reported low levels of sensitivity and specificity. According to interviewed key informants, this is currently under scrutiny as part of an on-going research by the Medical University of South Africa (MEDUNSA).

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*“A patient may be positive and on treatment, but when the same patient is tested with the test kit, the results are negative”. Key informant, Gauteng Province*

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### 3.4.2 Featured model: iTEACH Traditional Health Practitioner and HIV-TB Warrior's programme

As part of on-going efforts to improve integration of the delivery of HIV and TB services, an organisation called iTEACH (Integration of TB in Education and Care for HIV/AIDS), based in Edendale Hospital, a government-run hospital in KwaZulu-Natal, works closely with traditional health practitioners (THPs). iTEACH trains THPs on how to carry out quality HCT services, screening for TB, and referring clients to the health facilities. The first graduation class of THPs from the programme was in 2009, with each graduate awarded a certificate of competency as a trained counsellor. The THPs helped in the development of a client referral form for traditional healers to refer clients to health facilities. In 2010, Edendale hospital launched the provision of HCT by certified THPs, and by 2011, the programme expanded to reach the other districts in the province (Uthukela, Ilembe, and Uthungulu district) with new graduates of THPs providing HCT in the facilities. In addition, the provision of customised HCT services by THPs in the community has helped increase uptake of HCT services in very hard to reach areas such



as in farming communities. The evaluation of the programme's success are based on a measure of knowledge and retention rates; pre-and post-training exams; practicums, and role-plays; and 50 observed HCT sessions carried out by each THPs with all of these information logged, using a THP passport, which helps with keeping track of individual performance.

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*"THPs are not held to the same standard as other trained counsellors. We hold them to a higher standard, which is necessary because of incorrect views of THPs". Presentation from key informant, Edendale Hospital, KwaZulu-Natal*

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The use of traditional healers was reported to be widespread, according to key informants and discussions with clients. In addition, key informants highlighted how traditional healers were underutilised and are willing to work with the health system.

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*"Many people use traditional healers. I had a meeting with them last year in August. We talked about cervical screening and maternal health. We asked them please don't give pregnant women things. But after that meeting they didn't come again, they insisted on having their transport paid and to have food when they were here. For them to come here, as long as we can get them here they will come. They want to cooperate. If you phone them now they will come tomorrow. They are open to working with us. But we are helpless. People trust the healers. Before the patients come here they go to the healers first. They won't come here straight. And after here, they will go back to the healers. So if we can work with them and teach them, then they will refer patients early to us. We will benefit more than them if we work with them." Key informant, Limpopo Province*

*"There are a lot of people who go to the sangoma." Key informant, KwaZulu-Natal*

*"We talk also to those who don't adhere. They usually come by ambulance very sick. We can see from their files that they were on treatment last year. When we ask them why they stopped they tell you they went to a traditional healer. They said they wanted to come back to clinic once the therapy from the traditional healer was finished." Key informant, Limpopo Province*

*"Around two in ten go to traditional healers. But the defaulters will go there. Working with them will help us. When we do a campaign we invite them. The healers want to come to help. They learn, they help, they also do the tests during these campaigns. We need them. Because they are one of our extended arm for our healthcare. Whatever it is, HIV, TB or something else, they have to know." Key informant, Limpopo Province*

*"Everyone goes to traditional healers. They prefer to drink muti than take medications." Stable client on ART, Limpopo Province*

*"So many people here don't believe that HIV exists. They think it's things to do with witches. Everyone goes to traditional healers." Stable client on ART, Limpopo Province*

*"Lots of people go to traditional healers because they trust them more." Stable client on ART, Limpopo Province*

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Another core initiative of iTEACH is the use of TB warriors in district hospital wards to improve TB testing, and treatment outcomes via integration into existing HIV programmes, in a facility that sees about 300 new cases of TB per month. To strengthen the care of TB clients at Edendale, iTEACH helped reduce the fragmentation in services, and the number of HCWs managing the care of TB clients decreased from approximately seven HCWs per client to an integrated package of care provided by one HCW. This approach of using fewer staff assigned



very concrete responsibilities led to improvements in care and close supervision of TB clients by a physician, including a reported increase in laboratory testing and confirmation of test results of clients with suspected cases of TB who had their sputum collected (from 13% in 2005 to 85%).<sup>f</sup> The success of the TB warriors programme has led to expansion of the programme for the delivery of HIV services to clients using HIV warriors.

### 3.4.3 Other initiatives to improve collaborations with Traditional Practitioners

Operation "Sukuma Sakhe" (translated to "people working together") comprises of people from different sectors working together in war rooms in each ward. Operation "Sukuma Sakhe" works directly with community care givers (CCGs) in the communities, and carry out household profiling to research on the issues related to health and financing housing, among others. These issues are presented at the war-room and are referred to the applicable sector to be resolved. The operation was implemented in KwaZulu-Natal Province about three years ago, and collaborates closely with traditional healers who serve as members of the team.

To further improve testing in Umgungundlovu district, an operational plan to undergo outreach in the community was developed. An operation called "Mbo" (Zulu word) is carried out, and involves *"a congregation of people with services taken to the people"*. To obtain proper buy-in from the communities, local politicians/heads are closely involved in the process. Services offered include HCT, and preventive therapy (Isoniazid preventive therapy (IPT) for those who test positive before referral to clinic); routine TB screening; and blood pressure/hypertension screening. Specific interventions targeted at men in the district include the provision of HCT services after work hours and weekends to reach those working during the day. In addition, a men's forum is organised in the district, which is chaired by a district chaplain to discuss issues that specifically affect men, and address how these issues can be resolved.

### 3.4.4 Khethimp'ilo Patient Advocates and Index Trailing Staff

The Khethimp'ilo (KP) model makes use of Patient Advocates (PAs) from the identified catchment areas of clients to upscale the number of clients who get tested in the communities, and to improve the adherence of all clients on ART. In Umsunduzi sub-district of KwaZulu-Natal province, there are a total of 90 PAs catering to approximately 12,000 clients that receive services in clinics located mostly in sub-urban areas, with six of these clinics in rural areas.<sup>g</sup> Generally, PAs can be assigned to about 280 clients classified as stable (see Chapter 8 on maintenance phase), and VIP clients.<sup>h</sup> Every client living with HIV is matched to a PA immediately after testing, and is tasked with referring these newly diagnosed clients to the clinics for a CD4 count. PAs provide pre-test counselling to the households of clients and encourage family members to consider testing for HIV, other STIs, and screening for TB. Additionally, "Index trailing" of clients is conducted by a total of 19 KP staff that work closely

<sup>f</sup> Data derived from key informant interview in KwaZulu-Natal

<sup>g</sup> Data derived from key informant interview on the community service cluster

<sup>h</sup> VIP clients under the KP model include HIV+ pregnant women, children and adolescents

with PAs to further encourage testing in the communities and households. Once a client is tested and diagnosed positive, a KP staff who serves as a representative of the DOH, trails clients back into their family after obtaining permission from the client to conduct household visits (the typical mode of PA interaction with clients). Upon obtaining consent via receipt of a signed consent form, family members are tested, and the test results are provided to the data capturers in the facilities for entry into the system.

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*“Our patients are attached to KP PAs for life once paired with a PA. Most of our patients sign the consent forms; those that don’t sign say it’s because they are always at work”. Key informant, KwaZulu-Natal Province*

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KP PAs also encourage early bookings of pregnant women in the PMTCT programme by working closely with quality nurse mentors. For ANC clients that test HIV positive, they are immediately started on ART the same day, preferably on fixed-dose combination (FDC) if there are no contraindications.<sup>i</sup> PAs closely follow pregnant women and monitor their status post-delivery. They also trace clients with infants who have a positive PCR test (polymerase chain reaction) result, which is highly prioritised to understand what areas need to be strengthened to prevent future PCR-positive cases among infants.

The use of KP PAs has been expanded to reach eight high prevalence districts in four provinces, with the scale up of the programme reported to be a result of the success rates recorded in the provision of HIV services to clients. Findings from a study by Fatti et al reported an increased likelihood of viral load suppression at six months in adults clients initiated on ART (adjusted odds ratio (aOR) 1.49 [95% CI: 1.40–1.58]), and at any given time point in children (aOR 1.60; 95% CI: 1.35–1.89;  $P < 0.0001$ ); and a 35% reduction in mortality in adults (aHR: 0.65; 95% CI: 0.59–72). Data on the impact of PAs on the uptake of HIV testing was not reported.<sup>43,44</sup>

However, some insights provided on the model are in relation to the recently increasing turnover of PAs, especially those employed from January 2014. This turnover rate is attributable by a key informant to the insufficient stipend paid to PAs, especially serving as a demotivating factor for those who have no passion for the work thus leading to the development of a weak relationship with clients.

### 3.4.5 MomConnect

MomConnect, described in more detail in Chapter 6, is a partnership between the National DOH and UNICEF, which seeks to register, via mobile phones, all pregnant women in the country. It serves to equip pregnant women with all mother and child health services and provide them with a channel to report on poor services. The first pilot of the programme was carried out in KwaZulu-Natal province, and has recently been rolled-out nationwide. The system serves to remind mothers to frequently utilise ANC services, including enrolment in early HIV services during pregnancy and post-pregnancy. There is a high optimism with

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<sup>i</sup> Contraindications include toxicity of FDC level that may be harmful to the client.

regards to the national roll out of MomConnect (endorsed and rolled out by the NDOH in August 2014) especially in regards to ensuring that identified HIV positive pregnant women enrol early into the PMTCT programme.

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*“The PMTCT programme is working 100%. I have two children and they are HIV negative, they must be encouraged about exclusive breast-feeding”. Client stable on ART, North West province*

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### 3.4.6 Featured model: HIV self-testing

HIV self-testing is a process whereby a person who wants to know his or her HIV status collects a specimen, performs a test and interprets the test result in private. In 2012, the United States Food and Drug Administration (FDA) approved OraQuick as the first testing kit available in the United States market. In South Africa, the distribution and use of self-test kits are reported to be largely unregulated due to the current legal and policy framework in the country.<sup>45</sup> To regulate the distribution of self-test kits, the South African pharmacy council enforced the Good Pharmacy Practice (GPP) standards. However, it is reported that because the GPP does not apply to general supermarkets and corner cafes, it inhibits the implementation of accurate well-regulated self-test kits such as OraQuick.<sup>45</sup>

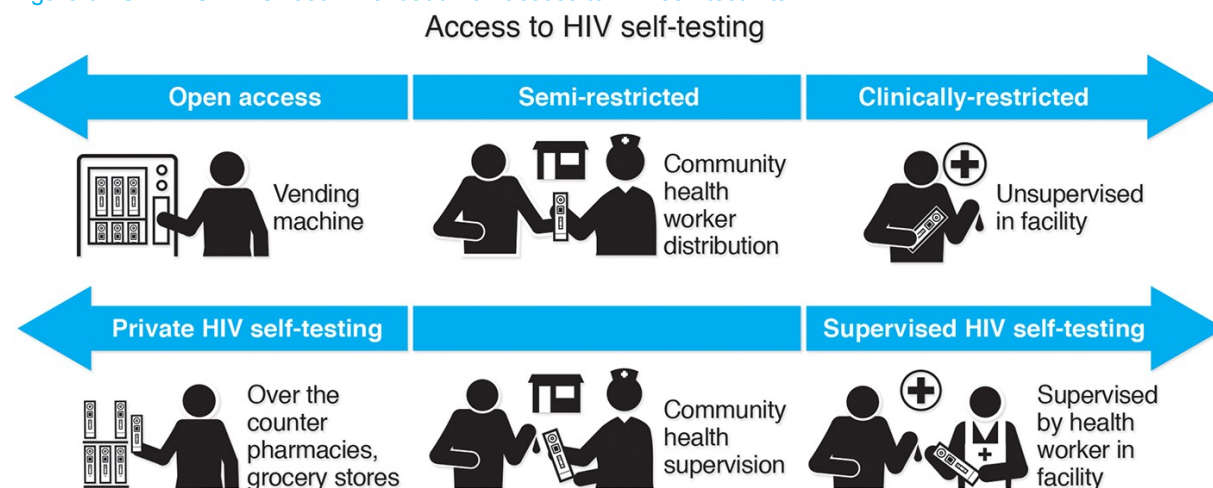
Results from a cross-sectional study carried out by iTEACH in KwaZulu-Natal showed that 99% of laypersons that performed an HIV test using a self-test kit obtained a valid self-test result that was properly interpreted, with 98% understanding next steps of care.<sup>46j</sup> Some potential benefits of the availability of self-test kits could translate into increased access to HIV testing especially for populations with recorded low uptake, such as men, adolescents, and pregnant women who normally do not utilise ANC services and are thus unaware of their HIV status, as well as other key populations (men who have sex with men, transgender people, sex workers and people who inject drugs).<sup>47,48</sup> However, it is also important to consider alongside the benefits, some risks with the use of self-test kits. A review recently carried out by Napierala et al., (2013) highlights that a major risk to consider with the use of self-test kits is in depriving clients access to a range of critical support services including pre- and post-test counseling.<sup>49</sup>

A UNAIDS update on the feasibility of self-test kits recommends provision of pre- and post-test support, provided by healthcare workers, for individuals that test in private via distribution in health facilities, and other vendor distribution channels that are closely supervised and monitored within the communities<sup>48</sup> (Figure 6). Other factors to consider include target population, and the best settings for distribution i.e., rural, urban or peri-urban.

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<sup>j</sup> Data derived from I-teach on the self-testing pilot study in KwaZulu-Natal represent preliminary results; study abstract were presented at the 2014 IAS Conference.

Figure 6. UNAIDS/WHO recommendation on access to HIV self-test kits



Source: Reproduced based on figure from UNAIDS (2014): A short technical update on self-testing for HIV<sup>48</sup>.

The models described above hold some potential to improve uptake of testing. However, emphasis must be placed on the need for HCT models that are developed alongside an effective platform for the linkage of newly diagnosed clients to HIV care along every step of the treatment cascade.

## Chapter 4. Results: Linkage to HIV care

### 4.1 Key points

- Between HIV diagnosis and the first assessment of ART eligibility, many clients living with HIV are lost from the HIV care system, with chief reasons cited being the secrecy around HIV diagnosis towards family and employers, geographical access to CD4 testing services, facility characteristics like long waiting times and insufficient human resources, and the inability to people to take time off work (due to unsuitable opening hours) and disclose at work.
- The cascade experiences two significant leakages: people lost between the positive HIV test and the CD4 test (often 40% or more), and people lost between the CD4 test and the return visit for the CD4 test result (loss across the two steps up to 65%).
- Point of care CD4 testing is promising but expensive and currently small scale. In addition, although it is associated with significant increases in getting ART eligibility assessed, and in some studies also to get clients initiated on ART (if the test time is below 45 minutes according to one study), this benefit must be balanced by questions of whether this would warrant investment. The current climate of moving towards scale-up of viral load assessment and earlier treatment may mean that the buying point of CD4 test technology is not the best use of limited programme resources.
- Data on point of care viral load testing suggest that this technology becomes more affordable with economy of scale and by using a higher viral detection limit to avoid unnecessary treatment switches.
- Overall, remedial interventions need to better link clients testing positive for HIV to care.

### 4.2 Data on linkage to HIV care

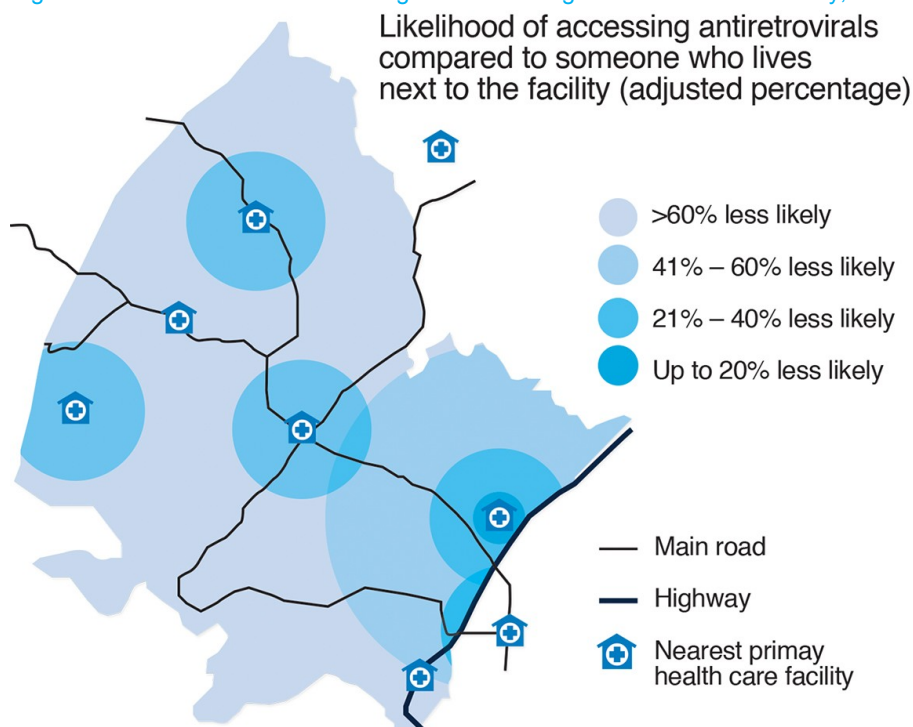
There are three distinct stages between HIV diagnosis and commencement of ART<sup>50,51</sup>. “Linkage to HIV care” is the first stage, beginning at HIV diagnosis and ending with the first assessment of ART eligibility (covered in this chapter). The two other stages, “pre-ART care” and “ART initiation”, are addressed in chapters 5 and 6 respectively.

Common to all three of these stages are “barriers” at both the supply and the demand side. A systematic review<sup>52</sup>, with more than a third (38%) of included studies coming from South Africa, found the most commonly cited barriers to linkage to care, retention in pre-ART care and initiation of ART to be:

1. transportation costs and distance to facilities;

In KwaZulu-Natal, for example, rates of treatment utilisation decline as the distance an individual needs to travel to obtain treatment services increases (Figure 7)<sup>53</sup>.

Figure 7. The likelihood of accessing ART according to distance to the facility, KwaZulu-Natal



Source: Reproduced based on UNAIDS (2013), “Location, location: Connecting people faster to HIV services”.

Similarly, a prospective cohort study conducted in Free State Province found that the odds of initiating ART decreased with increasing distance to ART initiation site ( $p < 0.001$  for trend)<sup>54</sup>.

2. stigma and fear of disclosure; and
3. long waiting times at the clinic, which is associated with reported human resource challenges.<sup>55</sup>

In addition, a variety of other barriers, including not being able to take time off work to attend facilities during working hours, and having a higher CD4 count are commonly reported.<sup>52,56</sup>

#### Phase 1 key informant interviews confirm the evidence from the literature:

*“We are losing a lot of people after testing. This is because of the stigma. There is also a problem with disclosure of status, which is across the board. Acceptance in the community is poor and there is still a lot of stigma around HIV.” Key informant, Gauteng Province*

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*“Most of our patients live in villages, some of them live 20 to 25 km away from the facilities. You can’t access this by foot. You must have money to access it. Transport, distance and unemployment are all challenges.” Key informant, Limpopo province*

*“When people get tested positive for HIV they get sent to another room upstairs to do the CD4. Sometimes they see a big queue and they leave and say to themselves, “I will come back another day””. Key informant, KwaZulu-Natal Province*

*“Most of our patients work. They find it difficult to take time off work.” Key informant, KwaZulu-Natal Province*

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**Informal discussions with clients highlighted similar barriers.** The majority of clients also reported knowing many people in their community who do not wish to come to the clinics due to perceived poor quality care, long queues and due to the fact that they feel well and therefore don’t believe that they need to access care and initiate treatment:

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*“There are many people here who don’t want to come to take treatment. It’s because of the stigma. They don’t want people to know they are HIV positive.” Stable client on ART, Limpopo Province*

*“Transport is a problem. It is difficult for us to come here so much.” Client on ART, Gauteng Province*

*“I work every day and it is hard to take time off work. I can’t tell my work that I am positive. I am afraid. I haven’t disclosed and I would never want to disclose my status.” Stable client on ART, Gauteng Province*

*“My brother doesn’t want treatment. He would rather die than wait in the queue for someone to help him.” Stable client on ART, Gauteng Province*

*“There are many people who don’t want medication. They feel OK. They only come here when they are very ill.” Stable client on ART, Limpopo Province*

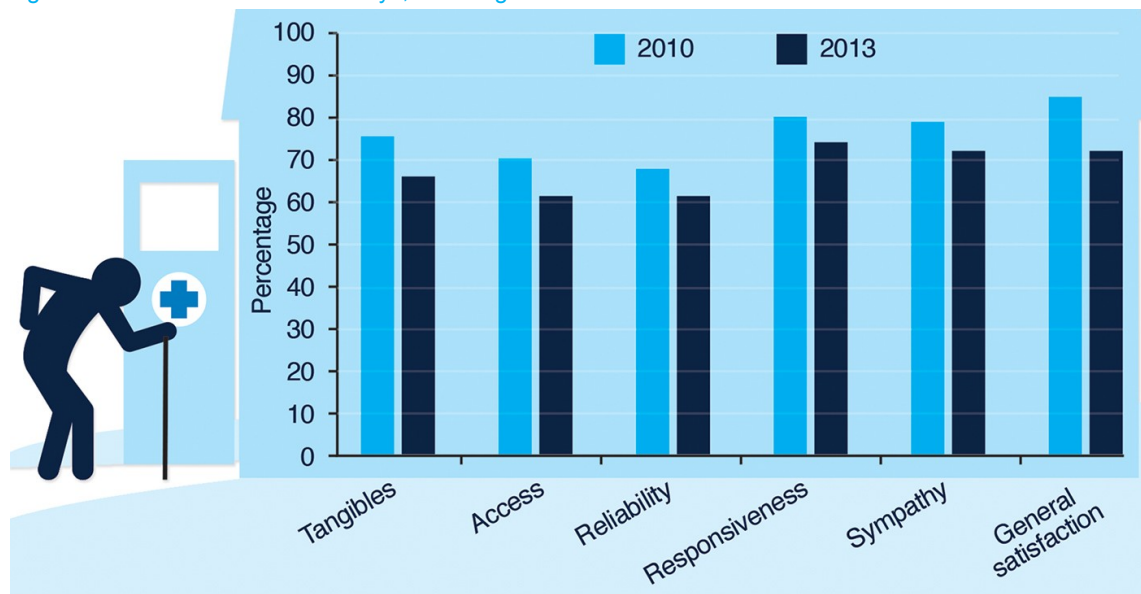
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Known key client factors that can predict poor uptake of the relevant diagnostic and care services are alcohol abuse, homelessness and non-adherence to other long-term treatment regimens<sup>57, 58</sup>.

Data from client satisfaction surveys, carried out in 2010 and 2013, were observed on the white board of one visited facility during the team’s fieldwork. The surveys show declining satisfaction among clients in the visited facility between 2010 and 2013 (Figure 8).



Figure 8. Client Satisfaction Surveys, Gauteng Province



Source: White board, public-sector facility visited in Gauteng Province

While HIV testing strategies have been extremely successful in increasing testing rates in both facilities and communities, linking those who are diagnosed HIV positive to care is generally poor. As one key informant stated in Western Cape, many clients are lost post-testing, as linkage to care was never prioritised. A study conducted in a hospital in Durban found that almost half (45%) of those who tested positive for HIV did not receive a CD4 test.<sup>59</sup> CD4 testing was offered, at a cost of 90 Rand (around US\$ 8) in an adjoining building, three hundred metres away from the HIV testing site. Those who lived more than 10 km away from the hospital, had a history of TB, and who had been referred for HIV testing by a healthcare provider rather than self-referring were less likely to return to have CD4 test. In addition, of those that did return for a CD4 test, 15% did not return for the result.<sup>59</sup> On the other hand, a study from Cape Town found poor linkage to care despite free services that were located in close proximity to the clients. The study reported poorer linkage among those who self-referred for testing (53.5%) compared to those who had been tested through PICT at STI services (84.1%). Overall, the study found that more than a third (37.4%) of clients testing positive for HIV did not return for a CD4 test within six months of HIV diagnosis. Of those that did return for a CD4 test within six months of testing for HIV, only 4.3% did the CD4 test the same day as the HIV test. More than a quarter (26.3%) had no recorded CD4. Of those who were ineligible for ART, less than half (46.3%) returned for a repeat CD4 at six months.<sup>60</sup> More than a quarter (27%) of individuals testing positive for HIV in mobile clinics in Western Cape do not return for their CD4 result; the CD4 result was available within 72 hours and the client made aware of the result availability telephonically or through a home visit or letter if no contact number was available. Women, those with a CD4 of 350 or lower and those with a mobile phone were more likely to receive their CD4 results. In addition, of those who accessed their CD4 result, almost half (47.5%) failed to link to HIV care; linkage to care was defined as someone who was newly diagnosed with HIV who had attended the facility at least once after testing in the mobile unit.

Barriers to linkage to HIV care included being unable to take time off work (41.4%), long distances to the clinic (15.7%), fear of side effects (12.6%) and fear of disclosure due to stigma (8.8%).<sup>56</sup> In a hospital in Johannesburg, 84.6% of walk-in clients to HCT had a CD4 test within 12 weeks of testing positive for HIV. Of these, almost two-thirds (65%) did not return for their CD4 test result, which is made available after one week. Those with a CD4 count of less than 200 cells/m<sup>3</sup> were more likely to return for their CD4 result (51.3%) than those with a CD4 of more than 200 cells/m<sup>3</sup> (14.9%)<sup>61</sup>.

## 4.3 Models and interventions

A recent survey carried out among representatives from the President's Emergency Plan for AIDS Relief (PEPFAR) agencies, the Ministry of Health and implementing partners<sup>55</sup> identified several strategies in South Africa to facilitate linkage to HIV care and improve retention in pre-ART care, which included:

- Task-shifting, including to volunteers
- Offering “one-stop-shop” services
- Point-of-care services such as CD4 testing
- Decentralisation of services from facilities to communities
- Integration of HIV and mother and child services
- The use of peer educators or counsellors such as those who are living with HIV and adolescents e.g., the Integrated Access to Care and Treatment Programme (I ACT) (Chapter 5)
- Standardising referral forms and systems
- Bidirectional referrals
- Increasing male involvement in community-based care activities
- The use of Smart Cards<sup>k</sup> for health management information systems
- The use of SMS or other technology for reminding clients of their appointments and/or medications.

Detailed operational information on the above strategies was not reported by the study. The key informants were asked to tick all the strategies that applied to their context without providing operational detail.

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<sup>k</sup> A Smart Card is an identity card with an embedded microprocessor that stores personal details along with a digital photograph and fingerprints, which are used instead of an ID book. <http://www.zdnet.com/south-africa-prepares-to-launches-smart-id-card-project-7000017680/>

### 4.3.1 Featured model: Point of Care CD4 testing

Linkage to HIV care requires an assessment of ART eligibility, and—based on the South African treatment guidelines for non-pregnant TB negative adults and adolescents<sup>62</sup>—this implies CD4 testing. Those who test for HIV in the community in general need to be referred to a health facility to have blood taken. There is no way usually to monitor who doesn't return for a CD4 test result (or who don't return for pre-ART care or for ART initiation if point-of-care CD4 tests are available in the community). While referral letters provided from the community to the clinic have been shown to help clients link to pre-ART and ART care<sup>56</sup>, key informants highlighted logistical challenges in actually following up who attends the facilities and who doesn't. Clients tested for HIV in the facility must be referred from the counsellor to a clinician or a nurse to have blood taken. They will then have to return to the clinic to receive the results of their CD4 tests. It usually takes between two days and two weeks for the results to return from the laboratory, according to the staff that were interviewed by the research team in the visited facilities. With each additional visit to the facility that is needed to be made by the client there is more opportunity to lose them along the way. In one visited facility in Gauteng Province, laboratory services had been suspended for one month, due to the laboratory not "being paid". The facility reported four other facilities with similar problems. Clients tested positive were not being tested for CD4.

Given these significant losses between HIV test, CD4 test and CD4 result visits, point-of-care CD4 testing (POC CD4) has been developed. This measure aims to reduce the need to revisit facilities between HIV diagnosis and ART eligibility assessment, and thus increase the likelihood of being linked to care.<sup>63–67</sup>

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*"Point-of-care CD4 works, in a safe, tightly controlled setting." Key informant, Western Cape*

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POC CD4 refers to same day CD4 testing and results using point of care technology such as the Alere Pima machine, the first portable point of care testing machine<sup>68</sup>. This strategy was once utilised in Khayelitsha's maternity wards to improve rates of ART initiation among pregnant women, before the country and Khayelitsha shifted to Option B and Option B+ for pregnant women respectively<sup>69</sup>. The machines have now been donated to the two wellness hubs in the township. The wellness hubs (Chapter 5) are community-based clinics<sup>70</sup>—run by enrolled, non-professional nurses<sup>1</sup>—designed to act as an intermediate base between the community and the facility. POC CD4 is also being utilised for HIV positive youth in Khayelitsha, more than half (60%) of whom are reported to not return for their CD4 results<sup>71,72</sup>.

Patten et al (2013) tested the POC CD4 strategy among youth using a before-and-after observational study in Khayelitsha, and found that youth who had received POC CD4 were more than twice as likely to have their ART eligibility assessed compared to those who had

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<sup>1</sup> There are four categories of nurses in South Africa: 1) enrolled nursing auxiliaries who train for one year; 2) enrolled nurses who train for two years; 3) registered nurses and midwives who train for four years and (4) specialist nurses who train for five to six years (Uys and Klopper, 2013; [http://www.sajs.co.za/sites/default/files/publications/pdf/Uys\\_commentary.pdf](http://www.sajs.co.za/sites/default/files/publications/pdf/Uys_commentary.pdf))

laboratory CD4 testing (relative risk =2.4, 95% CI: 1.8–3.4,  $p<0.0001$ ).<sup>65</sup> In a study from Johannesburg, HIV positive clients who had their CD4 measured using a Pima POC CD4 Analyzer were more likely to attend the facility for further HIV care (relative risk 1.25, 95% confidence interval 1.00 to 1.57).<sup>73</sup> A randomised controlled trial conducted in inner city Johannesburg found that same day CD4 results more than doubled the odds of initiating ART.<sup>74</sup> Study participants were randomised to three arms: 1) same day CD4 results; 2) receipt of written information and CD4 results after one week; and 3) receipt of CD4 results after one week without written information (standard of care). ART eligible clients who received their CD4 results on the same day as their HIV diagnosis were more likely to initiate ART compared to those who received standard of care (risk ratio = 2.1; 95% confidence interval = 1.39 to 3.17). Those who were ineligible for ART were not more likely to enrol into pre-ART care, however. Those who received written information (arm 2) were also not more likely to report for pre-ART care. But, those that did tended to come sooner, by a median of six days earlier. Matambo et al reported on ART initiation outcomes after POC CD4 tests were made available through a mobile service targeting migrant farm workers, and found that ART initiation increased after the introduction of the service (83%; 95% CI 78%-88%) compared to before the service was introduced (51%; 95% confidence interval 46%-56%) (OR 6.3, 95% CI 3.9-10.3)<sup>75</sup>. Another study from Johannesburg found little impact on initiation of pre-ART and ART of point of care CD4 testing that was not rapid (two to three hours for the results rather than the usual 45 minutes) compared to standard care (CD4 results after one week), however.<sup>76</sup> A recently published (January, 2014) systematic review and meta-analysis<sup>64</sup>, where more than half of the included studies were conducted in South Africa, found that **point-of-care CD4 testing significantly increased the odds of both having CD4 measured [odds ratio (OR) 4.1, 95% CI 3.5-4.9, n=2] as well as of receiving the CD4 result (OR 2.8, 95% CI 1.5-5.6, n=6)**. The time to being tested for CD4 and to receiving the result were also significantly reduced<sup>64</sup>. The evidence for increased treatment initiation was however mixed.<sup>64</sup> The pooled data that was used for the outcome of treatment initiation among ART eligible clients came from four studies, three of which were conducted in South Africa and are described above<sup>65,74,76</sup>. The fourth, from Cameroon, found that POC testing resulted in a significantly higher proportion of ART eligible clients initiating ART (87%) compared to before (33%)<sup>77</sup>. Overall, no difference was found between POC CD4 testing and standard of care for treatment initiation among ART eligible clients (OR 1.0, 95% CI 0.8-1.3). When expanding the analysis to all clients regardless of eligibility, however, the pooled likelihood of initiating ART was greater when POC CD4 was used (OR 1.8, 95% CI 1.1-2.9). A recently published report on best practices and experiences from fourteen sub-Saharan countries on linkage and retention in pre-ART care also identified point of care CD4 services as one of three best practice models of care.<sup>55</sup> In addition, a study published in Plos Medicine in September 2014, Hyle et al highlighted the clinical and economic impact of point-of-care CD4 testing in resource-limited settings<sup>78</sup>. The authors used published data from Mozambique and applied this to a mathematical model - the Cost-Effectiveness of Preventing AIDS Complications–International (CEPAC-I) model—to assess the clinical impact, cost, and cost-effectiveness of point-of-care CD4 testing compared to standard laboratory CD4 testing. The **modelling results suggested that using point-of-care CD4 testing saves lives**; the model estimated that 65% of clients graded using POC CD4 would survive at five

years compared to 61% if using laboratory CD4 when treatment was initiated at a CD4 of 250/mm<sup>3</sup>. The calculated cost-effectiveness ratio was US\$500 per year of life saved when using point-of-care CD4 testing rather than laboratory CD4 testing. A study from Gauteng Province in South Africa using data from a mobile HCT programme in 2010 estimated that the cost per point-of-care CD4 test using a Pima Analyzer to be US\$23.76<sup>79</sup>. This estimation did not include costs associated with on-going training, supervision, and quality assurance, however. An international comparison of POC CD4 test costs by MSF found an average cost of US\$7.33<sup>80</sup>.

While the evidence for improving linkage to care using a POC CD4 strategy looks promising, the **reported challenge to its scale up** is twofold, according to interviewed key informants.

1. Concerns about test sensitivity and specificity—particularly if using capillary blood rather than a venepuncture sample. This may become less of an issue as the ART eligibility criteria shift to CD4 500. Nevertheless, training is critical to ensure blood samples are taken appropriately.
2. Concerns related to monitoring—the results from the PIMA Analysers are not linked to the main laboratory databases.

With the exception of selected facilities and services in Western Cape, the research team did not observe POC CD4 services elsewhere during the field visits.

#### 4.3.2 Featured model: Point of care viral load testing

According to data recorded on TIER.net, just over a third (36%) of adults active on ART have a VL test done<sup>10</sup>. The 2013 WHO consolidated guidelines strongly recommended using the VL for detecting and/or confirming treatment failure among those with evidence of clinical and/or immunological failure<sup>31</sup>. In a systematic review and meta-analysis, published in 2013, which included data from South Africa, the use of viral load monitoring was found to result in re-suppression rates of 70.5% (95% confidence interval: 56.6% to 84.4%)<sup>81</sup>. Delays in the use of VL monitoring were associated with onset of drug resistance. With the challenges associated with traditional methods of monitoring clients, such as self-reported adherence, pill counts and pharmacy appointments, the VL provides an objective and sensitive method to monitor—and differentiate between - client adherence and drug resistance<sup>31</sup>. The VL is preferred to the aforementioned monitoring tools and to the CD4 for monitoring.

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*“The viral load doesn’t lie.” Key informant, Western Cape*

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Barriers to VL testing are similar to those associated with CD4 testing. In addition, VL tests are relatively expensive. Decentralising and scaling up VL testing is expected to reduce these barriers.

In a Treatment as Prevention workshop in Vancouver this year (2014), the future of POC VL testing for resource-limited settings was discussed<sup>80</sup>. It was reported that several POC VL testing machine, some not requiring electricity but relying on battery power only, were due to come on the next market over the next few years, which would only require a drop of blood

giving results within minutes. Logistical barriers to VL testing scale-up, such as transportation of samples and limited human resources, can be overcome by VL point-of-care technology.

Although South Africa is the largest purchaser of viral load tests in the world<sup>82</sup>, only around a third of clients receive viral load testing in South Africa<sup>10</sup>. As previously mentioned, the relatively high cost of VL tests has been one barrier to scale-up.

MSF studied four machines: the Alere Q HIV test; the DRW SAMBA test; the Wave-80 EOSCAPE-HIV test; and the Lumora “BART” test. Although these tests would be more expensive (manufacturer’s cost of an average of \$7.28) than laboratory VL tests (average \$4.36) POC VL tests would become cheaper the more they are used. It was estimated that the *final* cost of a POC method would be around \$42 per test if the machine was used to a quarter of its capacity and \$33 if it was used at three quarters of its capacity, highlighting the importance of the economy of scale. A mathematical modelling study using longitudinal data from Cape Town concluded that the cost-effectiveness of POC VL testing is improved when a higher VL detection limit is used (>1000 copies/ml)—using a lower limit (<1000 copies/ml) would result in unnecessary switches—and when taking into account the number of new infections that would be averted and the assumed reduction in the number of cases of treatment failure that would be prevented, through identification and targeted adherence counselling of those at risk of failure<sup>83</sup>. International efforts in helping bring down the cost of VL testing have been fruitful. A new Global Access Program<sup>82</sup>, launched by global partners and Roche Diagnostics, announced on 25 September 2014, is expected to reduce the price of POC viral load tests by more than 40% in low- and middle-income countries, including in South Africa. With this price-reducing initiative, scale-up of VL testing is expected in South Africa in the near future.

Other strategies that have been implemented elsewhere in an attempt to reduce VL testing costs, and therefore increase scale-up, is **viral load pooling**, initially piloted in Malawi by MSF<sup>84</sup>. To reduce the cost of VL testing, the MSF clinic decided to pool five dried-blood spots and sample them all together. If the test was negative—defined as less than 1000 copies/mL—then all the samples were assumed to be negative. In this was one test is used rather than five. If the test was positive then all samples were tested individually. This strategy reduced the number of VL tests by almost a third (30%) saving the district up to \$207,000 a year. The strategy has also been assessed among paediatric populations. In a study from Kenya, viral load pooling among children, using archived blood samples of children who were HIV positive, estimated that viral load pooling would have resulted in 24% fewer assays needed for a cost savings of \$1180 per 100 samples<sup>85</sup>.

**For South Africa’s planned scale-up of ART and earlier treatment initiation for therapeutic and HIV prevention purposes, it seems essential to address the large leakage at the “linkage to HIV care” stage in the cascade. This could involve linking HIV and CD4 testing more effectively, and bringing CD4 testing and result availability together in one clinic visit. However, investments in POC CD4 technology must be balanced with potential future testing and treatment strategies that may remove the need to carry out CD4 tests at all.**

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## Chapter 5. Results: Pre-ART care

### 5.1 Key points

- Pre-ART care (between the first assessment of ART eligibility and ART initiation) is no more a major focus in the South African public sector service.
- Poor record keeping and tracking of pre-ART clients combined with lack of staff confidence in managing pre-ART clients and no 'visible' guidelines are reported challenges in pre-ART care provision.
- Weak pre-ART care is seen as major contributor to overall ART adherence problems.
- Promising interventions and models are: Integrated Access to Care and Treatment Programme (I ACT), a six-module structured national education and support programme for newly diagnosed PLHIV, which has, however, generated mixed feedback from clients and health care workers about its implementation; pre-ART support groups, which appear to often struggle to retain clients as no additional incentives (such as food) can be offered; client tracking to prevent LTFU and increase re-entry into pre-ART care; Isoniazid preventive therapy; and Wellness hubs, which have late opening hours and offer pregnancy screening and some family planning services, among others.

The dynamics of pre-ART care will change with the new eligibility threshold in 2015, bringing ART initiation forward by on average 2.5 years compared to the current CD4 350 cells/mm<sup>3</sup> threshold. This will therefore remove an extended pre-ART phase for many clients. If a test and treat strategy is incorporated in the future, the pre-ART phase will no longer exist, except for clients who want to postpone or refuse treatment.

### 5.2 Data on pre-ART care

“Pre-ART care” (sometimes also called “pre-ART retention in care”) concerns the period between the first assessment of ART eligibility and ART initiation. The duration of this period will depend on the actual eligibility criteria and whether the client presents for testing early or late. In South Africa, the duration of pre-ART care will soon be shortened as the country prepares to shift the eligibility threshold, from a CD4 of 350 to a CD4 of 500, in January 2015. Under the current threshold criterion of CD4 350, newly diagnosed clients become eligible for ART after an average of 5 years post-HIV infection. The change to CD4 500 is projected to reduce the time to eligibility to 2.5 years, therefore changing the dynamics of pre-ART care.<sup>86</sup>

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*“The dropout is massive. But do we have the resources to keep them? That is the big question.” Key informant, Western Cape*

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As part of pre-ART care for those currently ineligible for treatment (clients with a CD4 of >350), the current South African treatment guidelines (2013) recommends: transfer to a wellness programme for regular follow-up and repeat CD4 testing every six months; advice on how to avoid HIV transmission to sexual partners and children; Isoniazid Preventive Therapy (IPT) if asymptomatic for TB; counselling on nutrition and contraception; and annual pap smears for women<sup>62</sup>.

Pre-ART retention in care in South Africa, like many sub-Saharan countries, is generally poor. It is considered a weak link in the cascade—most of the losses in the cascade occur during the pre-ART phase. A HIV clinic in Johannesburg reported that only a quarter (26%) of pre-ART clients return for their first scheduled appointment<sup>87</sup>. A study published in May 2014, reporting on pre-ART retention in eight communities with a high burden of HIV and TB in the greater Cape Town area, reported that only 43% of clients who had accessed pre-ART care were retained (retention was defined as having had a CD4 count within the last six months)<sup>88</sup>. Another study carried out in Cape Town found that although a package for pre-ART care is clearly defined, the package is inconsistently implemented.<sup>89</sup> The study reported gaps in quality of care (less than a third of women (32.2%) had a PAP smear), missed opportunities for integrated care (only two-thirds of clients (67%) were symptomatically screened for TB) and positive prevention (less than half of clients (48.3%) had their contraceptive needs assessed). Furthermore, less than half of ART eligible clients (47.2%) are referred appropriately to the ART service. The authors conclude that these weaknesses in the continuity and quality of service delivered at the pre-ART level undermine the programme objectives of provision of positive prevention and timely access to ART. It is also important to point out that clients who are lost to follow-up during the pre-ART phase have higher mortality rates. They usually return for ART initiation much later, when their CD4 is very low and they feel sick.

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*“South Africa used to have a good pre-ART programme but we decided to scale down dramatically. The consequence now is that adherence is poorer.” Key informant, National Department of Health*

*“The first treatment guidelines in South Africa were really focused on how to get people on ART. Pre-ART was neglected though not intentionally. We just thought that pre-ART was easier to do. Now we know this is not necessarily the case. If you focus on pre-ART, you can take forward the benefits and approaches all the way to post-ART.” Key informant, Academic, Gauteng province*

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A pre-ART gap analysis report, published in June 2013, reported on two key gaps in pre-ART care management.<sup>90</sup> The first relates to the fact that there are no comprehensive guidelines on how to manage people living with HIV who are not yet eligible for ART that are ‘visible’. Staff had difficulties accessing pre-ART guidelines, which are embedded in other guidelines. It was reported that service providers are generally more confident managing ART care than pre-ART care. Secondly, the gap analysis found poor record keeping and tracking of clients who are in pre-ART care in facilities; these clients are at risk of being lost to follow-up.

## 5.3 Models and interventions

### 5.3.1 Featured model: Integrated Access to Care and Treatment Programme (I ACT)

The Integrated Access to Care and Treatment Programme (I ACT) is a six-module structured education and support programme provided to people who are living with HIV (closed groups) and who are HIV negative or positive (open groups). Each session takes around two hours to complete, and provides information, interactively delivered by group facilitators, on HIV, TB, ART, stigma, positive living, acceptance and disclosure of status. An adolescent specific I ACT programme has been launched in 2014. The training for group facilitators takes two weeks to complete. The aim of the programme is to “promote referral and retention of newly diagnosed PLHIV in care and support programmes.”<sup>91</sup> Clients are usually offered time slots that suit them to complete the sessions. Each session is usually done at weekly intervals, though this varies between facilities. The closed groups are offered to all those who are newly diagnosed with HIV in facilities where I ACT is offered. Initially implemented in Eastern Cape in 2009 by SA Partners, it is now being rolled out in other provinces though has not yet been endorsed by the NDOH. Initial results published at the International AIDS Society conference in 2012 showed a completion rate of the programme—defined as completing at least five sessions—of more than 80% (81.6%), with women aged 25 to 49 years being more likely to complete, and positive changes in care and treatment seeking behaviour reported by graduates of the programme at six months<sup>91</sup>. A more recent prospective analysis<sup>92</sup>, conducted between July and December 2013 by the University of Minnesota in collaboration the National Alliance of State and Territorial Directors (NASTAD) in the Free State (n=341) reported that more female clients attend the I ACT programme (80%) and three-quarters of all participants are already on ART prior to commencing the programme. The study found that knowledge on HIV improved significantly after the sessions among participants ( $p < 0.05$ ).

#### Interviewed key informants reported mixed findings.

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*“90% of clients finish I ACT, meaning they attend at least five sessions.” Key informant, KwaZulu-Natal*

*“We see a big dropout after the first session in closed groups. This is usually because when the clients go there for the first time they may recognise someone. It is a shock for them. They don’t want to disclose. They don’t come back. It is very stigmatising for them. So open groups are better, especially in rural communities.” Key informant, KwaZulu-Natal*

*“People are not taking to I ACT. If ten people test only three will go forward for I ACT. Those that do it usually don’t finish all six sessions. If ten start I ACT, only five will finish. People don’t like to come to the facility too many times. They often live far away. Many people rely on grants and will only come to the facility once a month. This means it is difficult to complete the sessions in time. Stigma is still a very big problem here. People don’t like to join groups.” Key informant, Limpopo Province*

*“People prefer closed groups.” Key informant, Limpopo Province*

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*“We tried I ACT in Western Cape. It doesn’t work.” Key informant, Western Cape*

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*"We are not getting clients that we expected to get for I ACT. Work related issues are the main reasons why people drop out of I ACT." Key informant, Limpopo Province*

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*"I ACT is not being accepted by patients." Key informant, Limpopo Province*

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Those who do complete the programme are usually referred to other on-going support groups, if available at the facilities.

### 5.3.2 Other approaches using pre-ART support groups

The use of support groups to improve retention in pre-ART care was reported in several visited facilities. Others reported previously having support groups that were not sustained due to clients not wanting to come or due to facilitators moving on from the facility. Several key informants reported that unless incentives were given, such as food or reimbursement of travel costs, clients were unwilling to come to support groups.

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*"We tell them the CD4 is high, we tell them how to maintain a healthy life style, practice safe sex, how to de-stress, and we tell them to come to the clinic if they feel sick. We try to get them to go to support groups but they don't like them. They are too shy. They don't want people to know they are HIV+. And they want to know what they will get if they come to the support groups. When you tell them they're not going to get anything they don't want to come. They always want something." Key informant, KwaZulu-Natal Province*

*"We still have the old support groups. After six sessions of I ACT they go to these support groups. They share their experiences. They also do extra activities. But people tell us we're not going to support groups unless there's lunch there." Key informant, Limpopo Province*

*"We have tried support groups in past years but they always fail. Because people want food or something more, like jobs. We tried to set up a garden for them so they can grow vegetables but they were not interested. They did not receive anything. It was just for support. They have all stopped now. We used to have more than 20 people. When we held the meetings, each time there were fewer and fewer people until we had no more." Key informant, Limpopo Province*

*"I ACT is not being accepted by patients. We had a meeting last week with the facilitator who complained that the patients are refusing to come. We talked about giving them drink or food. Because when they have lunch they do come. So we advised him to make sure that he gives them a date that is the same day that they come to collect their treatment. Don't give them another day because they will say they are busy. But if they are coming here anyway there is no way they can say they are busy. He will try to do that now. With the open group there are less problem. With the closed group that's where the problem is. Because they all know they are positive. We will speak to our partners also to see if they can provide a lunch, which will help. Say once a month. Maybe they will then come. But now they are not coming. We used to have support groups in the past and they never worked. We tried and tried. And now this new one is stuck too." Key informant, Limpopo Province*

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In addition, to make support groups work, requires dedicated staff members according to interviewed key informants.

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*"I used to run support groups and they are not easy. You have to have a passion for it. You have to sacrifice your family time. It really needs people who are very dedicated. As long as*

*there is no-one coordinating the whole process, someone who is committed, it is difficult to make them sustainable.” Key informant, NDOH*

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### 5.3.3 Featured model: The Hlanganani Programme for HIV-positive adolescents

The Hlanganani Programme (Coming Together) is a structured support group for HIV-infected adolescents. Snyder et al reported preliminary results from pilot project from Western Cape, published in the journal Elsevier's October 2014 edition<sup>93</sup>. The Hlanganani youth support group model was adapted from an intervention for pregnant women living with HIV called Project Mamekhaya<sup>94</sup>, due to an understanding that HIV positive adolescents often do not understand the urgency of entering HIV care in the same way that pregnant women may do for the benefit of their babies as well as social differences and barriers to care among youth. The youth pilot project consists of three structured support group sessions, each lasting two hours, which are held once a week and are facilitated by laypersons. The youth included in the groups were those aged between 16 and 24 years old who had been diagnosed HIV positive within the previous 12 months. The sessions covered three main themes (the curriculum was devised with the help of focus group discussions and interviews): coping and support (session 1); HIV health (session 2); and positive prevention (session 3). Each session was opened by a role-play carried out by the facilitators followed by a group reflection on the issues raised and relaxation exercise. Interactive discussions were also a feature of the sessions, which covered topics around physical and emotional health. At the end of each session, participants set achievable goals relating to the week's material, such as going to the clinic to get one's CD4 result or disclosing one's status to someone they trust. Results from the first phase of the evaluation, which was the initial groundwork and programme design consisting of qualitative, formative work through focus group discussions with youth and key informant interviews highlighted the challenge of engaging youth in this type of service and emphasised the importance of confidentiality. The youth in the focus groups voiced their reluctance to attend a support group at their local clinic for fear that they may be known to have HIV. The second phase of the evaluation, conducted between July and October 2009, involved a brief piloting of the programme in order to establish feasibility of recruitment and implementation. The issue around youths' reluctance to be associated with HIV was reiterated, highlighting the importance of finding a way to avoid branding Hlanganani purely for those living with HIV while maintaining the programme solely for those who are HIV-positive. The third phase of the evaluation of the programme involved the piloting, which was done between January and December 2010. More than a hundred (109) participants were enrolled. Groups comprised between three and ten members. This third phase evaluated the feasibility and acceptability of the intervention through attendance registers, post-session surveys, and semi-structured post-intervention interviews with participants and facilitators. **Results from the evaluation suggest that the model is indeed feasible and acceptable and found measurable improvements in short-term behavioural outcomes among youth utilising the model including safe sex and linkage to ART care.** Self-reported condom use at last sex increased from 71% to 83% at follow-up ( $p < 0.05$ ). Linkage to care was 100% of all ART eligible participants ( $n=13$ ) among participants compared to 58% in those who did not attend any sessions ( $n=31$ )<sup>93</sup>.

### 5.3.4 Client tracing during pre-ART

The practice of tracing clients who are not yet on ART varies between facilities. Those facilities that do implement tracer teams, finding clients is not always easy, with clients changing homes frequently or giving wrong addresses.

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*“Tracking of patients is usually not very successful. People give wrong addresses or they move.” Key informant, Western Cape*

*“Our people who come here to the clinic are usually those who have come into the city to work. They live here for a bit and then they change homes. They lose their phones or change their SIM cards. We then send the tracer teams but sometimes they don't find the people. The new tenants may tell you that they went home because of a death in the family or other reasons. That's the challenge we really see. Most people here are tenants and they don't normally live locally. They change homes often.” Key informant, KwaZulu-Natal Province*

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One strategy that was recommended by key informants to overcome these challenges is to **check clients' addresses at each visit to the clinic**. Tracing those who are lost to follow-up in pre-ART care has been shown to be feasible and effective in improving ART services in rural settings. In Eastern Cape, lay counsellors, who received additional training and mentoring from an experienced HIV nurse from the UK, traced pre-ART clients that had been lost to follow-up, successfully returning 18%.<sup>95</sup> Of these, ART was later initiated in 25%. The cost of recall was 130 Rand per client.

Key informants have however voiced concerns that tracing ART ineligible clients may not be best practice, as facilities may not have the capacity to keep these people in routine care, particularly as they will feel healthy and well.

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*“It is still a struggle sometimes to make sure people come back for the CD4 result. Usually the clinic would keep a record of those who haven't come back and they inform the NGO that is linked to the clinic to go and trace them. But not all clinics have that system in place.” Key informant, Gauteng Province*

*“If they don't come back to us for their CD4 result, and if the CD4 is low, we send the community care givers to go and trace them. They are not traced if the CD4 is high.” Key informant, KwaZulu-Natal Province*

*“It is difficult to justify going out and tracing people with a high CD4 count. We have nothing really to offer them at this stage. And they feel well. And our clinics are swamped as it is.” Key informant, Western Cape Province*

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### 5.3.5 Mobile clinics and other decentralised pre-ART services

Matambo et al assessed the impact of a weekly integrated mobile HIV/TB service for migrant farm workers on pre-ART retention in care in Limpopo<sup>75</sup>. Prior to the mobile service, only half (51%; 95% confidence interval 46%-56%) of those who were eligible for ART were initiating ART. With the mobile service, 83% (95% CI 78%–88%) of those eligible had initiated ART, representing a 32% (95% CI 25%-39%;  $p < 0.0001$ ) increase in the proportion of those eligible that are initiated on ART. Considering the large farmer population in Limpopo and the



difficulties they have in accessing the facilities—due to difficulties in taking time off work and/or costs of transportation—this model of care represents one potential best practice in reaching these rural populations. Key informants from Limpopo, however, reported that such services are sometimes discontinued due to a lack of human resources.

“The problem is that many people, especially those working in the farms or those who don't have money to come to the clinics, used to get their medications from the mobile clinics. But now it is not working. Because the nurse who used to do it no longer works here so there is no one to do it. We really need the mobile clinic to come back. This will really help the farmers. We should do HCT there, do support groups there, do everything there.” Key informant, Limpopo Province

### 5.3.6 Isoniazid preventive therapy

Isoniazid Preventive Therapy (IPT) is one way to incentivise clients to remain in pre-ART care, and has been shown to significantly reduce the incidence of TB among those who are HIV positive<sup>96, 97</sup>. It has been described as an “ideal component of pre-ART care”<sup>98</sup> as it provides clients with a form of treatment, keeping them closer to the clinic, and is a potential tool to monitor adherence issues prior to ART initiation.

In 2010, the South Africa ART guidelines recommended IPT for six months for all HIV-positive persons regardless of tuberculin-test result. Removing the reliance on a tuberculin skin test to initiate IPT among HIV persons was done in an attempt to improve the implementation and scale-up of IPT in the country. Although this resulted in an impressive scale-up of IPT services across the country, IPT coverage remains poor with only 36.1% of HIV clients on IPT<sup>28</sup>. The most recent guidelines (2013) recommend at least 36 months of IPT to tuberculin skin test positive persons (for pre-ART and on ART), IPT for six (pre-ART) or twelve months (on ART) to tuberculin skin test negative persons, or 6 months of IPT for those whose tuberculin skin test result is unknown (both pre-ART and on ART)<sup>62</sup>.

A Joint Review of HIV, TB and PMTCT programmes in South Africa, published in April 2014, found several key strengths and challenges with regards to IPT<sup>28</sup>. TB screening and IPT initiation among pregnant women was identified as a strength and an achievement. On the other hand, inconsistent recording and reporting of IPT coverage and adherence among children under five years old was highlighted as a key challenge and constraint. The main barrier to proper reporting of IPT scale-up and coverage was the lack of standardised registers across facilities and the authors reported observing a “consistent gap” in the integration of IPT TB prevention and TB screening and diagnosis in pre-ART care. IPT completion rates were reported to be between 10% and 96%. The authors recommended the integration of IPT initiation, follow-up and completion into pre-ART and ART registers in order to overcome these challenges.



Interviewed key informants echoed these feelings.

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*“The only challenge is the recording and the reporting. HIV positive patients might be appearing in the ART register as being screened for TB but they may not be appearing in the TB register. It may be there are too many registers or it may be that people are not recording. If it’s not written it’s not done. That is the challenge. We find some of the patients are not recorded.”* Key informant, National Department of Health

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*“Most people take IPT but adherence is not very good.”* Key informant, KwaZulu-Natal Province

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Furthermore, in Western Cape, key informants highlighted the fact that there is currently no routine monitoring of client adherence and completion of IPT; only those who initiate IPT are captured by the data systems. It was recommended that IPT adherence be monitored and suggested that this may be a better way to monitor pre-ART retention rather than adherence to appointments.

### 5.3.7 Other strategies to potentially improve pre-ART care

Other strategies that are used to improve pre-ART retention in care include STI screening and treatment, condom promotion and distribution, family planning services and Pap smears. The two community **Wellness Hubs** in Khayelitsha, set up by MSF in mid-2013 (six months apart), are providing some of these services in the community. The hubs employ an enrolled nurse and counsellors who carry out testing for HIV, TB, diabetes and hypertension, pregnancy screening, some family planning and TB sputum collection. Point of Care CD4 testing is available at the hubs. The hubs have extended opening hours. Hub 1 is opened between 0730 and 1130 and again between 1500 and 1900. The second hub is opened between 0900 and 1300 with the same evening opening hours as the first hub (the morning sessions were being underutilised so the morning opening time changed to 0900). The same staff members do both the morning and evening sessions. One of the hubs has been taken over by the Western Cape Department of Health while the other is currently in the process of handover. According to clinic data presented to the research team during field visit, almost all of the cases seen in the hubs were for family planning; 96% and 88% of users in the hubs attend for family planning. The users are mostly women with very few men utilising the service. Of those referred from the hubs to the clinic 28% are ART eligible, 49% are ART ineligible and 8% are pregnant and HIV positive. The challenge with the Wellness Hub model relates to the fact that the hub employs only enrolled nurses (rather than professional nurses). Enrolled nurses are not certified to start STI treatment and family planning. They are also unable to manage chronic diseases. Interviewed key informants emphasised the importance of maintaining late opening hours for the hubs.

## Chapter 6. Results: ART initiation

### 6.1 Key points

- The ART programme scale-up leads to over 50,000 new initiations per month on average, and there has been a gradual rise in average CD4 initiation over the past decade.
- In 2013, an estimated 42% of all PLHIV in South Africa received ART<sup>99</sup>.
- Documented risk factors for low initiation rates or low ART uptake are being male, young, unemployed, unmarried, and having low education levels, among others.
- Elements of strategies and models with potential: the MSF ART initiation counselling model which is client-centred and accompanies the client post-initiation; task-shifting to increase ART initiation capacity; support initiatives for HIV positive pregnant women and mothers using mobile technology (MomConnect) and mentoring (Mother-to-Mother-to-be programme); and cotrimoxazole provision.
- The announced change in treatment eligibility, to a CD4 level of 500 cells/mm<sup>3</sup> and lifelong ART for all HIV positive pregnant women from 2015 will accelerate the growth of the ART programme.

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*“Willingness to initiate is a real marker of adherence later on.” Key informant, Western Cape*

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### 6.2 Data on ART initiation

South Africa has been a rapid scale up of ART with on average approximately 50,000 new adult clients and about 2,500 children initiated per month during 2013<sup>10</sup>. Increasingly, healthier clients are being initiated, with a move to ART eligibility from CD4 of 200 to a CD4 of 350, and now to 500 in January 2015. The average CD4 count at initiation is currently 210–220 (2013)<sup>10</sup>.

Looking across the entire HIV positive population of South Africa, an estimated 42% of all PLHIV received ART in 2013<sup>99</sup>. Of those who are ART eligible, 20%—or half a million South Africans, based on current South African guidelines of a CD4 of <350 cells/mm<sup>3</sup>—have not commenced ART<sup>99</sup>. In a modelling study that included eligible clients who are on ART (i.e. excludes those that have stopped ART), it was estimated that significantly more women were receiving ART by the middle of 2011 (60%, 95% CI 53–65%) compared to ART eligible men (41%, 95% CI 36–46%)<sup>9</sup>. Although the average CD4 count at initiation has risen, about a quarter of new ART clients in 2013 still had CD4 counts below 100 by the time they started ART.

ART initiation in South Africa is heterogeneous across population groups. A systematic review—published in August 2014—of quantitative studies reporting on equity in ART

utilisation in South Africa found differences in ART initiation according to sex, age, severity of disease, area of residence and socioeconomic and marital status<sup>100</sup>. In two out of ten studies included in the review men were shown to have lower rates of ART utilisation compared to women while the remaining eight studies found no differences according to sex. Half of the studies reporting on age (4/8) reported lower ART initiation among younger people with the remainder showing no association according to age. ART coverage was also shown to be different between the nine provinces in both studies reporting this data, with highest coverage being in Western Cape in both studies (up to 2005 and up to 2008). Contradicting results were reported for severity of disease. Some studies also reported lower ART use among those who were unemployed, had lower education and who were unmarried.

Interviewed key informants and clients reported several barriers to treatment initiation, including a perception that clients feel well and therefore don't return to the facility to be initiated, stigma, fear of disclosure and weak adherence counselling provided:

### **Why people don't want to go on ART: Selected client views**

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*"I know people who don't want to come to the clinic. It's because they don't feel ill. They don't believe there is anything wrong with them. So they refuse treatment". Stable client on ART, Limpopo Province*

*"There are many people who don't want medication. They feel OK. They only come here when they are very ill." Stable client on ART, Limpopo Province*

*"I have friends who don't want to take treatment. My boyfriend is HIV positive and he doesn't want to take medication. I don't know why." Stable client on ART, Limpopo Province*

*"There are many people here who don't want to come to take treatment. It's because of the stigma. They don't people to know they are HIV positive." Client on ART for PMTCT, Limpopo Province*

*"There are many people who don't want to test because they are scared of HIV. My brother doesn't want treatment. He would rather die than wait in the queue for someone to help him. He is scared of people knowing he is HIV positive. His girlfriend died last year. He hates clinics. It would really help him I think if he has his medications delivered or if the person treating him was a male." Stable client on ART, Gauteng Province*

*"They don't think that taking treatment every day will solve anything." Client on ART for PMTCT, Limpopo Province*

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## 6.3 Models and interventions

### 6.3.1 ART preparation: education and counselling

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*“You inherit a problem down the line if you don’t treat counselling properly right at the start.” Physician, Western Cape*

*“I got tested for HIV and for TB. I saw a counsellor and a dietician and a social worker. This was very useful.” HIV/TB client, on ART for two months, Gauteng Province*

*“I received counselling twice at the hospital and it really helped me. They told me how to eat well and that I should only drink juice.” Stable client on ART, Limpopo Province*

*“Counselling really helped me.” Stable client on ART, Limpopo Province*

*“The thing that works, that helps people progress through the cascade is proper counselling, on everything, from HIV to their treatment to the side effects. We need to tell them the truth from the beginning. That is what will bring them back. If you hide the side effects from them they won’t come back. We have to tell them the truth from day one. We need to give the patient a chance to ask questions and answer all their questions. If they understand they will be happy.” Key informant, Limpopo Province*

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As per South Africa’s HIV treatment guidelines, education and counselling is provided to all clients prior to initiating ART. On-going counselling is also provided to those who are identified as not adhering to their appointments and/or treatment (described in the next chapter). **Education and counselling, as well as the use of SMS messaging, has been shown to improve adherence, with high quality evidence<sup>101–108</sup>.** ART preparation in the form of education and counselling sessions are delivered by lay counsellors, who usually receive a stipend by NGOs or other non-profit organisations. The team noted differences in the nature, duration and frequency of counselling sessions between facilities and counsellors during field work, and from the literature<sup>109,110</sup>. Most counsellors interviewed did not use a standardised tool to deliver counselling sessions. However, they reported covering similar themes, including information on HIV, ART and expected side effects, issues around disclosure, the importance of adhering to their treatment and the consequences of non-adherence. These sessions were either carried out one-to-one or in a group, with or without the presence of a treatment supporter. Generally, three ART preparatory sessions were held on three separate days, usually at one-week intervals. The reported duration of each session varied between counsellors, from as little as ten minutes per session to more than one hour. The final session is usually completed by an assessment of the client’s readiness to initiate treatment. They are then referred for treatment to be initiated by a physician or a NIMART-trained professional nurse. Counsellors reported that it was very rare for clients to refuse treatment once they have completed the required counselling sessions.

In a study conducted in the greater Cape Town area each of the 11 organisations surveyed who are involved in preparing clients for ART reported different structured programmes of client preparation activities. Difference between programmes included differences in the number of sessions (between two and seven), type of sessions (one to one counselling versus grouped session or a mix of both), use of treatment supporters (recommended versus required

and differences in the number of sessions where partners attend) and in their approaches to substance abuse and depression<sup>110</sup>. Clients were generally required to complete all sessions before they are able to commence ART, resulting in delays to ART initiation of between two and six weeks.

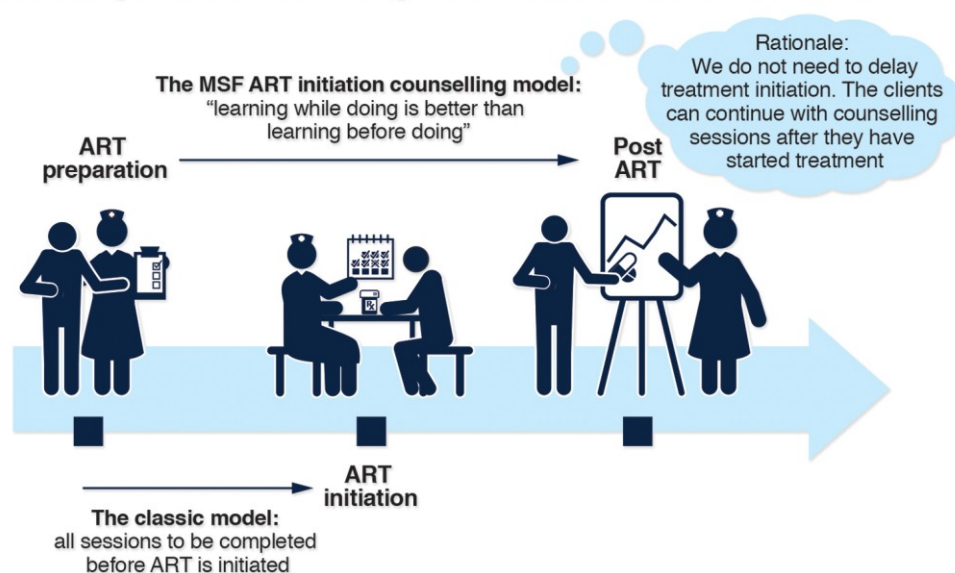
A new counselling model, designed by MSF and described in Western Cape during the team's provincial visit, aims to improve ART initiation by reducing the delay to treatment initiation by shifting some counselling sessions to post-ART.

### 6.3.2 Featured model: The MSF ART Initiation Counselling model

The MSF ART Initiation Counselling model differs from the classical three-day ART preparation counselling model in several ways (Figure 9). The MSF model has four sessions, one conducted prior to ART initiation, the second at initiation and the final two after ART initiation. By shifting some of the counselling sessions to post ART initiation, the model aims to reduce losses to care prior to ART initiation and strengthen the support provided to clients post-initiation, so that adherence and retention post initiation is not compromised.<sup>111</sup> The sessions are facilitated by lay counsellors, who follow a structured and standardised methodology, comprising the 14 standardised adherence steps, which form the 'adherence plan' of the client. This plan includes practical information such as where the client will store their medication and how they will remember to take them. The clients fill in the adherence steps during the counselling sessions on the 'adherence plan' sheet, which is given to them (a carbonated copy is also kept in their clinical notes). This counselling model focuses on the goal of an undetectable viral load. Clients with tuberculosis follow a similar counselling model but their goal is to complete six months of TB treatment. There is also a similarly structured counselling model for those diagnosed with drug-resistant TB (DR-TB), described in the next section.

Figure 9. MSF ART initiation counselling model

Counselling models for those starting ART: the classic model versus MSF model



Source: Author's figure based on MSF description of model

### The 4-session plan of MSF's ART initiation counselling model looks as follows:

**Session 1:** The first session commences with the client identifying three reasons that they want to stay healthy and alive. They are given red stickers to take home to place somewhere to remind them of these reasons each day, with the aim of helping them adhere to their treatment. During this first session, the counsellor goes through the first four adherence steps. The first step is an HIV education session, which is delivered using a standardised flip chart. The second and third adherence steps cover the client's support system and how they will get to appointments. The fourth step assesses the client's readiness to initiate treatment. If they are not ready, they are referred to an ARV treatment readiness group. If they are ready, they are given an appointment to return for the second session counselling session, which is the same day as their treatment initiation date.

**Session 2:** The second session includes adherence steps five (medication schedule), six (how to manage missed doses), seven (reminder strategies), eight (where to store medication) and nine (how to deal with side effects). ART treatment is initiated on the same day.

**Session 3 and 4:** Session three is held once a client has initiated ART and focuses on planning for trips away (adherence step 10), how to deal with substance abuse (asked of all clients, adherence step 11) and who the client's focal person in the clinic will be (step 12). Adherence steps 13 and 14 are included in the last session. These focus on how to manage making 'mistakes' while learning to take ART and an education session on the viral load.

### First experiences with the MSF model

The MSF ART initiation counselling model has been piloted in Nolungile Community Health Centre in Khayelitsha Metropolitan District, Western Cape, and has since been rolled out in all Western Cape city clinics. A tool kit is expected to be published by the end of 2014. Since the pilot initiation, 560 clients have completed the sessions, 535 of whom have initiated treatment (95%). In addition, 93% of those newly initiated on ART suppressed at their first viral load.<sup>111</sup> MSF colleagues cite several advantages to the model including its client centred focus (the client makes their own adherence plan and has the option to say they are not ready—in such cases they are offered an additional session that focuses on understanding why the client is not ready), the fact that it speeds up ART initiation without compromising adherence (the client doesn't have to wait until all sessions are completed before they can initiate treatment) and the fact that the model includes sessions while the client is on treatment.

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*"Learning while doing is better than learning before you have done something." Programme manager, MSF, Western Cape*

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Interviewed counsellors in Western Cape, who had almost a decade of prior counselling experience with different counselling methods, were critical of this model however. They felt that the counselling curriculum was not flexible and that the sessions were too time-consuming. They believed that the clients did not easily understand many of the questions, as they were irrelevant and/or inappropriate to ask at that particular time. It was suggested that some of the practical questions—e.g., where to store the medications—may be better asked in a group



setting. The counsellors also reported being extremely uncomfortable asking clients to identify their reasons for staying alive and giving clients stickers to remind them of these reasons. Unfortunately, the research team did not have an opportunity to discuss these issues with clients who have received counselling using this model.

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*"It's very difficult asking the clients some of the questions. They look at you funny. Why are you asking me about holidays? What do you mean what will I do when I go on holiday? It takes so long to go through all the questions. Sometimes we are giving them ideas just because it takes so long." Lay counsellor, Western Cape*

*"It is very embarrassing giving people the stickers and asking them to stick them on their wall at home. Some of them just leave the stickers on the table or stick it on the wall here. It's embarrassing. It's like we are treating them like children." Lay counsellor, Western Cape*

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### 6.3.3 Provision of cotrimoxazole as part of HIV care

Cotrimoxazole is recommended in South Africa to be prescribed to all those who are eligible for ART as well to clients with WHO grade 2 disease. Clouse et al investigated the impact of prescribing cotrimoxazole within the first two months of CD4 staging on ART initiation within the first year<sup>112</sup>. The study found that almost all clients (96.5%) who started cotrimoxazole later initiated ART, while almost all who didn't start cotrimoxazole (91.4%) didn't initiate ART ( $p < 0.0001$ ). Of those who didn't initiate ART, around three quarters (76.8%) were lost to follow-up. In 2012, around 55% and 58% of adults and children were on cotrimoxazole at ART initiation respectively<sup>10</sup>.

### 6.3.4 Task-shifting from doctors to nurses

In an attempt to scale-up ART nationwide in the context of limited human resources, the South African government implemented a task-shifting strategy in 2011 that allowed trained nurses to initiate ART (Nurse Initiated Management of Antiretroviral Treatment). Since the start of the programme, thousands of nurses have graduated and are now NIMART trained, increasing overall ART initiation rates. Not only have task-shifting strategies been shown to be effective in increasing ART initiation rates when there are shortages of staff<sup>113</sup>, but they do so without compromising quality of care<sup>114–117</sup>, including among paediatric populations<sup>118</sup>.

## 6.4 Special populations: Pregnant women

Initiation of ART for PMTCT in South Africa is reported to be 83% (target is 100%).

Various factors have been reported in the published literature to be associated with PMTCT ARV uptake in South Africa. A systematic review by Gourlay et al (2013) reported several barriers to PMTCT uptake including poor knowledge of HIV/ART/vertical transmission, lower maternal educational level; psychological issues following HIV diagnosis; stigma and fear of status disclosure.<sup>119</sup> After delivery, barriers to retention in care in the context of Option B+ are manifold. Focus Group discussions with postpartum women receiving ART as part of Option B+ in South Africa highlighted three main barriers to postpartum retention in care: conflict with



work commitment, negative treatment from health-care workers, and lack of disclosure related to stigma<sup>120</sup>.

### **Late antenatal care bookings are a challenge to ARV initiation for PMTCT**

Interviewed key informants reported that generally all women who present for antenatal care (ANC) are tested for HIV and put on treatment the same day if the HIV test is found to be positive. Therefore the challenge for ARV initiation for PMTCT is not so much related to acceptance of testing but related to late ANC bookings.

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*“The biggest challenge for PMTCT is that women book for ANC very late. If she only has a few weeks until delivery and we have to start treatment according to WHO staging criteria or CD4, the process would take too long for her. From last year we are saying that as soon as a pregnant woman is tested positive, she should be put on treatment right away. Later on you can decide whether to do it for life or not.” Key informant, NDOH*

*“I remember going to visit a district in Limpopo in 2011 because the positivity rate among the babies was very high. When we went back to see who these babies were, we picked up that most of them were from un-booked cases. The women didn't book for ANC. And if they booked, they only attended once. So it says to you that we may have the drugs in the facilities, we may have the nurses who are NIMART trained but the woman is not coming.” Key informant, NDOH*

*“If pregnant women come here they really do get tested for HIV. Every woman that attends ANC we test and they don't refuse. And they don't refuse treatment.” Key informant, Gauteng Province*

*“We are testing pregnant women. The challenge is the reporting period. They report late, after more than 20 weeks. But we are preaching them to report before 20 weeks. That what we want.” Key informant, Limpopo Province*

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#### **6.4.1 Identified strategies for improving antenatal care bookings and PMTCT uptake**

##### **Incentives**

A clinic in Limpopo is providing women with free baby clothes donated by the community in an attempt to improve ANC bookings.

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*“For pregnant women we try to get them in before 13 weeks. Any one that books in before 13 weeks gets a present. We get lots of donations from the community like blankets and baby clothes. This means we can get them in earlier for testing and we put them immediately on FDC if they are positive.” Key informant, Limpopo Province*

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Women are also incentivised to take ARV for PMTCT for the sake of their babies.

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*“Pregnant women don't refuse treatment. We make it clear to them that we are doing this for the child. If they don't want to take ARV for themselves we tell them it's OK. But for now do it for your child.” Key informant, KwaZulu-Natal Province*

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Empowerment of women as a tool to improve service delivery through the use of mobile technology and peer mentoring

Several interviewed key informants highlighted the power of women empowerment as a tool to improve uptake of PMTCT services and overall service delivery.

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*“The main gap that I think we need to focus on as a country is community empowerment. Or woman empowerment. What we want is a nation whereby the woman goes to the clinic and says I am pregnant, please test me for HIV. If the test is positive I know how to ask for my treatment. This is the woman that wants. That doesn't wait to be followed-up to make a decision. The same woman who is taking her antihypertensive treatment. The same woman who is taking her diabetic treatment. But it's only through our initiatives that we can get to that type of a woman who walks in and says please give me my medication. That is what we want.”* Key informant, NDOH

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*“What is important is for us to empower you—to know your diagnosis and how to prepare for your future. Empowerment is a solution. Knowledge is power.”* Key informant, Limpopo Province

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Several initiatives are being implemented in South Africa that will help achieve that woman who is empowered, who comes to the clinic and requests the services that she knows she needs. **MomConnect** is one such initiative.

#### 6.4.2 Featured model: MomConnect

The MomConnect service is a mobile technology service for pregnant women, which sends pregnant women messages throughout her pregnancy and into the postnatal period that are relevant to the pregnant woman and her pregnancy stage, and is linked to community care givers who support the women outside the facilities. Initially piloted in KwaZulu-Natal, a modified MomConnect service relying on mobile technology rather than a computer information system, was endorsed by the NDOH and rolled-out nationally in August 2014 during the research team's field visit.

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*“With MomConnect women will be now be able to say, “I didn't receive folic or I didn't receive calcium”. They can also report if a sister was not good or was rude. So I think it will also be a part of service improvement. They will remind the sisters what they need.”* Key informant, Limpopo Province

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*“Pregnant women will be empowered now because they will receive the relevant messages. And it's free. And even after you deliver you will receive a message that will congratulate you.”* Key informant, KwaZulu-Natal Province

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Not only will the mothers be able to remind the clinic staff about the services they need, the modified service also provides women with direct access to the national level to complement the system, make a complaint and/or make recommendations. While the old system was “focused only on sending information to women”, the new version of MomConnect is “really focused on the quality of care for all pregnant women”.

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*“All the women are directly linked to the national level. Now there is an “open door” for them to say whatever they want to say. We need to be on our toes as soon as this is launched. Because we need to set our systems right. So that when a patient comes she needs to receive the quality of care that she deserves. Because if she doesn't somebody will have to*

*be accountable for that and we will have to answer.” Key informant, KwaZulu-Natal Province*

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With the national rollout of MomConnect it is expected that antenatal care bookings, and therefore uptake of PMTCT, will improve. UNICEF released a tender for the evaluation of the MomConnect programme in South Africa in June 2014.

*“Women can self-register for the system themselves at home, after they are identified by our community care givers. We should see some improvement in ANC bookings.” Key informant, KwaZulu-Natal Province*

*“We need to use MomConnect program. MomConnect if properly used can assist us. It replaces that district health nurse who’s going around with her briefcase going to each woman. It’s sort of a follow-up done through the use of technology. It keeps the communication link open. I really believe it can work. We tried it in KwaZulu-Natal. I know a lot of people have been using it in Gauteng and even in Western Cape. We saw it working.” Key informant, National Department of Health*

*“We really should see an improvement in early ANC booking, testing and postnatal care.” Key informant, KwaZulu-Natal Province*

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#### 6.4.3 Featured model: Mother-to-Mother-to-be Programme (M2M2B)

Another initiative that attempts to empower women is the **Mother-to-Mother-to-be Programme (M2M2B)**, which is a mentoring programme of HIV positive pregnant women and mothers. The programme provides education and support to women delivered by their peers. Recognising that often the best people to deliver such support and education are fellow mothers who have ‘gone through it all before’, mentors are based in the facilities to help support newly diagnosed pregnant clients and empower them.

*“Mother-to-Mother-to-be is working on empowering you as the woman. To say I am HIV positive, look I need my treatment. Look I want to live. I want to feed my baby. You don’t hear it from the nurse. You say it. Women who come out of the programme are so vocal. Are so empowered that they’ve got that will to live for themselves. The only thing with is that it is facility based, it’s not following the client up to the community level, and it only accommodates mothers who are HIV positive. And at a certain time they have to exit the program. And it sort of stops that continuity and that bond between women supporting each other.” Key informant, NDOH*

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Although the initiative has been around in South Africa for more than a decade, having been initially piloted in Western Cape in 2001, the programme is still in the process of expansion with reported challenges in finding mentors who are willing to participate, due to reported stigma and fear of disclosure.

*“We are now in the process of using the Mother-to-Mother-to-be program. We started in Waterback district in Limpopo. We started with mother mentors but we are finding that people are not ready to say, “Here, I am in the facility”. We need a person who can tell their story and who found out she was HIV positive when she was pregnant. Someone who can act as a case study. But people are not willing to stand up and say this. They don’t want to disclose to everyone. M2M2B started here in April this year. We identified 10 facilities in which we wanted two mother mentors in each facility. As I am speaking we have a*

*challenge. We are looking for mentors. Some of the ones we had selected dropped out. Mothers who just got tested respond well to mother mentors. It is nice to be told a story by someone who is in the same place as you. It works well. The mother mentors stay in the facility every day.” Key informant, Limpopo Province*

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## 6.5 Health system strengthening: improving staff attitudes and integration of services

Poor health systems and lack of customer care were underscored as barriers for clients to come to the facilities for services.

*“I honestly want to tell you, as a nurse today in this country, why we are not meeting our targets. It is because of the implementers. They are not complying with policies and guidelines. You go to the clinic and the person doesn't have a nametag. They don't greet you. She doesn't tell you what to expect. Nothing. So really we have to deal with the health system itself even before anything else. Our staff have lost that code of conduct. They have bad attitudes. Why do we go to the private sector? It doesn't have anything special over the public sector. We go because of the quality of care. When you go there they make you feel special. When I come in they greet me. When I sit down I only sit for five minutes. When I get up they say I am going to take your blood pressure. When I give you your medication I will tell you about it. I will give you cold water and not hot water. People stay at home and die. Why? Because they are scared to come. Even to collect their treatment.” Key informant, NDOH*

*“I know many people in the community who don't want to come to the clinic. They say they get shouted at when they come.” ANC client, L Province*

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**Key informants highlighted training of staff and proper management** as key to improving staff attitudes. In KwaZulu-Natal, **weekly staff meetings in the form of ‘grand rounds’** to discuss new and innovative findings relating to HIV care, new guidelines, and complex cases were highlighted to be very helpful in keeping staff up to speed with HIV and help keep them motivated. **Best employee competitions** are also being utilised in several visited facilities to help incentivise staff to provide better quality care.

Quality improvement programmes for health systems strengthening, through the use of additional resources, protocol revision, learning workshops, and other initiative such as **better integration** between ANC and ART clinics as well as having a ‘Mother's Day’—a weekly clinic dedicated for pregnant women needing ART and the M2M2B programme helped reduce the proportion of HIV-exposed infants testing positive from 7.6% to 5% ( $p < 0.05$ ) in Western Cape<sup>63,121</sup>. The proportion of pregnant women booking for antenatal care at less than 20 weeks gestation increased from 18% to 33% following the interventions ( $p < 0.001$ ). A significant improvement was also observed in the proportion of women who had initiated ART by the time of delivery, from 10% to 25% ( $p < 0.001$ ). In another study among pregnant women from Western Cape, however, pregnant women attending antenatal care using three different service delivery models (referred to an ART clinic within 5 km, an ART clinic on the same premises but not in the same building and an integrated service whereby outreach doctors came to the ANC clinic twice a week) had comparable ART initiation rates<sup>122</sup>. In a study from

Gauteng, pregnant women who were served by an ART doctor who came to the clinic once a week initiated ART quicker (median of 37 days after ART eligibility; according to previous guidelines) compared to those who were referred to an off-site ART clinic (56 days) ( $p < 0.05$ )<sup>123</sup>. Assessing the impact of human resources for health capacity on ART initiation rates, a study by Ingle et al., found that low ART healthcare provider to client ratios are associated with a reduced probability of starting ART after enrolment at HIV care facilities.<sup>54</sup> In a before and after observational study among pregnant women from Cape Town, results were presented comparing standard of care to two interventions: 1) enhanced linkages, through the use of lay counsellors as navigators to guide pregnant women from ANC to ART services and 2) integration of ART into ANC services, by having midwives screen and initiate ART without the need to refer. The study found that more eligible women were screened and initiated ART for those with enhanced linkage (53% and 49% respectively), served by an integrated model (93% and 86% respectively) compared to those served by standard of care (26% and 21% respectively) ( $p < 0.001$ ). Reduced delays to ART initiation among the intervention group were also observed<sup>124</sup>.

The result of investments in staff capacity building, quality control and development of HIV services can lead to positive client feedback:

#### Positive HIV service experiences: Selected client views

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*"I am happy with the service". Client on ART for 11 months, Limpopo Province*

*"I get good quality care here. It's easy for me to ask questions." Stable client on ART, Limpopo Province*

*"The service here is very good. But it is sometimes slow." Client on ART for PMTCT, Limpopo Province*

*"I have no difficulties with my medication...I come here every month and I don't have to wait very long. I have disclosed to my work and they are happy for me to come. It's easy for me to come here. It's not far." Stable client on ART, Limpopo Province*

*"My CD4 was very low. I received counselling twice at the hospital and it really helped me." Stable client on ART, Limpopo Province*

*"Counselling really helped me." Stable client on ART, Limpopo Province*

*"The clinic is opened on Saturdays which really helps." Stable client on ART, Limpopo Province*

*"There is always medication when I come here." Stable client on ART, Limpopo Province*

*"It's very easy to ask questions here. The sisters are helpful." Client on ART for 11 months, Limpopo Province*

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## 6.6 Special populations: Youth

Youth are at high risk of HIV infection, and of non-adherence and retention at all stages of the HIV cascade, often engaging in high-risk sexual behaviour, poorly developed coping skills and poor access and engagement with health services. Despite this, there is a gap in services

specifically tailored to youth to improve youth's progression through the cascade, from HIV diagnosis to ART initiation, adherence and retention.

A recent systematic review (September 2014) of a wide array of studies, including randomised, non-randomised, prospective and retrospective cohorts as well as reports on routinely collected programme data, investigating the effectiveness of youth-specific interventions at all stages of the cascade, identified only one study carried out among youth in South Africa<sup>125,126</sup>. This single study was a randomised study carried out among adolescents aged between ten and 14 years enrolled in two hospital-based HIV care clinics in KwaZulu-Natal. The study assessed the impact of family-based counselling (six sessions using cartoon aids or usual care). Adherence was measured through self- or parent-reports at baseline and at three months with no significant differences between the two groups for "last time missed meds". Overall, there were 11 studies—including the South African study—reporting on individual and group counselling and education; motivational interviewing; peer support; case management; directly observed therapy; financial incentives; and interventions to improve the adolescent-friendliness of clinics. The overall quality of the evidence was reported to be poor with ten of the eleven studies judged to be at high risk of bias. The authors of the systematic review concluded that "rigorous evaluation of a wider range of existing and new interventions applied at the individual, health facility and policy levels are urgently required".

### 6.6.1 Featured model: The MSF youth specific retention model

The MSF youth specific model has several key components. Combining point of care CD4 testing with the MSF ART initiation model means that there is no delay to starting treatment; testing, CD4 and the first counselling session can all be done on the same day, minimises missed opportunities.

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*"We have seen our treatment initiation rates increase among our youth using this strategy."*  
Key informant, Western Cape

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The model combines pre-ART clients, those who are newly initiated on ART and those who are stable on ART (see Chapter 8 on Maintenance phase) to enhance learning among youths in order to reduce fear of initiating treatment among pre-ART clients and those newly initiated on ART. It also allows clients with co-morbidities to be included. With the adult model, clients are temporarily suspended from such clubs.

During the group sessions youth specific topics are discussed using very structured lesson plans and incorporates activity-based learning. Because it incorporates the MSF ART initiation counselling model it is linked to the MSF Risk of Treatment Failure Program, described in the next chapter. The model also utilises social media (WhatsApp and Facebook virtual chat groups that includes youth from all groups) to create a much stronger peer bond.

In Limpopo Province, one nurse also highlighted the important use of social media to allow her to communicate with her clients.



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*"I am telling all the nurses now about WhatsApp. If people agree, I say let's take their numbers, and I message them if they are comfortable. I ask them to please take their medication to remind them. Then the patient can ask questions. This will help. On Facebook I formed two groups. There I discuss everything about the clinic. There they can also give me comments. They can ask questions. I tell them here is the number for the clinic. Please call us. For the women's forum, for example, I told people to come for cervical screen on women's day. I tell them come tomorrow. You won't have to wait. You can go straight to maternity. We will be there waiting for you and we do everything. Cervical screen, breast exam. To encourage them to come I tell them we will measure their bra sizes. People often don't know their size but they want to know. We will tell them we will measure you when you come. So everyone in the group will see this. In the group, they can ask anything. I had someone ask me about implants the other day. People tell me they are feeling weak and I tell them to come to the clinic. With the WhatsApp I don't use the people's names. I use a code. I give everyone a code. So no one knows who is who, they don't even know when it's me talking. We all just talk on the forum. With the names it's not good, as people will know each other. This is really working. I have Facebook for the CHW, I have it for the breastfeeding women. I have more than 200 women on the clinic forum and more than 150 on the women's forum group. People just joined the group, mainly through word of mouth. WhatsApp and Facebook groups are not linked. The way it worked is that through the Facebook group, some people complained, telling me that sometimes with Facebook they don't get my messages fast. When you are at work, it's not easy to get to Facebook. So with WhatsApp they told me that it will be easy to get the messages fast. So they asked me to set up another group. The same group but on WhatsApp. So we can get messages urgently and easily." Key informant, Limpopo Province*

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**Once initiated on ART, clients will need to be supported and monitored during the initial ART consolidation phase, which is usually twelve months long.**



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# Chapter 7. Results: ART consolidation phase

## 7.1 Key points

- An increasing percentage of each annual treatment cohort is already lost in the first six months; of the 2012/2013 treatment cohort, approximately 20% of initiated clients (or about 120,000 individuals) had dropped out of the cohort by six months.
- Client characteristics for non-adherence include: food shortages; lack of education; alcohol abuse; difficulties in accessing ART services (long waiting time, distance and transport, work preventing clinic visits due to unsuitable clinic opening hours); and the stigma associated with HIV positive and ART.
- Elements of strategies and models with potential are: 'diagnosing' the true reason for non-adherence and 'prescribing' an individualised action plan; the MSF risk of treatment failure programme based on early viral load measurement and tailored support, leading to re-suppression in many clients (also run for paediatric clients); The Adherence Community Care Worker Programme doing home visits; nutritional support for ART clients; text messaging; and the MSF counselling model designed for clients with drug-resistant TB.
- Fixed dose combination drugs have been shown to reduce adherence problems, and there is trial evidence that positive parenting, treatment buddies, and cash/in-kind support help ART adherence of adolescents.
- The attrition rate on ART is highest in the first six months, and this is reflected in mortality rates during treatment consolidation exceeding those in Europe and North America. Clients at facilities with larger client loads had increased attrition due to LTFU and reduced initial virologic suppression.
- Effective, scalable interventions during treatment consolidation will prevent clients exiting the cascade, facilitating their re-entry, and prevent AIDS deaths.

## 7.2 Data on ART consolidation

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*"We can go to 500. But do we know about the ones we already have? Can we keep them on treatment?" Key informant, Western Cape*

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The ART consolidation phase is the initial twelve months after ART initiation, which should be accompanied by the tracking of treatment indicators three, six and twelve months after initiation. The aim is to monitor the client more closely, who is usually not yet eligible for certain initiatives like MediPost and ART adherence clubs. In addition to newly initiated ART clients,

this phase also includes those who are struggling with their treatment and/or who are unstable. In this phase, the client might experience negative treatment side effects, or might feel better and discard treatment. There might be mental issues such as forgetfulness or lack of motivation to take their ART medication as prescribed, depression, and/or a lack of understanding of the relationship between adherence and disease progression. There is growing awareness that individual clients' support needs will differ during these important first months of ART.

Cohort data from the DOH suggest increasing losses during the consolidation Phase<sup>10</sup>. While older cohorts of clients starting ART eight or more years ago had over 90% of clients remaining on ART after 6 months, this figure now approaches 80% in the youngest cohort (initiation 2012/13).

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*"The first decade in South Africa was all about roll-out of ARV. This second decade will be all about adherence." HIV/AIDS Physician, Western Cape*

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Adherence to ARV treatment is essential to reduce morbidity and mortality among PLHIV, as well as for achieving the full benefits of treatment as prevention at the community level. Optimal adherence to ARV is the strongest predictor of HIV viral suppression, while sub-optimal adherence results in a high viral load and a susceptibility to drug resistance and treatment failure, meaning future options for treatment become limited. For older protease inhibitor based therapy, near perfect adherence—at least 95% of all prescribed doses must be taken –, is required. For newer ARV, non-nucleoside reverse transcriptase inhibitors (NNRTI) and ritonavir boosted PI therapy, it is thought that this optimal adherence threshold may be lower and more strongly associated with patterns of treatment intake over time (rather than simply related to the proportion of missed doses)<sup>127–131</sup>.

**Causes of non-adherence in South Africa include individual factors, system factors and community factors.** Interviews with key informants highlighted several client factors as barriers to adherence including lack of nutrition, lack of education and alcohol abuse. Barriers at the system level were repeated by many key informants to be related to long queues and distances to the facilities. Stigma was emphasised to be a major barrier to adherence.

**Client discussions also raised a number of issues that lead to sub-optimal adherence and treatment interruptions including being unable to take time off work, and stigma.** Many of these barriers to treatment and care are shared across the cascade (see also Chapter 4). Despite the efforts to protect the HIV positive employees against unfair discrimination, through the Employment Equity Act 55 of 1998<sup>m</sup> and HIV workplace policies, ART clients suffers from discrimination and stigma, as illustrated by these client statements:

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*"My friend lost her job because she lied to her work about what she was doing. She didn't want to tell them that she had to go the clinic. There is still a lot of stigma here." Stable client on ART, Gauteng Province*

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<sup>m</sup> <http://www.labour.gov.za/DOL/downloads/legislation/acts/employment-equity/Act%20-%20Employment%20Equity.pdf>

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*“I used to be a cheese maker. I told my work that I was HIV positive and I got fired. We can never tell our work.” Male client on ART, Gauteng Province*

*“I can’t lie to work every month. I can’t tell them the truth.” Female client on ART, Gauteng Province*

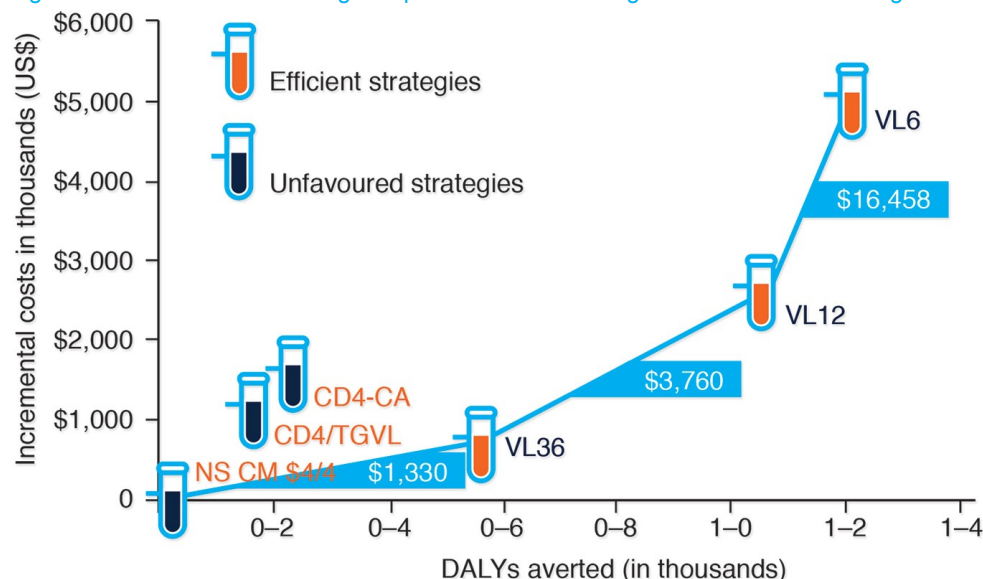
*“I work every day and it is hard to take time off work. I can’t tell my work that I am positive. I am afraid. I haven’t disclosed and I would never want to disclose my status. I would rather get treated at my local clinic instead of here but I don’t want people to know my status.” Stable client on ART, Gauteng Province*

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Although multiple methods have been used as a means of measuring and monitoring adherence to antiretroviral treatment—such as pill counting and pharmacy prescription refills—the viral load is considered to be the best marker for clinical decision making after initiation of ART. It indicates the effectiveness of the treatment and is useful to detect early signs of treatment failure and determine the best time to switch to an alternative treatment regimen. Recent studies suggest that a delay in the initiation of second-line ART among people who experienced first-line failure was associated with higher mortality compared with those who had earlier initiation of second-line ART. VL monitoring is a particularly useful tool for monitoring adherence to treatment, performing sentinel surveillance and diagnosing HIV infection in children aged below 18 months.

Models have compared VL monitoring at different frequencies with CD4 counts and clinical staging, in combination or alone, to manage treatment in ART clients. The use of VL monitoring every six or 12 months and without the inclusion of CD4 counts provides the greatest estimated reductions in morbidity and mortality (Figure 10). Price reductions of VL technology and increased use of VL test capacity are essential to achieve high cost-effectiveness of regular VL monitoring, otherwise, models predict that more health impact can be generated by increasing ART coverage or expanding ART eligibility<sup>132</sup>. The additional costs of VL assessment may however be balanced by avoidance of unnecessary switches to more expensive ART regimens, as shown by another modelling study<sup>133</sup>.

Figure 10. Viral load monitoring compared with immunological or clinical monitoring and DALY impact



Source: Keebler, D. et al. (2014)<sup>132</sup>

### Making VL monitoring cost-effective

Since VL monitoring as a routine approach used universally might not be cost effective, different strategies could be applied to increase its cost effectiveness and phase in the roll-out of VL monitoring<sup>134</sup>.

1. **Use of VL monitoring tailored for certain client populations**, including individuals with adherence problems. In this case, adherent persons with undetectable VL are followed less frequently and those with detectable VL following treatment initiation are followed more closely.
2. **Adapting the frequency of VL monitoring**, an approach that is already implemented.<sup>n</sup> The drawback of this approach is the risk of delaying a needed treatment switch.
3. **Selective VL monitoring based on immunological or clinical criteria**, where VL monitoring is used only to confirm virologic failure upon immunological or clinical assessments. This also runs the risk of delays before switching regimens.
4. **Targeting VL assessment to treatment as prevention (TasP) priority populations**, especially pregnant and breast-feeding women and sero-discordant couples, as virologic failure in these cases carries an increased risk of onward HIV transmission.
5. **Combined VL targeting strategies to help find an acceptable compromise between benefits and costs**, such as the use of different thresholds for the definition of virologic failure (e.g., 1,000 vs. 5,000 copies/mL) and varying frequencies for VL monitoring (e.g., every six, 12 or 24 months). The threshold of 1,000 copies/mL for virologic failure is meaningful for TasP (based on studies looking at the risk of transmission), whereas lower

<sup>n</sup> Note that the 2013 WHO guidelines recommend VL monitoring six months after ART initiation and every 12 months thereafter, with a threshold of 1,000 copies/mL for plasma samples and of 3,000-5,000 copies/mL for dried blood spot samples.

thresholds of detectable viraemia, such as 200 copies/mL, are meaningful to clinical and immunological outcomes.

These options for increasing cost-effectiveness of VL monitoring could be extended further (based on the International AIDS Society-Industry Liaison Forum symposium in Lusaka in May 2014 and other discussion forums<sup>o</sup>):

- **Ensure that VL monitoring is implemented effectively by clinic staff** - MSF data from South Africa show that of 7,094 clients on long-term ART, only 4,041 (57%) had had at least one VL, and 37% of these had a most recent VL result above 1000 copies/mL but no clear action to address this had been taken<sup>135</sup>
- **Combine VL monitoring data with targeted counselling and other adherence strategies that are proven to be effective and efficient.** Analysis of MSF programme data from Swaziland showed that attending three sessions of counselling, as advised by the programmatic algorithm, did not increase the likelihood of ART clients achieving viral suppression.
- **Communicate about the VL monitoring results with the client.** It is possible that the knowledge of the VL result can help motivate improvement in clients' adherence. If HIV VL monitoring is to be truly useful, it may be that clients need to be able to understand the VL result, and maybe even motivate a VL assessment. Access to VL data may strengthen clients' empowerment and self-management of their chronic disease. Access to routine VL testing could also enable programmes to reduce the number of clinic visits for clients with viral suppression while ensuring that clients with clinical needs are getting the additional input they require.

In summary, VL monitoring is the gold standard for monitoring ART clients' response to treatment and is the WHO recommended strategy of choice, however, it is expensive and competes against other investment options in the ART programme. To not just retain clients on ART but to retain them with an undetectable VL, strategies around VL targeting, frequency and use of results by health staff and clients need to be considered urgently. It appears that if large-scale and point-of-care introduction of VL monitoring is to succeed, the health providers and ART clients need to work together.

## 7.3 Models and interventions

### 7.3.1 Diagnosing non-adherence for correct 'prescriptions'

In many visited facilities the strategies for addressing non-adherence were not focused and individualised. The usual prescription for non-adherence was more education and counselling and reducing the ARV supply duration to 1 month meaning that clients have to return to the facility more frequently. The reason a client is not adhering may well be that he or she could

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<sup>o</sup> For instance: Helen Bygrave, Médecins Sans Frontières, <http://blogs.plos.org/speakingofmedicine/2014/01/27/hiv-viral-load-testing-africa-longer/>

not make it to the clinic due to work commitments. Therefore the 'prescription' is not necessarily aligned to the root cause of non-adherence. In addition, not all causes of non-adherence are the same. In order to align the strategy or 'prescription' to the 'diagnosis', a thorough investigation with the client, utilising a client-centred approach is required. Keeping those who are struggling with adherence at clinics may not be the best option. These clients may be the ones that would be better served in the community.

Many clients highlighted the fact that it was difficult for them to take time off work to collect their medications and said that having a longer supply of drugs would really help them with adherence.

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*"I had a problem last month with my medications. I couldn't take time off work so I sent my wife to come here to get my treatment for me. But they didn't give it to her. From last Thursday until today I have not been able to take my medication because of this." Male client on ART for eight months, Gauteng Province*

*"Having more than one month supply of medication would be very good." Stable client on ART, Limpopo Province*

*"If they gave me more medications each time I come this would really help me." Client on ART for 11 months, Limpopo Province*

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Figure 11 shows how having the same strategy for all—in terms of focus and approach—is not efficient, nor effective. Instead, we must have a stratified approach whereby those who need the most support—the 'strugglers' or those who are unstable—receive more support, which is tailored to their individual needs (Figure 12).

Figure 11. A 'blanket' approach for all is inefficient and ineffective

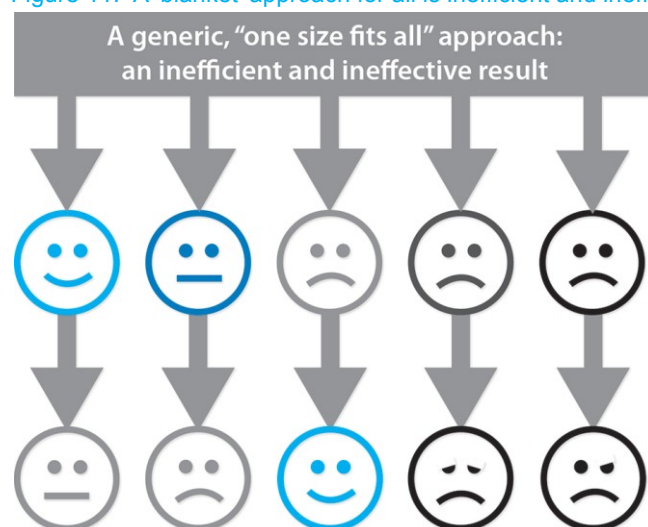




Figure 12. Focusing on the 'strugglers' and or those who are unstable with an individualised approach

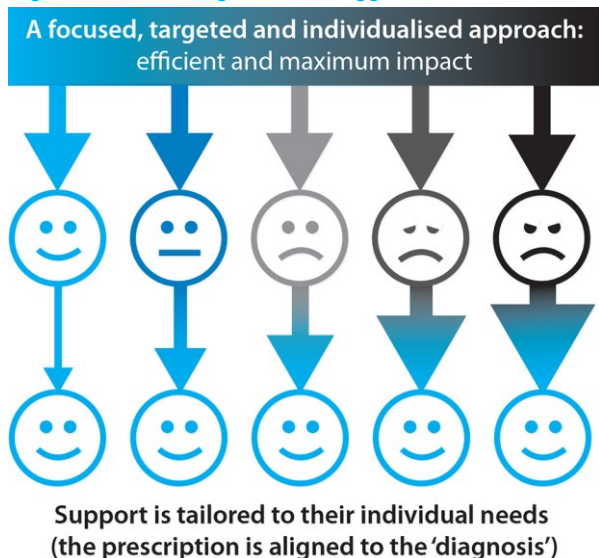
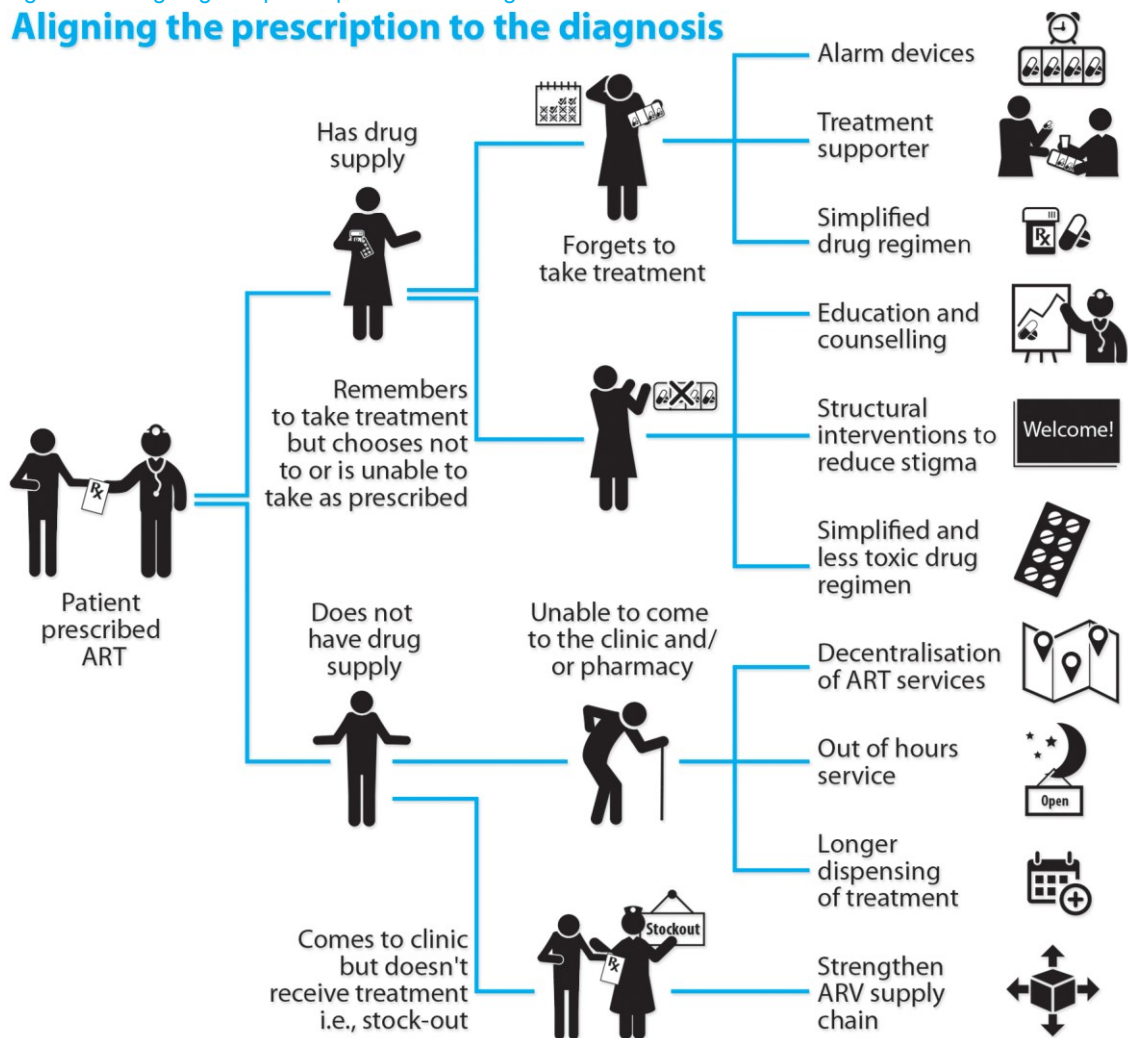


Figure 13 highlights some of the strategies for improving adherence correctly aligned according to the 'diagnosis' of non-adherence. It is important to bear in mind that such a model requires heavy system investment including for drug supply and order on demand. There is an opportunity for using electronic pre-ordering of medication as part of client self-assessment and self-monitoring.

Figure 13. Aligning the 'prescription' to the 'diagnosis'



*"The number one reason people don't adhere to their treatment is misunderstanding. We need to focus on adherence and not on side effects. A lot of the counselling that we did in the past was focused on side effects and not on adherence. We didn't have a chance to understand how patients interpret information. Half of VL failures are caused by us. We didn't understand the mind-set of patients. For example we tell them not to mix alcohol with their ARVs. So men don't take their ARVs in the weekend. We need a problem solving approach. That is what new counselling approaches are all about." Key informant, Western Cape*

### Standard didactic adherence counselling methods are not inferior to intensive motivational based counselling methods

In a RCT from KwaZulu-Natal, standard didactic counselling was compared to more intensive individualised motivational adherence counselling<sup>136</sup>. Both groups received two initial pre-initiation didactic sessions. After randomisation those in the didactic arm received another didactic counselling session, in line with most practices from visited facilities. Those randomised into the motivational counselling arm received five individualised motivational counselling sessions at intervals up to 6 months after initiation of ART. The study found no

differences between standard didactic counselling approaches and more intensive motivational based adherence counselling in adherence, measured pill counts at six months (RR 0.96, 95% CI 0.85–1.09,  $p=0.51$ ), and in virological suppression at nine months (RR 0.98, 95% CI 0.90–1.07,  $p=0.62$ ), again with high rates of adherence and VL suppression in both groups. The study concluded that “less resource intensive didactic counselling was adequate for excellent treatment outcomes”. In an evaluation of the nature of counselling delivered by counsellors on adherence, the study found that counsellors usually rely on didactic, information giving methods to deliver advice relating to non-adherence issues<sup>109137</sup>. In addition, a qualitative study from Western Cape, counsellors were reported to struggle with some of the elements of motivational interviewing techniques, such as assessing readiness-to-change and facilitating change talk<sup>138</sup>.

In another RCT<sup>139</sup>, also conducted in KwaZulu-Natal, ART eligible clients initiation ART were randomised to receive either a standard adherence intervention package plus a structured three session group intervention or to a standard adherence intervention package alone. A standard adherence package consisted of monthly visits with physicians (5 min), nurses (10 min), and pharmacists (5 min) with a one-month of ARV supply being issued to the client. The structured three-session group intervention consisted of monthly interactive group sessions, for a total of three months, each lasting one hour, providing information on HIV-related issues, assessment of adherence and potential barriers to adherence, the use of a buddy system and problem-solving exercises around non-adherence issues. Although knowledge around adherence issues increased significantly in those who underwent the three-session group intervention in comparison to those receiving standard of care only, the study found no significant improvements in adherence between intervention and control arm, with high levels of adherence exhibited by both treatment groups.

### 7.3.2 Featured model: The ‘Masivukeni’ multimedia-based ART adherence counselling model

Remien et al (2013) reported a pilot acceptability study of Masivukeni (means ‘Let’s wake up’ in Xhosa), a six-session multimedia counselling intervention for clients and their treatment partners delivered through a laptop<sup>140</sup>. This process evaluation was carried out in a healthcare clinic located in a high HIV prevalence township in Cape Town. Masivukeni was adapted from the SMART (Sharing Medical Adherence Responsibilities Together) Couples intervention, initially developed in the U.S. Advantages to the model include the fact that it provides standardised adherence education and support, emphasises treatment support and problem-solving skills and the fact that it is interactively delivered. In addition, the programme can also monitor client progress (e.g., treatment regimen, pharmacy refill schedule, social support network, adherence barriers, etc.) and information on the counselling sessions such as which content was delivered and on which dates. The challenges to the model include the fact that it is currently only available in English. Participant also reported that they found some of the sessions long and repetitive. Its reliance on technology means its sustainability is not uncertain; the programme has been discontinued at the pilot site after the donated laptop broke. However, the model does not need an Internet connection for delivery of sessions.

### 7.3.3 Featured model: The MSF ‘Risk of Treatment Failure’ programme for those identified as having sub-optimal adherence

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*“Counsellors weren’t trained to deal with adherence. We need people who have received additional training around adherence to deal with adherence issues.” Key informant, Western Cape*

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MSF, in partnership with the Western Cape Government, piloted a ‘risk of treatment failure’ intervention at Ubuntu Clinic, a large community health centre in Khayelitsha, Western Cape, with more than 7000 adult clients on ART (of whom around 10% are on second-line treatment)<sup>141</sup>. The programme identifies clients who are at risk of failing their treatment (viral load >400 copies/mL) and provides them with focused and structured support in the facility. In brief, the programme comprises several components, once a client has been flagged as being at risk of treatment failure, when he or she presents to the reception staff to collect their folders for their appointments:

1. A ‘high viral load’ adherence support group—facilitated by a counsellor who has undergone a basic mentoring programme and who follows a structured session plan—is held daily at the facility. Flagged client must attend this group prior to their clinical appointment. The idea behind grouping clients with sub-optimal adherence is that it may promote honesty and openness around the true causes of non-adherence, which may not otherwise be disclosed to the healthcare provider.
2. Once the client has finished the support group session, they either go for a routine consultation with a clinic nurse (if it is their first elevated viral load) or for an individualised consultation with a ‘risk of treatment failure’ nurse, who provides adherence support in combination with clinical management.
3. After the consultation, the client passes to the clinic pharmacy to collect their medications
4. If the client succeeds in suppressing their viral load, they can potentially qualify to join an adherence club, described in detail in the next chapter.

The advantages of this model are manifold. Firstly, by using the viral load to identify those who are at risk of treatment failure, those who are not adhering to their medication—and thus need additional support—can be identified quickly; the South Africa HIV guidelines recommends a first viral load to be taken at six months after treatment initiation<sup>62</sup>. The model includes a multi-disciplinary approach to adherence support. In addition, the model incorporates an individualised action plan for those at risk of treatment failure, which can be linked back to their initial treatment plan—if the MSF initiation counselling model is utilised in the same facility. In other words, the healthcare provider and the client can work together to better understand why the initial treatment plan did not work, and make changes accordingly. The model also encourages healthcare providers to not delay switching treatment, as otherwise the client may get demotivated if he or she begin to adhere to their treatment without seeing positive results (i.e., a suppression of their viral load). Providing clients with the opportunity to join the adherence clubs is also a strength of the model. Clients who have previously had difficulties with adherence may have done so due to difficulties taking time off work to return to facilities frequently, for example. Allowing them to reduce the number of visits needed through adherence club participation would support their continued adherence in the future. So far, the

programme has admitted 722 clients, 69% of whom were on first line treatment on admission. Preliminary results have shown that, using the programme, around 30%, 60% and 80% of clients on first line ART, second line ART, and those who are switched to second line ART can be re-suppressed respectively.

A similar model to the above, which utilises lay counsellors to deliver the enhanced adherence sessions rather than NIMART nurses, is the MSF 'enhanced adherence counselling model'. This model has been implemented by MSF in KwaZulu-Natal province and is a cheaper alternative to the 'Risk of Treatment Failure' model. An 'enhanced adherence counselling' approach has also been described by MSF in Swaziland, and the cost of delivering three enhanced counselling sessions was estimated at \$1.99<sup>142</sup>.

#### 7.3.4 Featured model: The MSF drug-resistant TB counselling model

The MSF counselling based model to support clients with drug-resistant TB is a structured, standardised counselling approach that can be used by lay counsellors and other healthcare workers to support DR-TB clients, structured in a similar fashion to the ART model. Clients receive three individual intensive counselling sessions at treatment initiation, which focus on treatment literacy and adherence planning. One of these initial sessions incorporates a home visit whereby contacts are identified and screened, information and education is provided to the family to encourage them to support the client, and an infection control assessment of the home. Once these intensive three sessions are completed, a fourth session is done where the adherence plan and any new issues are reviewed and additional support and encouragement is provided to help the client complete their treatment. Having multiple sessions over time is done with the idea that this gives clients time to process the information and ask questions as they come up.

Counsellors providing the sessions are equipped with a manual and toolkit to ensure that the messaging and information is standardised. This toolkit can also be used to assess the competency of the counsellors for quality assurance purposes. The manual is designed to help the counsellor focus the sessions, encouraging a "relational approach rather than [merely] an information relaying approach." The sessions include 13 adherence steps that are addressed by the counsellor and the client with the aim supporting the client in identifying and addressing potential barriers to treatment initiation and adherence. Similar to the ART model, clients are asked to identify three reasons to stay health and alive and addresses issues around treatment interruption and substance abuse. Clients who are identified with sub-optimal adherence and treatment interruption are provided with additional 'treatment interruption' sessions where the client and the counsellor work together to find out the reasons for treatment interruption. The original adherence plan is reviewed and a new condensed version is drawn up. The clients and the counsellor agree short-term goals, and follow-up sessions are arranged with nursing staff to ensure that the goals are met. The idea behind using nurses rather than counsellors for these follow-up sessions is for strengthening the nurse-client relationship.

**The session plan of MSF drug-resistant TB counselling model looks as follows:**

**Session 1:** This session targets those who are newly diagnosed with DR-TB and is carried out at treatment initiation in the clinic. Simplified information around TB and DR-TB is provided as well as an individualised plan of how the client plans to attend their appointments (adherence step 1), deal with side effects (step 2), get support at home (step 3) and at the clinic (step 4) and get screened for audiometry (step 5). Again the client must identify three reasons to stay alive and healthy and are provided with red stickers.

**Sessions 2 and 3:** The second session, which may be combined with the third, is carried out within one week of treatment initiation either at the home or at the clinic. Adherence steps six to ten are covered during session 2, which relate to how to prevent future mistakes (step 6), identify a treatment partner (step 7), communicate with the treatment team (step 8), manage weekend doses (step 9) and reminder strategies (step 10). The third session is carried out within the first month of DR-TB treatment initiation usually at home, and covers adherence steps 11 (how to protect family members), 12 (how to deal with substance abuse) and 13 (how to manage unplanned trips away). Relevant treatment literacy is also provided during these two sessions using a standardised flip chart.

**Session 4:** The fourth session is carried out at the clinic once the client has completed the three aforementioned intensive sessions. Treatment literacy messages are revised and the adherence steps are revisited to help ensure on-going adherence.

**Additional sessions:** Treatment interruption sessions target those clients who have interrupted their DR-TB treatment for two or more consecutive weeks or those clients who frequently interrupt treatment but for shorter periods, and are carried out either at home or at the clinic. Follow-up sessions are carried out one week later at the clinic and are nurse-led. In addition, there are extra sessions for those with extensive drug-resistant TB session (XDR-TB) and those requiring palliative care.

### 7.3.5 Featured model: Managing XDR-TB clients outside the hospital

The classic approach to managing those with pre-XDR-TB and XDR-TB is hospitalisation regardless of clinical status, as per national policy, for infection control, management of second line drugs and due to poor treatment outcomes among this population, leading to high rates of deaths, defaulting and treatment failure. Hospitalising everyone, however, may be inefficient and unacceptable by clients, who may live far away from specialist TB hospitals or just refuse long admissions, particularly if they are stable. In addition, there may be long waiting lists due to limited hospital beds. In Khayelitsha, Western Cape, a decentralised model of care for DR-TB has been utilised since 2007, whereby the majority of DR-TB clients are managed by the primary health care facility. In January 2012, this was extended to XDR-TB clients. MSF identified and traced both pre-XDR and XDR-TB clients and allowed those who were clinically stable and adherent to be managed by the primary health centre, after an initial short stay in a local sub-acute facility, using a modified drug regimen. The drug regimens were individually tailored and agreed by the TB hospital clinicians and other local experts. On-going



management and monitoring were done by the local health centre, who's staff received additional training on monitoring and management of adverse events and on-going clinical support. By May 2014, almost half (49%) of all identified cases (n=68) were initiated on treatment by the primary health centre or sub-acute in-client facility, with 18% completing treatment (6/33), 61% (20/33) still on treatment, one failed treatment and two clients each died, transferred out or were lost to follow-up. Of the 20 who were still on treatment, at least 13 reportedly had a negative sputum. The study, which was reported at a TB conference in June 2014 in South Africa<sup>143</sup>, concluded that managing clinically stable XDR-clients outside a hospital setting is feasible if staff are trained and are know how to manage DR-TB clients, where access to specialist support and in-client services is available when necessary and when the appropriate drug supply is assured. In other words, 'blanket' hospitalisation of all XDR-TB clients may be unnecessary and result in lower adherence and retention of these clients.

### 7.3.6 Directly Observed Therapy for ART

Directly Observed Therapy (DOT) is a practice, borrowed from TB treatment, whereby the client is observed taking their treatment on a daily basis by a third party, usually a community or facility based health worker or an assigned treatment supporter. By directly observing the client swallowing the tablet(s), adherence can be assured. DOT can be modified (mDOT) so that only a proportion of tablets are observed over a specified period of time.<sup>144–149</sup> Several RCT have been conducted in South Africa assessing the impact of DOT and/or mDOT on viral suppression<sup>149,150</sup>. One, conducted in Cape Town, comparing clients who had DOT-ART by a treatment supporter with clients who self-administered ART, was stopped early because the study could not show any effect of DOT-ART on virological outcomes.<sup>150</sup> Another RCT, conducted in South Africa and USA, found only marginal benefit of a modified-DOT strategy (Monday to Friday for 24 weeks), which was not sustained at 48 weeks, after discontinuation of mDOT<sup>149</sup>. A systematic review and meta-analysis, published in 2010, found no significant effect on viral suppression of DOT-ART when combining findings from randomised controlled trials<sup>151</sup>. Furthermore, DOT and mDOT have been criticised for being too 'mothering' of clients, and is not necessarily conducive to encouraging clients to be empowered to take control of their own treatment, according to interviewed key informants. In Khayelitsha, Western Cape, the practice has been discontinued for both ART and TB. It has been replaced by The Adherence Community Care Worker Programme, which is described below.

### 7.3.7 Featured model: The Adherence Community Care Worker programme

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*"Community Care Workers are our foot soldiers." Key informant, Western Cape*

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The Adherence Community Care Worker programme was started in 2010 in Khayelitsha, Western Cape to replace the practice of DOT. It was described by one key informant as a "middle ground" because they "didn't want to go from DOT to nothing so quickly." In a five-year observational multi-cohort study carried out in four provinces in South Africa (Eastern Cape, Mpumalanga, KwaZulu-Natal and Western Cape), the use of a community-based approach to



deliver adherence and psychosocial support through the use of home visits by lay health workers was shown to improve ART outcomes<sup>43</sup>. Those having home-visits for adherence support were more likely to be retained at five years (crude hazard ratio for attrition was 0.68 (95% 0.65–0.72). When adjusting for covariates, they were also more likely to have lower mortality (adjusted HR =0.65, 95% CI: 0.59–0.72) and LTFU rates (adjusted HR =0.63, 95% CI: 0.59-0.68) compared to those who did not receive the intervention. In addition, those who had the community-based intervention were more likely to be virologically suppressed at six months after ART (adjusted odds ratio=1.22, 95% CI: 1.14–1.30).

Community Care Workers (CCW) are trained to monitor and support TB, HIV and TB/HIV co-infected clients in the community. Six facilities are also supporting drug resistant TB clients. Each CCW is allocated to TB clients (45% of clients), HIV clients newly initiated on treatment (20% of clients) or TB-HIV co-infected clients (35% of clients). Clients are visited at home for pill counts by the adherence CHW three times within the first week of referral then weekly thereafter. Reported challenges to the model include the fact that the stipend for the CHW was too little, wrong addresses are frequently given by clients, CHW are not provided with airtime to contact clients, often the CHW are operating in dangerous areas, the working time allocated is too little for CHW to complete work (four and a half hour shifts) and the emotional distress experienced by some CHW due to challenging clients.

Interviewed CHW also reported that many clients did not accept pill counting. This integrated TB/HIV model is optional but the TB client is unable to receive a month supply of treatment without registering for the programme. Concerns were raised that clients accepted the programme in order to be eligible for the one-month supply and therefore initially accepted the CHW to come and visit. Later, when the CHW turn up at their home, they do not accept them and they do not accept the pill counting.

Concerns were also raised around the CCW uniforms. It was felt that having uniforms that do not have TB and HIV labelling, as is currently the case, would help overcome issues around stigma.

CCW have an opportunity to discuss their clients at a multi-disciplinary team (MDT) meeting conducted on a weekly basis. These meetings are designed to help 'get to the bottom' of the causes of non-adherence. However, these meetings need to be strengthened. The team observed one such meeting and found that the meeting was overcrowded with minimal input from the CCW and rather more like a tick-boxing exercise. One possible strategy to help improve these meetings would be to send only the CCW supervisors who would present the cases on behalf of the CCW. This would also free up CCW time that they could instead use to work in the community rather than spend it at the facility.

The research team shadowed CCW while they went to work. With the current model everyone gets visited in a similar fashion regardless of risk factors for non-adherence. A better approach may be to utilise screening questions at the first visit to highlight that those who are likely to be able to manage with less support, meaning that more focus could be put on those who need it.

### 7.3.8 Nutritional support

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*“We are working with nutritionists to integrate nutrition into HIV care. We think that was the long forgotten part, especially in the care of the women. For adherence, you need proper support. You need the proper nutrition in order to take your treatment for HIV and for TB.”*  
*Key informant, KwaZulu-Natal Province*

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In a study conducted in four settings—Lesotho, South Africa (KwaZulu-Natal), Namibia, and Botswana—published in 2010, the use of home-based care and/or food support services was associated with greater adherence (67%) compared to those who did not receive these services (58.2%) ( $p < 0.05$ )<sup>152</sup>. Similarly, a study from Zambia reported better adherence among those using food clinics (70%) compared to controls (relative risk = 1.5; 95% confidence interval: 1.2 to 1.8). This finding was maintained even when controlled for sex, age, baseline CD4 count, baseline World Health Organization stage, and baseline haemoglobin<sup>153</sup>. In a more recent study (2012), also from Zambia, medication adherence was significantly higher among clients receiving food assistance (98.3%) compared to non-recipients (88.8%) ( $p < 0.01$ )<sup>154</sup>. Specifically related to paediatric HIV care, a study by Adjorlorlo-Johnson et al., observed a significant association between favourable paediatric enrolment and nutritional support (aOR = 8.9; CI: 2.8 to 28.4)<sup>155</sup>.

### 7.3.9 Alarm devices and other reminder tools

**Phone alarm devices and other reminders such as TV shows** and the use of family members or other supporters were reported to be used by clients in South Africa to help remember to take their medications. **Treatment supporters are usually a client nominated ‘buddy’**, who attends adherence counselling sessions with the client and who supports them at home by reminding them to take their medications, attend their appointments and provide emotional support.<sup>156,157</sup>

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*“If it wasn’t for the Generation X TV show we would have a big problem.”* Key informant, Western Cape

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*“I put my alarm on at 7.59 to help me remember.”* Client stable on ART, Gauteng Province

*“I use my phone alarm to remind me to take my medications. I also have the Generation TV programme to remind me too as it starts at 8pm. Everyone here uses that programme to remind them. When it starts they all go home and pretend they want to watch it but they go home to take their medication.”* Client stable on ART, Gauteng Province

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### 7.3.10 Mobile phone text messaging for promoting adherence

In a recent Cochrane review<sup>107</sup>, which included two randomised controlled trials from Kenya<sup>104,105</sup>, carried out among adults, the impact of using weekly SMS of any length to promote adherence to ART was shown to be beneficial, with high-quality evidence. Table 2 summarises the results of the review.

Table 2. Summary of the impact of SMS on ART adherence: results from a systematic review and meta-analysis of two RCTs

Intervention	Outcome	Summary of findings
Mobile phone text messages vs. standard care	Viral load suppression at 52 weeks	Those in the intervention group were less likely to experience treatment failure compared with clients receiving standard care (RR 0.83, 95% CI 0.69–0.99).
Weekly text messages vs. standard of care	ART adherence at 48–52 weeks	In a meta-analysis of both RCT, those in the intervention were less likely to report non-adherence compared to standard of care (RR 0.78, 95% 0.68–0.89).
Daily text messages vs. standard of care	ART adherence at 48 weeks	There was no statistically significant impact on adherence of using daily text message; short daily (RR 1.00, 95% CI 0.79–1.27); long daily (RR 0.98, 95% CI 0.77–1.24)
Weekly vs. daily text messages	ART adherence at 48 weeks	Those receiving weekly messages of any length were less likely to report non-adherence compared to those receiving daily messages of any length (RR 0.79, 95% CI 0.64–0.99)
Short vs. long text messages	ART adherence at 48 weeks	There was no reported difference in the risk of non-adherence in clients receiving short or long messages (RR 0.99, 95% CI 0.78–1.27).

Source: Horvath et al (2012)<sup>107</sup>

### Key informants recommended the increased use of SMS for HIV services.

*“If I was a Minister of Health, I would recommend using SMS more for our patients. Everyone has a phone here. If they don’t someone at home has one. We should use it as a tool to communicate with people out there.” Key informant, Limpopo Province*

Other key informants and clients, however, raised some concerns about some clients’ fear of using SMS for HIV services, due to a fear that someone may use the phone and the issue this raises around disclosure of status.

*“The problem with texting information is the disclosure. People are afraid of leaving their phone in case someone finds it. They want people to know they have HIV.” Client on ART for PMTCT, Limpopo Province*

SMS has also been used to promote adherence among pregnant women on ART for PMTCT. A small pilot study conducted in South Africa among seven pregnant women assessing the feasibility of using SMS messaging to improve adherence reported “overall satisfaction” by the included pregnant women<sup>158</sup>. The SMS programme connected the seven pregnant women to each other and to a clinician and was used for discussing HIV, health and pregnancy issues over a three-month period. The pregnant women reportedly recommended that such groups be used in the future. It is important to note that technological challenges were reported and the study was very small to allow concrete conclusions to be made.

### 7.3.11 National AIDS Helpline

The South African National AIDS Helpline is a 24-hour service (7 days a week) that provides clients with access to counsellors for telephone counselling and to report complaints. Reported complaints are escalated to the NDOH to address the highlighted issues. The service receives around 60,000 calls per month and is provided in different languages. Discussions with clients, however, highlighted the lack of knowledge of this service by clients. Clients were asked if they thought that having a helpline would be useful for them, with almost all clients saying that such a service would be helpful.

### 7.3.12 Simplified drug regimens

The use of fixed-dose combinations improve adherence by reducing clients' pill burden. In a recently published systematic review and meta-analysis (2014), a higher pill burden was shown to be significantly associated with lower adherence rates and worse virological suppression<sup>159</sup>. Increased pill burden has also been associated with 'treatment fatigue', which has been defined as a "decreased desire and motivation to maintain vigilance in adhering to a treatment regimen among clients prescribed long-term protocols."<sup>160</sup> On the 1<sup>st</sup> April 2013, South Africa started using fixed-dose combination ARV drugs in first line treatment. Interviewed key informants reported enhanced adherence with once daily simplified regimens.

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*"Some people forget to take their medication. But this is much better now with FDC." Key informant, Limpopo Province*

*"One pill a day FDC has really helped. Especially for those with MDR-TB. When they finish their treatment and are moved to FDC, they find it to be such a relief. They are then so compliant." Key informant, KwaZulu-Natal Province*

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## 7.4 Special populations: Children – helping the caregivers will help Children

Several key informants reported the importance of targeting caregivers in order to help children adhere to their treatment.

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*"Sometimes the children default from treatment because the care-taker was sick and wasn't able to go to the clinic to receive medication for the children." Key informant, KwaZulu-Natal Province*

*"The problem with the kids is that the caregivers aren't always consistent about coming to the hospital to collect their medications. There is a very high rate of defaulting there. A lot of these kids are orphans so they are shifted from one family to another. The caregivers aren't responsible enough." Key informant, KwaZulu-Natal*

*"Providing support groups for adults can be used to identify more children by reaching the adults first." Key informant, NDOH*

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### 7.4.1 Featured model: MSF child disclosure care-giver support intervention and family ART adherence clubs

Disclosure of status to children is highlighted as a key strategy to help adherence among children.

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*“Problems arise when parents don’t disclose to the children. They tell them they are taking medications for something else.” Key informant, KwaZulu-Natal Province*

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The WHO strongly recommends that all children of school age should know their status<sup>161</sup>. Youth who know their status are significantly more likely to be retained on ART (93.1%) than those who do not know their status (62.2%)<sup>162</sup>. In South Africa in 2012, MSF lay counsellors started supporting caregivers in disclosing the status of children using grouped and individualised sessions. With the model, disclosure of status to children is recommended according to the age of the child: <7 years old (disclosure not enforced); 7–9 years (partial disclosure encouraged); >9 years (full disclosure encouraged). An evaluation of the strategy still showed disclosure rates below target, however; only 30% of children between the age of 10 and 14 had their status fully disclosed to them<sup>163</sup>. Cited challenges are social in nature including having multiple caregivers and children attending alone without parental support.

MSF has also implemented family ART adherence clubs (next chapter) to help adherence and retention among children. Family clubs run in a similar fashion to adult clubs but include the whole family. There are currently six facility-based family clubs in Khayelitsha, Western Cape.

### 7.4.2 The MSF paediatric Risk of Treatment Failure model

This model is implemented in two facilities in Cape Town. An experienced physician manages children identified as being at risk of treatment failure. It was reported that the strategy “requires a lot of effort” but has been shown to be effective. Data presented during fieldwork showed 70% re-suppression rates among referred children.

## Chapter 8. Results: ART maintenance phase

### 8.1 Key points

- Maintaining ART clients on treatment over a longer time is today a greater challenge than when the client load in the ART programme was small and fewer people were initiated while feeling healthy.
- Fear of disclosure and stigma around HIV infection and treatment permeates even at this phase of the HIV care cascade, with clients not wanting to be seen at clinics, not wanting to be followed-up at their homes, and providing wrong contact details.
- The current data systems cannot track clients as they transfer between treatment facilities due to labour migration or other personal reasons. There is a perception that remaining on treatment (thus increasing CD4 count) leads to the removal of a government disability grant.
- Elements of strategies and models with potential for stable clients: decentralised ART adherence clubs for adherent stable adults and other family members; I ACT and the Khethimp'ilo Patient Advocates and Index Trailing Staff; and public-private partnerships for delivering medications to stable clients such as MediPost, Pharmacy Direct, and the General Practitioner's Programme.
- The 3D model is applied to Decentralise HIV services via down-referrals, supported by the Dispersion of community health workers, with the aim to Decongest health facilities.
- The [TIER.net](#) data system flags up clients who miss their scheduled appointments and default. But, this system capacity is not yet matched by adequate manpower to trace clients on the ground. Creating unique identifier numbers for ART clients and using mobile phone technology more widely at a national scale (beyond MomConnect) are promising avenues.

### 8.2 Data on ART maintenance

The ART maintenance phase usually commences 12 months after ART initiation, if the client has been adherent to their medications. The term “*retention in HIV care*” is sometimes also used. It relates to the continuous engagement of clients living with HIV with the healthcare providers and includes life-long ART and HIV care as well as the initial engagement with the care system from eligibility assessment to ART initiation<sup>11</sup>. A recent analysis of mortality data from ART clients found that while South African ART clients have higher mortality rates in the early phase of ART compared to clients in Europe and North America (chiefly due to lower CD4 counts at initiation), **the mortality rate in South Africa declines to levels comparable to or below those described in participating North American cohorts by four years, while**

**substantially narrowing the differential with the European cohorts.**<sup>6</sup> This suggests that many ART clients are successfully maintained on ART in the long-term.

Clients living with HIV on long-term ART are at risk of other chronic diseases. A study assessing the prevalence of chronic kidney disease (CKD) in stable HIV individuals on ART reported the prevalence of CKD in 87.8% of participants, with a significant association observed between the use of ART and proteinuria<sup>164</sup>. Another study assessing the impact of high blood pressure among adults with HIV in sub-Saharan Africa reported higher mortality risk among clinically stable men with a systolic blood pressure (BP) of  $\geq 140$  mm/Hg than clinically stable normotensive men (HR: 2.39, 95% CI: 0.94 to 6.08)<sup>165</sup>. A recent study in Tanzania on the relationship between hypertension, kidney disease and long-term ART concluded that hypertension screening and education are needed in HIV-clinics in sub-Saharan Africa<sup>166</sup>. At 28.7%, PLHIV on ART for more than two years had a two-fold greater odds of having hypertension than HIV-negative controls; the study had a small sample size, however. Findings from these studies support the need to incorporate the clinical management of cardiovascular diseases' risk factors into HIV primary care.

As the South African ART programme continues to grow in scale, however, there is an observed decline in the retention of cohort clients in care with current estimates at less than 70% of the 2.4 million people on ART in South Africa, among those remaining on treatment three years post-ART initiation.<sup>167</sup> The general report from the field suggests declining retention rates over time from the point of HIV diagnosis to 12 months on ART. This is in line with a study showing a declining cumulative retention rates from diagnosis over time.<sup>168p</sup> Similarly, a prospective cohort analysis of outcomes of adults (n=1803) enrolled in a rural HIV care programme in the Eastern Cape reports declining retention rates among women initiated on ART while pregnant; increased risk of LTFU post-delivery was observed to be significantly, and independently associated with initiating ART as an in-client or while pregnant.<sup>169</sup>

In 2009, the government implemented the current guidelines of expanding the eligibility criteria for ART initiation of clients from a CD4 count threshold of 200 cells/mm<sup>3</sup> to 350 cells/mm<sup>3</sup>. The rapidly growing volume of ART clients places a burden on the overstretched healthcare system.<sup>170</sup> At the same time, more people are initiated on ART before they experience the debilitating AIDS-related conditions, which may influence their long-term commitment to treatment.

As the government prepares to implement the new WHO guidelines of initiating clients with a CD4 count of  $< 500$  cells/mm<sup>3</sup> on ART, addressing concerns about the declining long-term retention rates requires urgent strategies and concrete steps to be taken to overcome these challenges. The 3D model of care—Decentralisation, Dispersion and Decongestion—is utilised as a strategy for providing decentralised care to clients including for the management of HIV-TB co-infection. In a TB hospital visited in KwaZulu-Natal, the decentralisation strategy in place

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<sup>p</sup> Clouse et al., classifies retention under four stages, namely: retention in pre-ART stage 1 (from HIV diagnosis to CD4 results notification in  $\leq 3$  months); pre-ART stage 2 (initially ineligible for ART with repeat CD4 test  $\leq 1$  year of first CD4 count results); pre-ART stage 3 (initiating ART  $\leq 3$  months after first eligible CD4 result); as well as at 0–6 and 6–12 months post-ART.



was implemented in 2011, and has helped reduce the length of time clients are kept in the facility, which took about four to six months prior to the decentralisation of services to the PHC level. Some of the highlighted strengths of such decentralised efforts according to interviewed key informants include reduced wait time, resulting in fewer complaints from clients, and reduced defaulter rates. Supporting these findings, a retrospective study carried out in four provinces in South Africa showed improved retention rates in clients characterised with more advanced WHO stage of HIV infection and who are initiated on ART at PHC facilities (80.1%; 95% CI: 79.3%–80.8%,  $p < 0.0001$ ) compared to clients with less advanced stage of HIV infection and receiving care at district and regional hospitals (71.5%; 95% CI: 69.1%–73.8%, and 68.7%; 95% CI: 67.0%–69.7% respectively;  $p < 0.001$  for all outcomes) after 24 months on treatment.<sup>171</sup> Another study by Brennan et al., reports similar findings with the outcomes of clients down-referred from doctor-managed ART clinics to nurse-managed PHC clinics; down referred clients from Thembaletu Clinic in Johannesburg were less likely to become LTFU (HR 0.3; 95% CI: 0.2–0.6), experience viral rebound (RR 0.6; 95%CI 0.4–0.9), and were less likely to die (HR 0.2; 95%CI: 0.04–0.8).<sup>172</sup>

However, the issue of fragmented care especially with HIV-TB co-infected clients was reported to still serve as a major hindrance. A key informant highlighted that in most cases they observe that a client will default from TB treatment first while comply on ART. This is because, at present, most facilities are still fragmenting the services, and "integration of these services is slow" despite the PHC re-engineering programme being in place.

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*"This thing of re-engineering—you cannot take a retired person with chronic diseases, and say she must walk about 15kms to look for patients that are lost to follow-up. There is no guarantee that the patient will be at home and it is a waste of resources; reengineering is good for access to treatment, but the way we are implementing it is the bone of contention. Safety for health care workers in the re-engineering programme is not guaranteed, and quality is compromised". Key informant, North West Province*

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## 8.3 Issues related to retention in long-term care

### 8.3.1 Stigma

Lack of disclosure due to the stigma associated with HIV remains a major challenge impacting retention in care of clients. In understanding further how stigma could serve as a barrier at every step of the cascade of care, Earnshaw and Chaudoir (2009) provide a classification of the three processes of stigma: 1) "enacted stigma" (the perceptions of discrimination from community members); 2) anticipated stigma (expectations of future discrimination); and 3) internalised stigma (self-endorsement of negative attitudes and beliefs about living with HIV).<sup>173</sup> This supports some findings during key informant interviews, where it was reported that some of the reasons clients default and become lost to follow-up is because they worry about recognising familiar faces in the health facilities when clients return to pick up their medications. In other words, they may adhere for a while but in the long-term they cannot put up with this worry. Increasing LTFU rates post-delivery in women initiated on ART while pregnant was also attributable to lack of disclosure due to fear of stigma from partners.

Similarly, findings by Clouse et al., (2014) show that stigma serves as a major barrier impacting retention rates among pregnant women in a primary health clinic in Johannesburg offering option B+ (lifelong ART) to pregnant women.<sup>120</sup> The discrimination around HIV infection contributes to the reason why clients provide wrong contact information thus posing a huge difficulty for the client tracking system. Despite the use of Community Care Givers (CCG), who are very familiar with the clients, it was reported that some clients are still not happy about receiving a visit from a CCG due to disclosure issues, which is especially common among clients dwelling in the shacks. A prospective study by Evangeli et al., however, found no significant association between stigma and LTFU in treatment eligible adults in KwaZulu-Natal (n= 380; 2<sup>nd</sup> quartile aHR: 0.77; 95%CI: 0.41–1.46; 3<sup>rd</sup> quartile aHR 1.20, 95%CI: 0.721–2.04; 4th quartile aHR: 0.62, 95%CI: 0.35–1.11; p= 0.27)). Higher LTFU rates were significantly associated with male gender while lower LTFU rates were independently associated with increased year of age, greater reliance on family and friends, and having children.<sup>174</sup>

### 8.3.2 Switching Treatment regimen

In KwaZulu-Natal, one issue highlighted as a challenge with retaining ART clients in care at the health facilities is in regards to changes in treatment regimen. Those that are required to switch from regime one to another may move to new clinics in the hope of getting placed back on to the familiar regimen and thus get classified as lost to follow-up by their old facility. It was reported that there is very limited follow-up and no method of keeping track of clients who don't come back thus sometimes propagating among healthcare providers a nonchalant mind-set—*"Abakaya - go home, we'll see you when you come back, when you're critically ill"* (key informant, KwaZulu-Natal Province). Additionally, it was reported in two of the five facilities visited in Umgungungdlovu district in KwaZulu-Natal that there is a dearth in the number of dedicated health care workers assigned to trace TB clients defaulting on treatment (one tracer assigned between two facilities).

### 8.3.3 Migration of Clients

Client migration is reported to be another major issue impacting on retention rates. This is particularly prevalent among clients migrating from the Eastern Cape to KwaZulu-Natal and the Western Cape for job opportunities. It was reported that clients living with HIV who visit another province become sick, and present to a health facility. Post-discharge, the clients migrate back home, with no method in place at the facilities to keep track of these clients. This problem was reported to be a common issue in a densely populated area in the KwaZulu-Natal province called Dambusa, which has a high influx of people from Lesotho. However, in the Western Cape (where data is linked), issues related to migration Issues has also been associated with poor data quality, and raises to the forefront the question regarding if data capturers are well equipped with the capacity to do the amount of job that will be required following the integration of care for the management of all chronic diseases condition *"in a growing cohort"*.

### 8.3.4 Grant eligibility

Another major factor reported to be affecting retention in care is with regards to the perception of clients on their eligibility to receive disability grants (DG) from the government due to an individual's HIV status. The following are direct quotes from key informants and clients:

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*"If a patient is not working, is it HIV that stops people from working because of getting so sick or lack of skills? Although overdramatizing of the disability is not unique to HIV, we need to remove the perception about getting grants because of being HIV positive, as being HIV positive doesn't stop one from being employed." Key Informant, KwaZulu-Natal Province.*

*"The government should stop the grant for TB as people deliberately take the sputum of a TB positive person in order to have TB, and be eligible for the grant because of poverty." Key informant, Gauteng Province*

*"Patients want to remain ill so they can benefit from the grant. Although this hasn't been tested, patients don't take the treatment so they are not taken off from the social grant. It is a health system barrier, as well as a patient barrier. This is very common. You hear them talking as part of the community that if you take your treatment regularly you will be taken off from the grant." Key informant, North West Province*

*"Most of the people decide to default because they are not given the grant anymore by SASSA<sup>q</sup>. Most of the people don't take their medicine because of that grant." FGD with clients, North West Province*

*"The Department of Health is working hard but the problem lies with the patient. After six months, people start defaulting treatment; in our community people default on purpose to have access to the grant." Key informant, North West Province*

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In 2011, the Department of Social Services reported that the number of recipients on the DG decreased by 5.6%, from 1,291,264 to 1,218,916,<sup>175</sup> a consequence of the development of policies to regulate access to disability grants in South Africa; as of 2013, it is reported that the South African Social Security Agency (SASSA) disburses the DG to approximately 1.14 million people (3.6% of the working class population).<sup>176</sup> In the past, major problems experienced with the DG were in regards to a lack of an appropriate definition of disability for the purpose of providing social assistance to eligible individuals, and a lack of standardised assessment tools resulting in observed inconsistencies in the medical assessment processes. To address these issues the Harmonised Assessment Tool (HAT) was created for the purpose of regulating DG grant accessibly, and was first piloted by the NDOH in 2006. The HAT was used to carry out disability assessment via the adoption of a clearly defined classification of disability.<sup>r</sup> However, due to the reported lack of appropriate training of health care workers to carry out these assessment and the limited capacity of the PHC facilities to provide nutritional support for individuals with chronic conditions who would automatically be cut off from the DGs, the NDOH announced that it wasn't ready to implement the HAT. Consequently, a standardised definition of disability was excluded from the Social Assistance Amendment Act of 2010.<sup>175</sup>

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<sup>q</sup> South Africa Social Security Agency, where beneficiaries can get different types of grants.

<sup>r</sup> As outlined for the purpose of the HAT, disability refers to "a moderate to severe limitation in a person's ability to function or ability to perform daily activities as a result of physical, sensory, communication, intellectual or mental impairment".

Along a related trajectory, a longitudinal study carried out in KwaZulu-Natal assessing the impact of disability grants on health outcomes of clients living with HIV on ART showed no significant association between loss of DG status and health outcomes (CD4 cell counts, adherence to ART and HIV symptoms) over 20 months (n=72; Cr OR: 0.999; CI: 0.998–1.00;  $p<0.0001$  for clients on DG at 6 months prior to ART initiation, and n=192; Cr OR: 1.00; CI: 0.999–1.001;  $p<0.0001$  for clients on DG at 6 months post-ART initiation). However, a significant association was found between loss of DG and lower CD4 count in clients after 12 months on ART<sup>177</sup>, and supports findings from a cross-sectional study carried out by Phaswana-Mafuya et al., (2009) in the Eastern Cape.<sup>178</sup> Further research is required in this area to understand better if DG eligibility has a significant impact on a client's decision to default on ART regimen and TB medication, and the extent to which these findings are outside of particular province(s).

## 8.4 Models and interventions

Several models discussed in earlier sections also aim to support stable clients:

- **I ACT** (Chapter 5), currently being adopted as a strategic method to improve retention of clients in care, by strengthening the referral of clients by CBOs for follow-up of clients, and to inform on next facility visits. It focuses on addressing identified barriers impacting on low retention rates, by improving PICT referrals for every client that visits a facility and supporting clients that are fast-tracked in the ART program, to ensure a functional strategy is in place to retain clients in life-long care.
- **Khethimp'ilo Patient Advocates and Index Trailing Staff** with patient advocates (PA) supporting stable clients (chapter 3)
- MSF youth specific retention model (chapter 6)

### 8.4.1 Featured model: ART adherence clubs for adherent stable adults and other family members

ART adherence clubs are provided to those who have been taking their medications for at least 12 months and who are stable (defined as having at least 2 undetectable VL and having no clinical conditions requiring regular follow-up), with the aim of decongesting the clinics and providing a quick service for those in clubs<sup>170</sup>. The clubs are lay worker led and supported by a nurse. Group size is no more than thirty. Club members attend every two months and stay at the club for no more than two hours. Often sessions are done very early in the morning to help those who have to go to work. During these sessions clients collect a two-month supply of pre-packed medications that can be issued by a layperson. During the Christmas holidays members are supplied with a four-month supply to facilitate adherence during the holidays when many people travel home. Club members are entitled to send a “buddy” to collect their medications with the exception of every second session. Members must also attend the clinic annually for blood testing and for clinical consultation. Clients who miss these mandatory

sessions are given a five-day grace period to return to the clinic. Failure to do so results in exclusion from the club.

Clubs can be facility-based, community-based or home-based. More recently, there has been a shift from facility clubs to community-based and home-based clubs, largely due to the large volume of clients in clubs. In Western Cape, 27,800 clients (24% of the ART cohort) are in clubs (personal communication, key informant, Western Cape). Club participation has been shown to reduce loss-to-care (by 57%) and virologic rebound in those clients who are initially suppressed (by 67%).<sup>119</sup> In addition, there are a reported 48 fewer visits per day at clinics in Khayelitsha since the implementation of clubs (personal communication, key informant, Western Cape.)

### The future of ART adherence clubs

As clubs start to **shift from facilities to the community and to homes**, recruitment of clients into clubs has started to be done according to area of residence “so you don’t have to split them up later.” It was reported that some clients do not want to move into the community due to stigma. There are currently three clubs running in homes in Khayelitsha, facilitated by the clients themselves.

With an aging ART cohort there was much discussion around the issue of whether it is better to **integrate ART clubs with other chronic diseases** or to keep them separate. Interviewed key informants in Khayelitsha were hesitant to integrate the clubs feeling that the ART clubs tended to have younger people compared to other chronic disease clubs. One proposed strategy to overcome this would be to recruit members into clubs according to age rather than according to disease. It was argued that in high burden areas it might be better to keep the two groups separate.

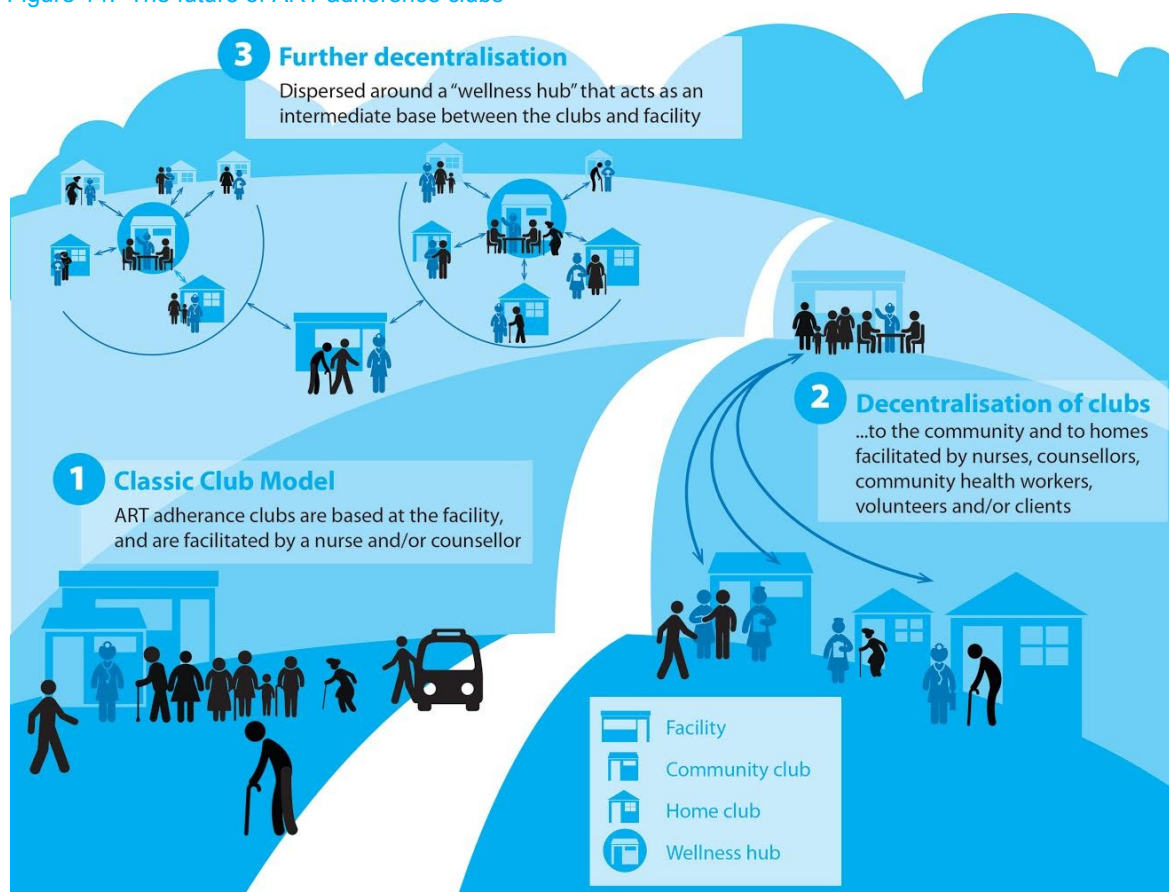
Data from the club members is currently captured using paper registers that are sent to the facility. The registers get sent to the facility later for data input into the computer system, meaning that good data quality is not always assured. One mobile health (**mHealth**) pilot that was recently implemented saw counsellors inputting the data from the clubs into their mobile phones. Inputting data at point of care was suggested as a means of minimising errors around data inputs. In addition the programme had checks that did not allow the counsellor to continue until the data, highlighted as incorrect (e.g., a weight of 2 kg), had been revised. The pilot was discontinued as it was felt that it was not efficient in its current format. With the current technology the data can’t be linked directly to the main data system (eKapa). It is instead linked to a separate spread-sheet that still needs to be manually inputted into eKapa by the data capturers. In the future, as further task-shifting occurs with, for example, clubs being facilitated by the clients themselves, there is potential that the clients themselves could input data.

In the future, it is anticipated that the two **Wellness Hubs**, described in more detail in Chapter 5, would act as a base for the clubs. The clubs would be dispersed around the hub “like spokes around a central point.” This would help overall coordination of the clubs, and the hubs would



screen clients to see who can be managed by the hubs and who really needs to be referred to the facility, further decongesting them (see Figure 14).

Figure 14. The future of ART adherence clubs



Source: Authors design based on data obtained from MSF during evaluation

#### 8.4.2 Bicycle Man model in Chronic Clubs

A 'bicycle man' model to get chronic diseases' medication in the communities is currently being used in the Western Cape as part of the Sackler Chronic Clubs model. The 'bicycle man' delivers chronic medications to members of the club who are unable to attend the support groups where medications are usually delivered. This is similar to an ART distribution model rolled out in the Tete Province of Mozambique in collaboration with MSF to improve retention in care (post-ART initiation) via community ART groups. Reported outcomes on percentage of clients that continued to use the community ART groups during a period of two years showed that over 97% of clients (n=1,301) remained in care.<sup>55,179</sup> This model was also highly effective in improving retention rates in pre-ART clients, by extending invitations to these clients to join monthly meetings to receive peer-support, and education on living with HIV healthily.

A similar model seen to be effective in improving retention rates in children on ART is the provision of community-adherence support for children. Findings from a multi-centre study in facilities spread out across four provinces in South Africa (Western Cape, KwaZulu-Natal,

Eastern Cape and Mpumalanga) showed improved retention rates of 91.5% (95% CI: 86.8% to 94.7%) versus 85.6% (95% CI: 83.3% to 87.6%) amongst children with and without community-based adherence support using Khethimp'ilo PA, respectively ( $p=0.027$ ).<sup>180</sup>

#### 8.4.3 SMS and other services to help those who are travelling

The team were informed by key informants in Western Cape of an initiative implemented in Eastern Cape whereby clients can use an SMS service to help them locate the nearest clinic to them to collect their medications when they are travelling.

Other strategies to help those who are travelling include the provision of longer treatment packs for those who are stable on ART. The MSF adherence clubs provide a four-month supply to their clients during the Christmas period, for example.

#### 8.4.4 Initiatives promoting Public-Private partnerships (MediPost, Pharmacy Direct and the General Practitioner's Programme)

Many facilities make use of MediPost, an initiative implemented earlier this year for the fast tracking of clients, and the delivery of chronic medications to stable clients in the communities. Other facilities adopt similar models such as Pharmacy Direct. To be eligible, clients must be stable, and able to provide blood result for the past month. Upon fulfilling these criteria, the client is fast-tracked to receive medications from the MediPost programme or a similar scheme. Additionally, clients receive reminder messages on a monthly basis regarding medication pick-up dates. After collection of medication, the information is entered into the system, although there is a reported gap in the capturing of client information in the central ART system. Presently, only ART clients are able to utilise the services of MediPost, and according to some key informants, the use of the service has helped bring down client wait time in the facility to about five minutes only. However, other key informants and clients highlight existing logistical challenges with the model including programme limitation to only those clients on fixed-dose combination drugs, lack of flexibility with appointment date, difficulties in capturing data, and refusing to dispense medication for minor misspelling errors of client names. As a result, key informants and clients were hesitant to refer to these models as an effective initiative presently.

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*"MediPost is supposed to take all our chronic stable patients. But now it's just for those on FDC. This is because of logistical issues. They are supposed to take all the stable ones ideally, regardless of drug regimen. They are doing it in phases. There are around 2000 patients there now. They are based here. Ideally they should be in the community delivering medication at fixed drop-off points. Most of our patients prefer to come here rather than their nearest clinic. With MediPost you don't have to take out the file. MediPost use a system that tells them who is coming each day for their medications. The patient has to sign when they collect. They have a scan now that they didn't have before. They know who has come and who hasn't come to collect. They send us information for our meetings so we know who hasn't come to collect and we send our PA to trace them. They are still our patients". Key Informant, KwaZulu-Natal Province*

*"There are problems with Tier.net and MediPost. We are trying to sort this out. Since they know who is coming we are trying to see if they can retrieve the files the day before so that*



*it can still be captured by Tier.net. There is a problem for data capturing the way it is now because the patient doesn't have to collect the file. Khethimp'ilo, who run the adherence clubs, are also trying to sort out the problem."* Key informant, KwaZulu-Natal Province

*"Although MediPost is good for shortening the queue I am worried about the files not being captured. The patient is collecting the medications but he is not retrieving the file".* Key informant, KwaZulu-Natal Province

*"It won't reduce the cost for the patients to come into facilities but it should reduce the waiting times especially in the larger facilities. Everything is already pre-packed. But patients have been complaining that there is no flexibility, if for some reason they can't keep their date, whether because they need to come early because they're going somewhere or if they are late. That will be sorted out hopefully as the operational manager does go to meetings at the district office and she will bring this up".* Key informant, KwaZulu-Natal Province

*"There is a big problem with Pharmacy Direct. We go there, and they always tell us to come back".* Stable client on ART, Gauteng Province

*"If I can't come to collect my medication on my day, I can't change my day. It needs to be more flexible."* Stable client on ART, Gauteng Province

Another private partnership that currently exists with the DOH is the General Practitioner's programme, which began in Gauteng Province, and currently exists in Gauteng and North West provinces. Under this program, the government utilises the facilities of private doctors to refer the most stable clients for medication pick-up as an effort to fast-track clients, and helps with reducing the workload in the public facilities. This is related to findings from a study carried out on a similar model of HIV care using private practitioners, which reported a 63% retention (alive and in care) rate in clients initiated on ART after 12 months (5,743/9,102), and a 6 months virally suppressed rate at 82% vs. 84%, 84% and 85% from 2005–2008 ( $p=0.66$ ); versus 12 months, 78% vs. 83%, 83% and 84% ( $p=0.05$ ).<sup>181</sup> At the time of the focus group discussions, it was reported that the General Practitioner's programme is about to be discontinued due to a lack of funding.

## 8.5 TIER.net System

TIER.net is the electronic data capturing system rolled out nationally by the National Department of Health in 2010 for the capturing of ART client profiles into the system. Prior to the roll out, the facilities were making use of clinical charts and ART paper registers. Most facilities visited had in place the tier system for capturing client information<sup>s</sup> and reported a general enthusiasm about how the system functions.

*"It is very user-friendly. It makes life easier, especially for the data capturer".* Key informant interview, KwaZulu-Natal Province

<sup>s</sup> Facilities in the Western Cape Province make use of eKapa for electronic data capturing of PLHIV

Defaulting clients are grouped under three categories:

1. **Early-missed appointments:** clients who are yet to visit the facilities three weeks after their scheduled appointment
2. **Late-missed appointments:** clients who after two months of missing their scheduled appointment have still not presented to the health facility
3. **LTFU clients/defaulters:** clients who do not return to the facility

A recent partnership occurring with TB-HIV cares, a key partner NGO in the Western Cape is making use of mobile clinics in KwaZulu-Natal to deliver services to hard-to reach areas such as those where farmers dwell, and areas with a high volume of sex-workers. Data capturers who drive the mobile clinics are tasked with ensuring that clients who have been identified are entered into the electronic data capturing (TIER.net) system.

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*“It is easier to retain patients identified via the mobile clinics because these communities (of farmers, sex-workers) stay in the same area. However with patients that come into the clinics, it is harder to retain them in the system, because they lie about their addresses”. Key informant interview, KwaZulu-Natal Province.*

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Although the TIER.net has the capacity to generate a list of clients who are identified as defaulting, insights from the field showed that a lack of adequate manpower within the tracing team poses a challenge with tracing clients back into the system. Some facilities report that the task of client tracing often falls on a single individual whose services are being shared among several facilities. Other identified challenges with the tier system include no routine monitoring of clients who adhere to and finish IPT (the information is only captured for those who start); and the misclassification of attrition rates due to mortality. According to interviews with key informants, LTFU updates are carried out at the same time the generated list is provided to CCGs, and as a result the list doesn't capture those who are LTFU due to mortality. This supports findings by Geng et al., (2010) about LTFU client populations, which unknowingly includes a mixed group of clients with varied outcomes including mortality, undocumented transfers to other facilities, and sporadic interruptions in client care.<sup>182,183</sup> Similar findings were also reported in a retrospective study by Ahonkai et al., which showed a decreased risk of LTFU with increasing enrolment year in participants initiated on ART (n=11,397; OR 0.49, 95%CI 0.39–0.62).<sup>184</sup> Key informants further highlighted that, since disclosure issues are still predominant, family members rarely report to the health facilities on the death of clients. Additionally, it was highlighted that some problems with the delay in data capturing bring about some backlogs, and as such, the tier system still needs to be further improved upon.

## 8.6 Plans for a Unique Client Identifier system

There are existing plans in place to implement a national unique identifier system for every client in order to properly trace clients who migrate to other facilities to receive services. Currently, the electronic systems in place at the facilities are not linked, and as such, clients who are not necessarily defaulting or LTFU are classified as lost in the system in the facilities. Having a unique identifier in place is expected to help ensure that electronic files records of

clients are properly transferred/retained in the system, and can be easily regenerated when a client migrates to a new facility. In the Western Cape, there are also plans to link the primary health care information system with eKapa (the system in place for capturing information on PLHIV) in an effort to reduce the currently existing parallel systems that poses a challenge with data capturing in the province. This is scheduled to occur in the last quarter of the current fiscal year.

## Chapter 9. Discussion

With the largest and fastest-growing ART programme in the world, South Africa's HIV care cascade is increasingly showing up weaknesses. Too many clients exit the cascade, and re-entry is not always facilitated with the currently used approaches. While a national system for monitoring clients is being developed and strengthened, good data on the number and type of PLHIV not in HIV care is not available. Accurate quantification of losses and re-entry is made difficult by poor reporting and integration of services and registers and the mobility of clients, particularly in the context of unlinked facility registers and in the absence of a unique client identifier code. With an increased number of HIV service points and the difficulties in officially transferring between service providers, mobile clients are self-transferring and are being defined as lost to follow-up in one place and categorised as a new client in another. Data systems that are linked, such as the eKapa system used in Western Cape, rely on a network, meaning that it can sometimes be very slow to use. The increased client load observed over the years has put significant pressure on data capturers. While task-shifting strategies have been utilised for healthcare staff to help overcome the challenges of the increased client load, this has not been done for data capturing. Although new technologies, such as using mobile phones to input data at point-of-care, will help with data quality, they are not yet able to connect the data directly from the client to the system. Therefore, they would still rely on data capturers. It is important to emphasise, however, that although there are issues with data quality, there is little doubt that there are still significant losses of clients along the entirety of the cascade. Clients' reasons for exiting and the barriers to re-entry into HIV care have been researched, and a plethora of individual, community and systems factors are at play.

In January 2015, the ART eligible population will increase considerably as South Africa revises its ART policy, in line with WHO's 2013 consolidated guidelines<sup>31</sup>. With this in mind, South Africa is currently drafting an adherence strategy that will guide implementers on how to best ensure that HIV positive clients are identified, put on treatment and retained in lifelong care. An evaluation of ART adherence and retention in care strategies in South Africa was initiated in July 2014 in collaboration with the World Bank. This report has presented the key findings of the first phase of this evaluation. The research team identified several key barriers—at both the client and the system level—to adherence to the HIV care cascade, and interventions to overcome these barriers, which are summarised in Table 3 according to client typology.

Table 3. Significant demand- and supply-side barriers and highlighted initiatives from Phase 1 according to client typology

Client	Demand-side barriers	Supply-side barriers	Highlighted Initiatives from Phase 1
<b>Does not know status</b>	<ul style="list-style-type: none"> <li>perceived stigma/discrimination around getting an HIV test;</li> <li>lack of understanding around HIV; lack of partner or family support and fear of partner leaving or divorcing;</li> <li>fear of HIV; depression and other mental health disorders</li> </ul>	<ul style="list-style-type: none"> <li>long queues at facilities;</li> <li>lack of space at facilities;</li> <li>quality assurance issues of test kits and stock-outs;</li> <li>weak pre-test counselling;</li> <li>lack of confidence of healthcare workers in initiating HCT;</li> <li>regulatory environment for self-testing; unsuitable opening hours for those in employment;</li> <li>limited human resources to provide HCT</li> </ul>	<ul style="list-style-type: none"> <li>VCT;</li> <li>PICT;</li> <li>opt-out testing strategy;</li> <li>self-testing;</li> <li>community campaigns;</li> <li>24/7 AIDS helpline to provide counselling and to report complaints;</li> <li>decentralisation of HCT services outside the facilities;</li> <li>use of gazebos, and mobile outreach teams for decentralisation of HCT services in the community and hard to reach areas (squatter camps, shacks);</li> <li>iTEACH's HIV/TB treatment warriors in the wards;</li> <li>iTEACH THP programme;</li> <li>self-test kits; after-hours testing services;</li> <li>"Pillantwana" programme—zulu for 'child survival'—encourages community members on the need to test children (works in close partnership with traditional practitioners);</li> <li>use of women's programmes (such as cervical cancer programme) to extend the provision of quality HCT services in the communities</li> </ul>
<b>Knows status (not on ART)</b>	<ul style="list-style-type: none"> <li>under-utilisation of referral services due to fear of treatment side-effects;</li> <li>dissatisfaction with services offered at the facilities;</li> </ul>	<ul style="list-style-type: none"> <li>inefficient linkage to care services especially after testing in the communities;</li> <li>lack of same-day CD4 count/ POC CD4 count results: average time to</li> </ul>	<ul style="list-style-type: none"> <li>I ACT;</li> <li>Isoniazid Preventive therapy;</li> <li>family planning;</li> <li>STI screening and treatment;</li> <li>condom promotion and distribution;</li> </ul>

Client	Demand-side barriers	Supply-side barriers	Highlighted Initiatives from Phase 1
	<ul style="list-style-type: none"> <li>stigma and disclosure issues (fear of being labelled as a community pariah due to HIV+ status), and includes work-place stigmatisation resulting in loss of job;</li> <li>providing wrong address to HCWs serves as a major hindrance to proper tracing of clients;</li> <li>denial of HIV status; high CD4 count (not feeling sick, thus refusing treatment); lack of education on HIV and benefits of ART</li> </ul>	<ul style="list-style-type: none"> <li>receipt of laboratory CD4 count result is a week; Limited infrastructure for e.g., space limitations for counselling impedes on client privacy;</li> <li>low healthcare provider to client ratio;</li> <li>lack of standardised registers across facilities for the integration of IPT, TB prevention and TB screening and diagnosis;</li> <li>congestion/increased client loads make it difficult to keep track of clients with high CD4 counts who are not yet eligible for treatment;</li> <li>lack of appropriate HCW training for the management of pre-ART clients (no standardised guidelines specific to pre-ART);</li> <li>lack of adequate professional nurses in decentralised services to initiate clients on treatment (for e.g., with the use of Wellness hubs in the Western Cape);</li> <li>poor record-keeping and inadequate tracer mechanism (both centralised and decentralised); poor incentives provided to CHWs impacts on morale</li> </ul>	<ul style="list-style-type: none"> <li>Wellness Hubs;</li> <li>integration of registers and inclusion of pre-ART clients in Tier.net;</li> <li>tracing of clients; point of care CD4 testing; support groups;</li> <li>MSF youth specific retention model; online forums</li> </ul>
<b>Stable on ART</b>	<ul style="list-style-type: none"> <li>stigma and disclosure issues;</li> <li>social issues;</li> <li>lack of support;</li> <li>employment meaning clients can't regularly take time off work; treatment fatigue;</li> <li>migration</li> </ul>	<ul style="list-style-type: none"> <li>increased client load in the health facilities with the expansion of the ART programme has resulted in over-burdened healthcare system (congestion, longer wait times);</li> <li>sporadic medication stock outs leads to sub-optimal adherence for</li> </ul>	<ul style="list-style-type: none"> <li>decentralisation of services;</li> <li>adherence clubs;</li> <li>bicycle man model;</li> <li>public-private partnerships such as MediPost, Pharmacy Direct and the General Practitioners Programme (DOH partnership with private doctors)</li> </ul>

Client	Demand-side barriers	Supply-side barriers	Highlighted Initiatives from Phase 1
		<p>clients; short supply of medication to clients;</p> <ul style="list-style-type: none"> <li>delayed access to treatment due to other logistical issues (misspelling of client names etc.);</li> <li>lack of a well-functioning client-tracing system could over-estimate number of clients LTFU, and provide an inaccurate depiction of clients who are not stable;</li> <li>facilities with high client loads have increased wait times in facilities;</li> <li>limitations with existing structures (for e.g., utilisation of MediPost limited to only clients on FDC)</li> </ul>	<p>to provide care to patients including medication pick-up);</p> <ul style="list-style-type: none"> <li>Khethimp'ilo PAs for addressing defaulting rates and LTFU;</li> <li>MSF youth-specific retention model;</li> <li>I ACT;</li> <li>longer dispensing of treatment; integrated services with other NCD</li> </ul>
<b>Unstable</b> (ART-initiated)	<ul style="list-style-type: none"> <li>stigma and disclosure issues including work place discrimination results in a lack of emotional support;</li> <li>forgetfulness to take medication; Substance and alcohol abuse;</li> <li>perceptions around grant eligibility and removal from government grant upon attaining higher CD4 count;</li> <li>food insecurity brought about by poverty and unemployment;</li> <li>poor client-provider relationship;</li> <li>non-adherence history with other chronic medications;</li> <li>traditional beliefs leading to the use of concoctions obtained from traditional healers;</li> </ul>	<ul style="list-style-type: none"> <li>lack of a well-functioning client-tracing system (limitations with the use of the current system—tier.net);</li> <li>high costs and delays in the use of VL monitoring of clients—could result in onset of drug resistance;</li> <li>assistance to support groups are minimal or non-existent; no routine monitoring of client adherence and completion of IPT;</li> <li>long distances to facilities from key populations;</li> <li>lack of appropriate adherence counselling well-tailored to individual circumstance;</li> <li>fragmentation of care in the delivery of HIV/TB services contribute to the stigma; unavailability of FDC in some facilities;</li> <li>long queues</li> </ul>	<ul style="list-style-type: none"> <li>client tracing if lost to follow-up;</li> <li>MSF risk of treatment failure programme;</li> <li>nutritional support;</li> <li>referral to social services; enhanced adherence counselling;</li> <li>SMS texting;</li> <li>simplified drug regimens;</li> <li>The Adherence Community Care Worker programme;</li> <li>DOT and mDOT;</li> <li>managing MDR-TB and XDR-TB in the communities;</li> <li>alarm devices;</li> <li>treatment supporters; out of hours services; social support</li> </ul>



Client	Demand-side barriers	Supply-side barriers	Highlighted Initiatives from Phase 1
	<ul style="list-style-type: none"> <li>switching treatment regimen, and side effects experienced from complex drug treatment regimen;</li> <li>treatment fatigue;</li> <li>high rates of migration</li> </ul>		
<b>Children</b>	<ul style="list-style-type: none"> <li>lack of parental support/biological parents are not easily accessible;</li> <li>inadequate training of caregivers;</li> <li>refusal of parents to disclose status to children living with HIV;</li> <li>migration of family;</li> <li>other social issues such as poverty and children often being orphaned with multiple caregivers</li> </ul>	<ul style="list-style-type: none"> <li>required signing of consent form by biological parents in order to test children;</li> <li>weak counselling services specifically tailored to children;</li> <li>clinical difficulties in diagnosing and managing TB;</li> <li>lack of confidence in managing children among healthcare staff;</li> <li>long queues</li> </ul>	<ul style="list-style-type: none"> <li>paediatric Blueprint for Action (BPA);</li> <li>home-based care;</li> <li>family ART adherence clubs;</li> <li>MSF disclosure support intervention; community care givers for follow-up to HCT testing;</li> <li>PICT for breast-fed babies born to mothers living with HIV;</li> <li>“Pillantwana” child survival programme for testing in the community (collaboration with Traditional Health Practitioner);</li> <li>MSF paediatric risk of treatment failure programme</li> </ul>
<b>Youth</b>	<ul style="list-style-type: none"> <li>Increased risky behaviours;</li> <li>fear of discrimination and stigmatisation resulting in reluctance to join support groups; generally higher reluctance among these age groups to begin treatment;</li> <li>misunderstanding around HIV;</li> <li>social problems; disclosure issues;</li> <li>anger around being HIV positive;</li> <li>alcohol and other substance abuse; migration of family</li> </ul>	<ul style="list-style-type: none"> <li>Weak adherence counselling specifically tailored to youths;</li> <li>Lack of adequate to youth-specific support groups;</li> <li>lack of youth-friendly clinics;</li> <li>long waiting queues;</li> <li>unsuitable opening hours;</li> <li>difficulties associated with transitioning from paediatric to adult care</li> </ul>	<ul style="list-style-type: none"> <li>youth-specific support groups and counselling models;</li> <li>POC CD4 testing; the use of social media for information and peer support such as the Adolescent Innovation project and the MSF youth retention programme;</li> <li>MSF disclosure support intervention; fast-tracking in clinics;</li> <li>risk of treatment failure intervention;</li> <li>I ACT for youth</li> </ul>

Client	Demand-side barriers	Supply-side barriers	Highlighted Initiatives from Phase 1
<b>Men</b>	<ul style="list-style-type: none"> <li>▪ general unwillingness to visit health facilities results in men presenting late (most often when critically ill);</li> <li>▪ denial of HIV status resulting in "shopping around";</li> <li>▪ issue with receiving HIV services from a female HCW;</li> <li>▪ work commitments resulting inability to take time off work;</li> <li>▪ depression;</li> <li>▪ alcohol abuse;</li> <li>▪ stigma and disclosure issues;</li> <li>▪ lack of family support</li> </ul>	<ul style="list-style-type: none"> <li>▪ Lack of male-friendly clinics;</li> <li>▪ Long waiting queues;</li> <li>▪ Unsuitable opening hours;</li> <li>▪ Conflict with work commitment;</li> <li>▪ Not enough male HCW in health facilities</li> </ul>	<ul style="list-style-type: none"> <li>▪ Men's forum; after-hours services; male-friendly clinics; grants;</li> <li>▪ decentralised services;</li> <li>▪ delivery of medications through public-private partnerships and adherence clubs to help those in employment</li> </ul>
<b>Pregnant Women, including postnatally</b>	<ul style="list-style-type: none"> <li>▪ presenting late for ANC or refusal to utilise ANC services;</li> <li>▪ poor knowledge of HIV/ART/vertical transmission, lower maternal educational level;</li> <li>▪ psychological issues following HIV diagnosis;</li> <li>▪ stigma and disclosure issues with partner; increased risk of LTFU post-delivery;</li> <li>▪ exclusive breastfeeding of infant is automatically connected to one's HIV status;</li> <li>▪ often young women with social problems;</li> <li>▪ teenage pregnancies</li> </ul>	<ul style="list-style-type: none"> <li>▪ conflict with work commitment;</li> <li>▪ negative treatment from health-care workers;</li> <li>▪ long queues;</li> <li>▪ poor knowledge and training of health care providers to manage needs of pregnant women;</li> <li>▪ distance to facilities;</li> <li>▪ poor counselling provided tailored to the needs of pregnant women</li> </ul>	<ul style="list-style-type: none"> <li>▪ MomConnect;</li> <li>▪ same-day ART initiation;</li> <li>▪ fast-track services in clinics;</li> <li>▪ incentives;</li> <li>▪ mentoring through initiatives such as the M2M2B programme;</li> <li>▪ integration of ANC and ART services;</li> <li>▪ option B+; grants</li> </ul>
<b>HIV/TB co-infected and other co-morbid</b>	<ul style="list-style-type: none"> <li>▪ stigma;</li> <li>▪ fear of disclosure;</li> <li>▪ feeling overwhelmed with co-morbidity;</li> </ul>	<ul style="list-style-type: none"> <li>▪ complex drug regimens;</li> <li>▪ side-effects;</li> <li>▪ long duration of treatment;</li> <li>▪ lack of integrated services;</li> </ul>	<ul style="list-style-type: none"> <li>▪ integration of services;</li> <li>▪ community care worker adherence programme;</li> <li>▪ grants;</li> </ul>

Client	Demand-side barriers	Supply-side barriers	Highlighted Initiatives from Phase 1
<b>populations</b>	<ul style="list-style-type: none"> <li>▪ fear of side-effects and long duration of treatment;</li> <li>▪ social issues including lack of nutrition/food</li> </ul>	<ul style="list-style-type: none"> <li>▪ poor confidence by HCW to manage complex co-morbidities;</li> <li>▪ transportation costs;</li> <li>▪ long queues;</li> <li>▪ stock-outs; poor counselling</li> </ul>	<ul style="list-style-type: none"> <li>▪ nutritional support;</li> <li>▪ PHC re-engineering;</li> <li>▪ ICDM model</li> </ul>
<b>Sex workers</b>	<ul style="list-style-type: none"> <li>▪ poverty;</li> <li>▪ alcohol abuse;</li> <li>▪ poor education;</li> <li>▪ higher levels of stigmatisation by HCW resulting in bad treatment in facilities</li> </ul>	<ul style="list-style-type: none"> <li>▪ lack of sex-worker friendly services;</li> <li>▪ unsuitable clinic opening hours;</li> <li>▪ long queues;</li> <li>▪ poor training of HCW on managing sex worker needs</li> </ul>	<ul style="list-style-type: none"> <li>▪ use of Mobile clinics to reach areas with high numbers of sex workers;</li> <li>▪ use of peer counsellors to provide increase uptake of HCT in community (partnership with HIV-TB Cares NGO)</li> </ul>
<b>Population setting</b> (rural versus urban)	<ul style="list-style-type: none"> <li>▪ geographical proximity;</li> <li>▪ high transportation costs;</li> <li>▪ high rates of unemployment and migration especially in rural settings/shack dwellers;</li> <li>▪ inaccessibility to HCT services in hard-to-reach populations such as within farming communities</li> </ul>	<ul style="list-style-type: none"> <li>▪ CD4 testing services is not well established especially in rural setting- results in significant leakages in the care cascade post-test, and pre-ART;</li> <li>▪ lack of adequate manpower within the tracing team to properly capture migrant population; poor data quality;</li> <li>▪ poor transport infrastructure</li> </ul>	<ul style="list-style-type: none"> <li>▪ mobile clinics;</li> <li>▪ point of care services to minimise the number of facility visits;</li> <li>▪ decentralisation of services;</li> </ul>

One key barrier to successful progression in the HIV care cascade was highlighted to be stigma and fear of disclosure. Fear of disclosure was particularly strong among those who were employed, for fear of losing their jobs. Although the stigma surrounding HIV infection has improved over the years, it is still a significant problem, particularly in rural areas. In such cases there is a balance between preferring to have services close by (distances being far to facilities) and actually preferring to travel to far away services (to avoid neighbours' knowing people's status). In rural areas, clients were reported to prefer attending open support groups (that do not identify them as living with HIV) than closed ones (only includes those who are living with HIV). In a youth-specific support group intervention, youth emphasised their reluctance to attend groups where they may be identified as HIV positive. One important strategy to help overcome the issue around stigma, therefore, is mixing of HIV positive and negative clients. In facilities, integration of services achieves this. On the one hand integration of services may help desensitise people to HIV and therefore potentially reduce the prevalence of stigma. On the other hand, integration of services helps prevent those living with HIV being identified as HIV clients. In addition, integration of services, by providing a 'one-stop shop' for clients, minimised the need for clients to attend facilities more than is necessary, which reduces the chance of losing clients along the cascade. Integrating ANC and ART services was shown to improve ART initiation rates among pregnant women and reduce mother to child transmission rates. However, some clients and interviewed health care workers reported a reluctance for integrated services. For some HIV clients without comorbidities, this represented slower services for them. Rather than being fast-tracked they now have to wait in the queue like everyone else. For healthcare providers, a lack of confidence with treating other conditions was an issue for many. Adequate training and further task-shifting strategies should help overcome some of these fears, through the gain of experience in dealing with a wide array of conditions. Integration of adherence chronic clubs was also a big topic that was raised during this study. One of the advantages to clubs is the informal peer support that it provides. Mixing people with a 'laissez faire' attitude may result in 'non-peers' being members of the same club. Therefore, while integrating clubs may be useful in some settings, particularly in lower HIV prevalence settings, in others it may work less well. Having young HIV positive people with chronic disease clients, who are most likely older, may not be the best approach. One strategy that should be examined however is **segregation of clubs according to age groups rather than according to disease**. This should result in the best of all worlds. Peer support can be maintained, stigma can be tackled and comorbid clients can be offered a 'one-stop' shop service. It should be highlighted that although peer support is reported to be beneficial, provision of this support through support groups without other incentives—such as getting their treatment or food - was shown to be unacceptable for many clients.

Disclosure of status can provide valuable support for those with HIV. ART must be taken daily for life. Hiding one's status from close ones is very difficult in this context and would not be conducive to optimal adherence. In addition, disclosure allows clients to obtain the support they need at home, including having close ones who can remind them to take their medications. Disclosure was highlighted to be very important among children and youth also. In 2012, MSF implemented a support intervention helping caregivers disclose the status of their children,

using both grouped and individualised sessions. However, due to social challenges—such as having multiple caregivers and children attending alone without parental support –, disclosure rates are still reported to be below target; only 30% of children between the age of 10 and 14 had their status fully disclosed to them<sup>163</sup>.

Key system barriers at all stages of the cascade include long queues at the clinics, long distances to facilities and unsuitable clinic hours meaning that clients are often unable to take time off work. With an expanding cohort and the consequent strains on already stretched services, the key theme emerging from the Phase 1 study is the importance of decongesting clinics and pharmacies, through **fast-track services for those who are stable, decentralisation of services** and through **better screening of clients, to help identify those that need less support and those that need more**. Reducing the number of required visits to the facility not only reduces clients' opportunity costs but also decongests the clinics. In Cape Town, it was reported that there were 48 fewer visits per day at facilities after the introduction of ART adherence clubs. In a hospital in KwaZulu-Natal, stable clients on FDC make up 40% of the client load (4,000 out of 10,000 ART clients). Taking these people out of the hospital would leave those who could receive more individualised and focused support, such as those on second line regimens, clients with adherence problems, children and those with other complex comorbidities. Many initiatives are being implemented in South Africa in an attempt to decongest the clinics and 'bring the care to the people'. For HIV diagnosis, **good uptake of testing has been demonstrated using community and home based testing strategies**. **Self-testing** may also be a promising strategy for the future in South Africa. Results from services providing point-of-care technology, which reduces the number of visits needed to attend facilities, have shown that point-of-care CD4 services facilitate linkage to care and ART initiation. The use of community health workers in Cape Town to follow-up TB and HIV clients in their own homes has meant that clients do not need to attend the facilities for their medications so frequently; those that sign up to the initiative are given a one-month supply and do not need to do facility DOT, which has been phased out. Mobile clinics were reported to be extremely helpful in accessing clients particularly in hard to reach areas. ART adherence clubs have significantly decongested clinics, with, for example, 24% of Western Cape's ART cohort being members of clubs. With such scale-up, the clubs are now being shifted from the facilities to the community and to clients' homes. It must be important to note that the true impact on decongestion may not be entirely apparent, as the client volumes continue to increase year on year. The clubs are helping the facilities not become overwhelmed with this increase in the number of clients, not just those who are HIV positive but also in the context of a chronic diseases' epidemic. Therefore, it is likely, that the true impact of adherence clubs on decongestion may be underestimated. The use of mathematical modelling may be one way to evaluate the true impact of clubs on decongestion of facilities. Khayelitsha's Wellness hubs, acting as a base between clubs and the facility, should reduce the number of people referred to the facilities. Delivery of pre-packed ART for those who are stable on treatment through public-private partnerships such as MediPost are another attempt to remove those who are stable out of the facility, providing them with a quick service. Repeat pharmacy scripts and longer duration of treatment issued are other strategies with a similar

aim. The limitation of strategies like the latter, however, is that they only target those who are already adhering to their treatment. Those who are newly initiated and who require more intensive monitoring are usually ineligible for such initiatives; they are the ones who are at most risk of non-adherence and loss to follow up. Although these initiatives don't directly impact these clients, indirectly they help considerably, by shortening the queue. It must be mentioned, however, that as services are shifted outside clinics, issues around data quality arise. It becomes more difficult to know how many people who are tested in the community and in their homes come to the clinic for a CD4 test and/or to initiate pre-ART or ART care. Test results from POC CD4 tests are not linked to the main laboratory database. Clients followed up at home often give wrong addresses or move frequently. ART adherence clubs utilise paper registers with reported concerns that sometimes the data is not inputted to the system, or people become classified as lost to follow-up when they join the clubs and therefore stop attending the clinic for their medication. Clients using the MediPost service don't have to retrieve their files, which means their visits are not registered on tier.net. Again, these clients may be misclassified as lost to follow-up.

In the Western Cape Province, the use of DOH-funded CHWs are not currently implemented due to the strong NGO presence in the province, and the identified need for the province to maintain existing relationships by working closely with the NGOs who serve as key partners. An evaluation of the MSF model for the delivery of ART within the community showed that ART clients in Khayelitsha metropolitan district had a 90% cumulative retention rate after 2 years post-referral into a community group.<sup>185</sup>

The beneficial impact of decentralised services is well documented. Decentralisation of HIV services was shown to be beneficial on client attrition in a recently published Cochrane review, where all but one included studies were conducted in Africa<sup>186</sup>. The review found lower rates of attrition from services with partial decentralisation models of treatment i.e. where ART is started in hospitals but is continued in health care centres (moderate quality evidence). In addition, where ART was initiated at home by trained volunteers, there were no differences in attrition observed when compared to care provided in facilities (moderate quality evidence). As services become further decentralised, reliance on task-shifting strategies will become even more important. It is important to bear in mind that decentralised services should not be considered an entire disconnect from the healthcare system. For example, clients receiving their ART medications through a community or home club are still clients of the facility. In addition, clients self-monitoring their condition using mobile technology - a growing business in South Africa with considerable potential for the future (see Box 1) - should also be considered clients of the facility. In other words decentralised services should not be viewed as a parallel structure but instead work in harmony with facilities. Figure 15 highlights some of the ways that decentralised services, mobile health technology and facilities can work together, as one harmonious system.

### Box 1. The use of mobile technology in HIV treatment and care (mHealth)

The steep rise in the use of mobile phones across the world in recent years has been unprecedented, with almost as many phones registered as there are people worldwide today. In the health industry the use of mobile technology is a growing business with huge potential in a wide array of areas including: health promotion and information dissemination; access to health information through internet chat rooms or call centres, point-of-care service, mobile device supported diagnosis, self - monitoring of clients with chronic diseases, linkages between health services; client monitoring including drug adherence monitoring; disease surveillance; health information systems interfaces; health education; and health financing including insurance schemes. Statistics South Africa reports 89 mobile phone subscribers per 100 population in 2011<sup>187</sup>. A recently published report on the overall mHealth landscape in South Africa reported 83 mHealth services that were active throughout South Africa in June 2013; around half of these (42) related to HIV services<sup>188</sup>. Ten were reported to be active and supporting clients around TB care and three for clients with diabetes. Gauteng and Western Cape had the most mHealth initiatives (25/83) of all nine provinces, due to “a strong and innovative Department of Health and entrepreneurial environment, great network coverage, and presence of most mHealth organisations.” The majority of mHealth initiatives use a mobile phone platform to transmit data.

The research team observed the use of mobile technology in a wide range of settings for services relevant across the entire HIV care and treatment cascade including:

- Facebook groups, forums and WhatsApp for youth (Chapter 6), men (Chapter 3) and pregnant women (Chapter 6)
- MomConnect (Chapter 6) and other SMS based services for pregnant women (Chapter 7)
- Data collection at point-of-care for community adherence clubs (Chapter 8)
- Locating nearby clinics for those who are travelling (Chapter 8)

mHealth is not a new concept in South Africa. As an example, SIMpill was an initiative that was piloted in South Africa a decade ago for TB clients<sup>189</sup>. The initiative saw clients' TB pill bottles attached to a device with a SIM card and transmitter that was able to send a SMS to a central server every time the pill bottle was opened. If the pill bottle was not opened within a period around the prescription time, the server sent a SMS to the client, family member and/or caregiver to remind the client to take the medication. If the client still didn't take the medication after the SMS reminder then health care staff were alerted in order to follow-up with the client by telephone or home visit. A feasibility study was carried out among 100 TB clients in Northern Cape in 2005, with 97% of clients reporting that SIMpill helped them with adherence, which increased from 83% to 92%. Another pilot two years later in Khayelitsha, Western Cape, reported improvements in adherence from 22-60% to 90%. The cost per client for SIMpill is estimated at around \$17.



While mHealth may not be new, it has room to expand considerably. The research team identified several key areas where the use of technology could serve better across all steps in the cascade:

### HIV diagnosis

The use of anonymous forums and internet groups can serve as an excellent platform to engage hard to access groups including men, MSM, adolescents, and other groups to test for HIV, and could be further supported. In addition, as the use of self-testing scales up, mobile technology is a great tool that could help clients access counselling and other HIV services.

### Linkage to HIV care

Linking clients to care and treatment after having tested positive for HIV can also be potentially supported through mobile technology. For example, those who test in the community can be linked to CD4 services and receive their CD4 results by SMS. The use of SMS by community health care workers during home visits in South Africa was used in a recent trial for data collection, to note the day and time of visit, length of visit, content covered, and the perceived impact of the visit. In addition to data collection and monitoring, the study reported that the use of mobile phones proved to be an effective supervisory tool. Such uses of SMS for data collection and monitoring could be expanded to other community services, helping with much needed linkages to health facilities and better monitoring of these linkages. For example, in addition to the monitoring and supervisory aspect of such an mHealth platform, health care workers could be linked to a system that would allow them to answer questions, correct mistakes, and to follow-up when action is needed.

One of the disadvantages to POC CD4 testing was highlighted to be the lack of linkage between the POC CD4 result and the laboratory database. The research team identifies an opportunity for mobile technology to be utilised here, with even clients potentially capturing (and potentially owning) this data themselves at POC. While the use of SMS for data collection was piloted for ART adherence clubs in Western Cape, this was discontinued due to lack of interoperability between the mHealth database and the main health system databases, which was deemed to be inefficient (as the data still has to be inputted by the data capturers from one database to another). As the technology further develops, initiatives such as these should be revisited, particularly as this will also help with much needed quality assurance. Data captured at point-of-care will usually be of better quality. In addition, the use of technology can allow 'checks' to be put in place to prevent errors in data inputting.

### 'Healthy' pre-ART clients

Pre-ART clients who feel 'healthy' could receive relevant information related to HIV, much like MomConnect, to engage them in care and provide them with an open

communication channel to share their experiences. In addition, they can be sent reminder messages to attend repeat CD4 testing and other services such as cervical smears for women as well as messages to encourage adherence to IPT, for example. Screening questions could also be sent to the clients that would allow the system to encourage clients to attend to the facility earlier, if required. Information gathered by the clients and sent to the client could be visualised through the use of graphs and pictures to allow clients to monitor their progress, further engaging and retaining them in care.

### Stable clients on ART, including those who would prefer to receive their drugs anonymously

Similar to the use of self-testing and for pre-ART linkage and retention, self-monitoring by clients on ART with support of technology is an approach that has great potential to decongest clinics and lower the burden on the health system. Such a platform, for example, could use a mobile app that would present clients with various questions to be answered by clicking through in a private environment without stigma issues and at a time convenient especially for the working population. They would respond similar to questions asked (and Standard Operating Procedures (SOP) followed) during a clinic visit. Such an app, for example, would give clients several results for next steps: 'green' (qualifies for drug refill); 'yellow' (needs additional assessment, i.e. laboratory test); 'red' (needs to see a health care provider). Data would be entered into a database using similar secure access as with mobile banking. In the near future, monitoring of vital parameters, such as weight, temperature, and eventually viral load and other lab tests could also be used.

In addition, the use of anonymous and time convenient health forums could provide clients with peer support, including key populations who are often highly stigmatised such as MSM and substance abusers. Employees who have not disclosed to their employers could also receive support outside normal office hours and will not have to take a day off from work to get access to information.

For clients who would prefer to receive their drugs anonymously, the use of mobile technology has the potential to allow clients to use their mobile numbers and a PIN code rather than their names. While such an initiative would have to comply with standard pharmaceutical legislation, it is an idea worth exploring further.

### Clients who are unstable and/or struggling to encourage adherence

The use of weekly SMS for improving adherence among ART clients has been shown to be effective, with high quality evidence. Such initiatives targeting those who are unstable and/or struggling could be explored for wider use in South Africa. In addition, struggling clients could be linked to their peers, such as the use of apps that allow you to find peers that are available and who live close by.

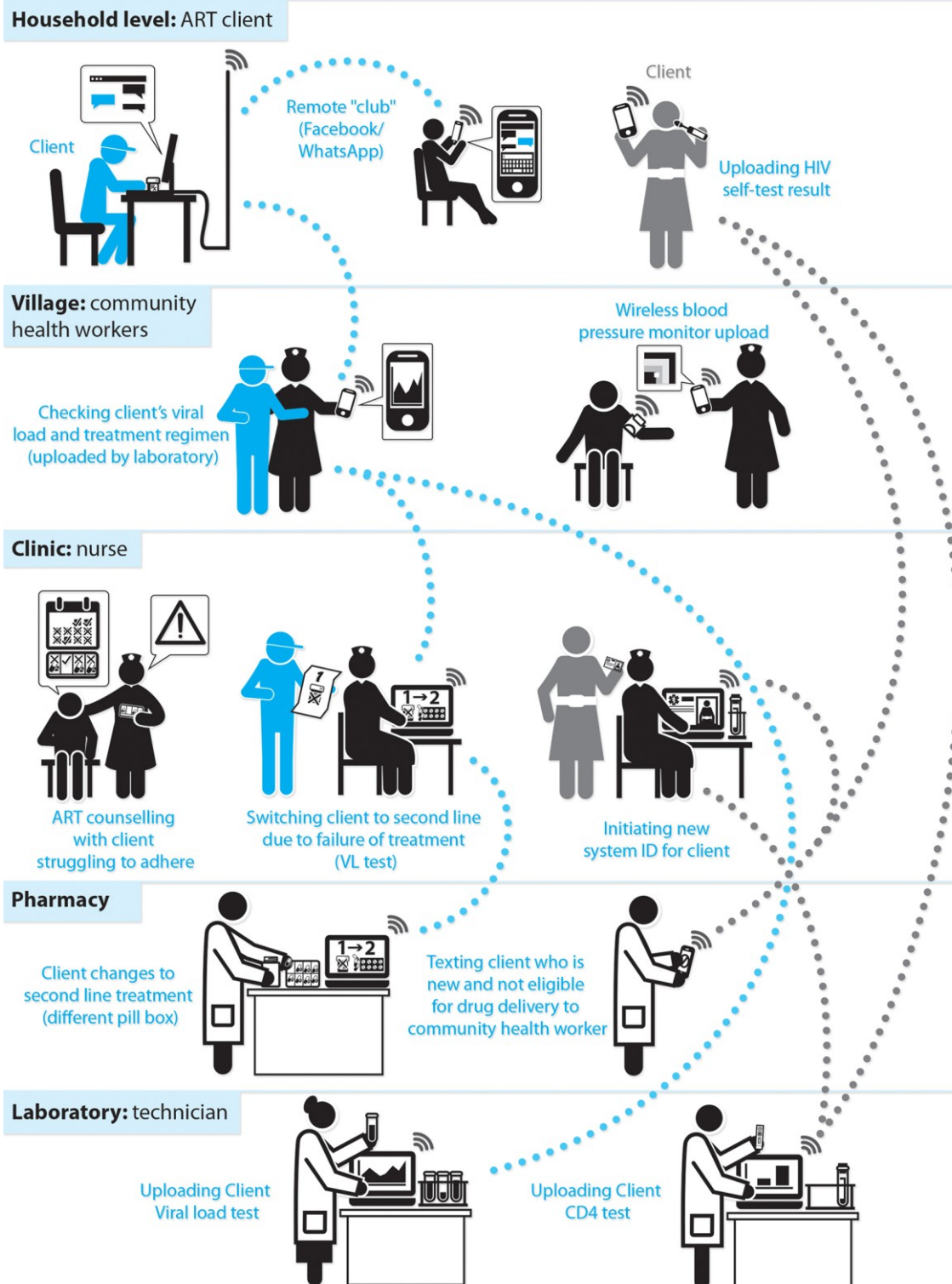
Like all technological tools, one must bear in mind the limitations—or 'reality checks'—of

scaling up such initiatives in the field. ‘Reality checks’ to scaling up the use of technology for health were reported to be three-fold, in a recent article published in Plos Medicine<sup>190</sup>: 1) Interoperability, which refers to the exchange and linkage between different data systems (much in the same way that the pilot for capturing ART adherence club data was discontinued due to lack of interoperability between the different health database systems); 2) open standards, which relates to having common standards that are publically accessible; and 3) evaluation for impact, which has been a big gap in supporting the wide-scale use of mHealth, with lots of pilots and not many high-quality studies providing strong evidence. In addition, as far as the research team is aware, no cost-effectiveness studies have been conducted in South Africa on the use of mHealth.

In general technology should be used where appropriate with the clear understanding that technology alone will not result in improved outcomes. However, without technology the massive scale up of ART cannot be achieved due to the numerous health systems challenges.

Figure 15. Health is going mobile

## Health is going mobile



Source: Author's own design based on findings of this Phase 1 evaluation

In addition to decentralisation, task-shifting has been successfully utilised in South Africa. For example, initiation of ART by nurses and midwives has been successful in improving ART initiation rates among pregnant and non-pregnant adults. In a recently published Cochrane Review—with the literature search date going up to March 2014—on the impact of task-shifting from doctors to non-doctors for ART initiation and maintenance, the authors concluded that “shifting responsibility from doctors to adequately trained and supported nurses or community health workers for managing HIV clients probably does not decrease the quality of care and, in the case of nurse initiated care, may decrease the numbers of clients lost to follow-up”<sup>114</sup>. The evidence was found to be of moderate quality. Simplification of drug regimen facilitates task-shifting while also reducing the incidence of side effects and non-adherence. Task-shifting strategies have also been utilised in South Africa for HIV testing—to lay counsellors and even to traditional healers—adherence counselling and issuing of treatment (pre-packed medication issued by lay persons). While such strategies are essential for dealing with the growing client burden, proper training, mentoring and the use of standardised tools were highlighted as essential components for maintaining good quality care. Counsellors and nurses are receiving additional training for providing adherence support in the MSF risk of treatment failure models for HIV and TB. New counselling models are using standardised tools, including those that are technology based, to deliver counselling sessions. Traditional healers are counselling and testing clients using standardised flip charts to do pre-test counselling, deliver the results and provide post-test counselling for both positive and negative tests. While standardisation helps with quality assurance, there must be some flexibility. Experienced counsellors from Cape Town emphasised the importance of providing individualised counselling support stressing that each client has different counselling needs. Therefore, the tools help guide the session but they should not have to be concretely followed. Mentoring of nurses undergoing training for NIMART has been shown to improve ART management; clinically mentored nurses were more likely to draw the required blood (91% versus 99%,  $p<0.05$ ) and assess adherence (50% versus 78%,  $p<0.001$ ) and WHO staging (63% versus 91%,  $p<0.001$ ). Mentored nurses also had improved confidence in initiating ART eligible clients, initiating more than three quarters (77%) of ART eligible clients, freeing up the time of medical officers to manage complex cases<sup>191</sup>.

Empowerment was highlighted as being a direct facilitating factor for health-seeking behaviour and adherence. Clients who are empowered take control of their own health. They do not wait for service providers to go out and look for them. They come of their own accord and know what they need. In addition, empowerment improves quality of service delivery, which further improves adherence and retention. Old practices such as DOT and pill counting were highlighted as being not in line with empowering clients. Elements of some new practices, such as the use of stickers to remind people of their reasons to stay alive, are also not in line with empowering clients, described as treating clients “like children.” In contrast, information provision, education and appropriate counselling were shown to promote empowerment. The use of mobile technology for bi-directional communication, such as MomConnect, aims to equip women with knowledge and provide them with open channels to ask questions and

report poor quality care. It is hoped that such initiatives will help empower pregnant women and improve overall quality of care.

In an attempt to promote empowerment among youths, several initiatives are being implemented in South Africa. A youth camp for boys and girls is due to be rolled out in a district in KwaZulu-Natal, and includes community dialogues with school governing bodies around the provision of family planning services in schools. Another currently active youth empowerment programme is called Stepping Stone, which is a training programme in gender issues, HIV, communication and relationship skills. A two-year evaluation of the programme, using a cluster randomised control design, in Eastern Cape, demonstrated an impact on reducing the incidence of HSV2 infection among men and women, by a third<sup>192, 193</sup>. The number of men reporting risky behaviour was also reduced. With the programme, a lower proportion of men reported perpetrating intimate partner violence, transactional sex and drinking problems at 12 months. There was no reported impact on HIV incidence. Some other highlighted youth initiatives in other provinces are the Red Cross FIFA centre, which provides peer education and psychosocial support for youth via sport activities. One facility in Limpopo, nominated to become an 'ideal clinic' and is categorised as a youth friendly service, is including youth in their clinic activities to engage youth in care. Overall, however, there is a lack of youth-specific strategies and models for youth, with limited evidence for the effectiveness of service delivery interventions supporting linkages of youth populations from HIV diagnosis to ART initiation, adherence and retention<sup>125</sup>.

The research team observed many different types of ART preparation counselling models, designed with the aim of providing clients with information on HIV and their medications to facilitate adherence, during their field work. While the models differed in terms of the number of sessions delivered and how the sessions are delivered, the classic models whereby all sessions must be completed before ART can be initiated results in substantial delays to ART initiation, providing an opportunity to lose clients. While the MSF ART initiation model is not perfect, one key element of the model is in accelerating treatment initiation, by shifting some of the sessions to after ART initiation. Combined with POC CD4 testing among youth, this has meant that youth can be tested for HIV, CD4 and receive the first session all in the same day. While fast tracking of ART initiation is positive, including among pregnant women, it is extremely important that client understanding is verified. There were some client reports that treatment was started so quickly they were left rather confused.

Although many clients reported being satisfied with the overall quality of services, there were others who were not. With the pressure associated with high client volumes, healthcare staff can become demotivated. Several strategies were highlighted as potential ways to help improve staff morale, including regular training and education, regular 'grand-rounds' as in the example from the iTEACH programme, and staff competitions. Results-based financing may also be an approach to incentivise and motivate health care staff and clinics to provide better services. As previously mentioned, having clients who are empowered with knowledge and decongestion of clinics were also cited as key strategies to improving overall service delivery. Failure to engage clients to get on to the cascade, through HIV diagnosis, and to keep them



engaged throughout, was reported to be particularly poor for youth and for men. In these cases, it was emphasised that current models of service delivery are usually not youth or male friendly. For men, having more male healthcare workers may promote male attendance to facilities. A male clinic has been opened in Western Cape, which offers out of hours services. Although uptake of men is still low, the clinic is relatively new and needs to be promoted better in the community according to key informants. Youth friendly services are key to engaging youth. In some facilities, youth are fast-tracked to promote their access, particularly during school hours.

Another key finding from the evaluation is the importance of having a targeted, client-centred approach to tackling issues around adherence. Just like no client is the same, the reasons for non-adherence are not the same. Although there are no reliable indicators for flagging up a client as being at risk of non-adherence right at the beginning, using the first viral load is a good way to flag these clients early, before they fail treatment and develop drug resistance. Scaling up access to viral load testing is pertinent. While awaiting scale-up of new technologies, such as point-of-care viral load testing machines, innovative strategies such as viral load pooling are being utilised with good results in other sub-Saharan countries. The use of the viral load to flag up those who are not adhering to their treatment is being used by MSF in Western Cape to provide clients with individualised support by trained personnel with good results. While many strategies observed on the ground were of a 'blanket' approach for all cases of non-adherence, the research team believes this approach may result in incorrect 'prescriptions' to cases of non-adherence. While clients may not be entirely honest with healthcare providers about the true cause of their non-adherence, using a grouped approach, rather than one-to-one questioning, may result in greater openness among clients. Grouped sessions were also highlighted as a potentially better approach for problem-solving activities prior to ART initiation that help clients prospectively make action plans to avoid problems with their treatment, such as how they will remember to come to the clinic and take their medications. With the current MSF ART initiation model, these action plans are made in an individual session with the counsellor. Another potential approach to help 'get to the bottom' of the causes of non-adherence may be to utilise traditional healers, who are trusted in the community. Social issues including alcohol abuse and food insecurity were highlighted as barriers to adherence. In such cases, a correct 'diagnosis' would ensure appropriate referrals of these clients to social services and to nutritionists and dieticians.

Although the focus of this study was on HIV, barriers to care and approaches to service provision are similar for other chronic diseases, which are on the rise in South Africa (Box 2). Similarly, the provision of HIV services including long-term ART must be an integral part of the PHC strategy. The roles and responsibilities of the ward based primary health care (PHC) outreach teams and the clinical specialist teams at the district level need to be carefully defined, and communicated to these local structures. Local health services should plan how these human resources can help support both ART initiation (with better reach to underserved populations) and ART adherence. In addition, local health services should closely monitor the implementation of these plans and the human resource requirements. Down-referrals—especially of stable ART clients—to community-based structures need to be



carefully orchestrated with medication delivery schemes, such as MediPost, the bicycle man model and adherence clubs. The TIER.net system should be accessible to these actors as it can help focus efforts to clients who miss appointments and default. The data system's capacity must be matched by adequate manpower to act upon the data (e.g., tracing defaulting clients in the field). The Integrated Chronic Diseases Management (ICDM) approach for the delivery of care to chronic disease clients represents a powerful vehicle for improving the nation's physical and mental health provision. The use of CHWs for the delivery of HIV services has been proven to work for improving reach, uptake and quality of HIV services, as well as the dignity, quality of life and retention in care of PLHIV. There is also a particularly important task to defragment TB and HIV treatment services for better TB outcomes.

#### Box 2. Other chronic diseases

Adherence to medication and a healthy lifestyle are also crucial for other chronic diseases, such as diabetes, hypertension and mental disorders. The burden of non-communicable diseases (NCD) is rising rapidly in South Africa—not just among the ageing population but also among younger people—placing considerable strains on healthcare services<sup>194</sup>. A study from Cape Town showed that while the prevalence of chronic diseases such as hypertension and diabetes increased with age, 20% of those aged between 18 to 35 had hypertension and 12% diabetes, increasing to 30% and 26% among those aged between 36 and 45 years respectively<sup>195</sup>. An analysis comparing NCD outcomes between rich and poor districts in South Africa reported that NCD accounted for 39% in rich and 33% of premature mortality in poor districts<sup>196</sup>. The same study reported that adherence to hypertension medication was less than 10% among those in the lowest socio-economic quintile compared to 80% among those in the highest quintile. According to the South African Stress and Health (SASH) study, the first large-scale population-based study of common mental disorders in South Africa, almost one in three (30.3%) South Africans will develop a mental disorder in their lifetime<sup>197</sup>.

In addition, the prevalence of co-morbidities—including HIV—is also on the increase, resulting in complex treatment regimens, drug interference, increased pill burdens and consequently poorer adherence and retention in care. Data from Cape Town suggest that 19% of HIV-infected clients on ART were also on treatment for another chronic disease; of these 77% were on treatment for hypertension and 17% for diabetes<sup>195</sup>. In another study, carried out in rural South Africa among those older than 50 years, 45% of participants reported having another current chronic co-morbid condition, including heart disease (angina), arthritis, stroke, hypertension, chronic lung disease, asthma and diabetes<sup>198</sup>. A multi-country study conducted in South Africa, Cameroon, Mali, and Tanzania, reported that clients with diabetes spent 13 times more days as an inpatient, and had 7.5 times more outpatient visits. They are also to take 5.6 times more medications than those without diabetes ( $p < 0.001$  for all outcomes). Clients with diabetes spent an average of 3.4 inpatient days per year, made 10.7 outpatient visits per year (excluding traditional healers), and were taking an average of 2.5 prescribed medicines when interviewed<sup>199</sup>.

Barriers to adherence for PLHIV are also similar for those living with other chronic diseases.

A qualitative study carried out among 23 primary care clients living with diabetes, hypertension or both conditions in a rural municipality in Western Cape highlighted key barriers including poor client-provider relationships, long waiting times, perceived poor quality care, financial problems such as high transportation costs and being unable to take time off work due to missed wages, poor social support networks, forgetfulness, fear of side effects and feeling well with absence of symptoms<sup>200</sup>.

Clearly South Africa, like many sub-Saharan countries, is facing a major chronic diseases epidemic that is putting additional strains on already stretched health services adding to challenges with adherence and retention as seen in the chronic ill anyway. In an effort to address these issues, South Africa is one of the first countries in Africa that has attempted to address the chronic diseases' epidemic through, 're-engineering' of its primary health care (PHC) system, the development of a National Health Insurance (NHI) strategy, and through its Integrated Chronic Diseases Management (ICDM) model among others, the latter two initiatives being piloted in eleven and three districts respectively<sup>201</sup>.

Re-engineering of PHC—launched in 2010 in line with WHO's Innovative Care for Chronic Conditions (ICCC) Framework<sup>202</sup>—incorporates three “streams”: deployment of ward based PHC outreach teams (WBOT); strengthening school health services; and deployment of district clinical specialist teams (DCSP)<sup>203</sup>. As part of this three-pronged strategy non-communicable diseases have been prioritised. Ward based PHC outreach teams provide preventative, promotive, curative and rehabilitative services to families in the community. Strengthening school health services includes screening, health education/promotion (particularly prioritising sexual and reproductive health education) and provision of some service delivery, with the aim of covering all students and schools. District based clinical specialist teams work with institutional specialists and are responsible for helping ensure that an acceptable standard of clinical care is maintained in the regions for which they are responsible<sup>204</sup>. The re-engineering strategy also incorporates the use of mobile communication tools for monitoring and evaluation.

In addition to the PHC strategy, South Africa has also developed a National Health Insurance Green Paper, describing the NHI scheme, which was launched in 11 pilot districts in 2011 with work already begun in some central hospitals preparing them for future financing under the NHI scheme<sup>205</sup>. One of the objectives of the NHI strategy is to improve access to quality health services that are integrated into the current PHC model and include chronic disease management, with the aim of providing universal health coverage<sup>205</sup>. The White Paper of the scheme is currently being discussed in the cabinet and it is unclear of the timeline of when the NHI will be implemented.

With the ICDM model, clients with chronic diseases receive healthcare services for all their conditions in one place ('one-stop shop') and are regularly followed up through health visits. The model incorporates nurse-led clinical guidelines to support PHC teams in identifying and managing multiple chronic diseases and a registry of clients with chronic diseases to assist with identifying, tracking and following up those who default from care. Community health

care workers as part of outreach provide links to the community, screen and identify clients with chronic conditions as well as follow up clients who are non-adherent.<sup>201,206</sup> Training of community health care workers on hypertension to improve adherence to medications in South Africa was deemed a potentially cost-effective strategy for prevention of cardiovascular diseases and “a very good purchase according to World Health Organization (WHO) standards”.<sup>207</sup> A cost-effectiveness analysis of such an intervention—training of CHW on causes and complications of hypertension along with skills for taking blood pressure - estimated that this would cost around \$8 per client per year. When the costs are offset by reductions in non-fatal cardiovascular events (by 2% over a lifetime) the intervention is estimated to cost even less, leading to an incremental cost-effectiveness ratio of \$320/DALY averted. The intervention would be cost-saving at an annual cost of \$6.50 or if the blood pressure reduction is 5 mmHg or greater per client according to the analysis<sup>207</sup>. In addition to the above strategies, the South African government has introduced legislation to control tobacco consumption and salt and trans-fatty acid content in food. Bans have also been put on advertising of alcohol to children.<sup>208</sup>

Screening and testing for chronic diseases is inconsistently done in South Africa. A recent study was carried out examining screening rates for chronic diseases, unhealthy lifestyle, HIV and cancer for almost two million privately insured clients across all nine provinces in South Africa in 2011.<sup>209</sup> The study found that across all nine provinces screening rates for diabetes (23.8%), cholesterol (20.1%) and HIV (8.2%) were very low. In addition, screening rates for cervical (16.7%), breast (13.3%), and colorectal (0.4%) cancers were found to be well below international targets (93%, 81.1% and 70.5% respectively). Another recently published study carried out among type 2 diabetic clients attending hospitals in South Africa’s North West Province reported that few diabetic clients were screened for long-term complications such as retinopathy (19.5% screened), nephropathy (1.11% screened) and diabetic foot problems (20.6% screened).<sup>210</sup> A recent review (2014) on adherence and hypertension concluded that there is “no gold standard method that is easy to perform, inexpensive and acceptable to patients [that] is available for non-adherence screening”.<sup>211</sup>

Several strategies aiming to scale-up NCD services and improve adherence to treatment and lifestyle changes have been described similar to HIV, such as task-shifting from physicians to other healthcare providers, education, counselling and motivational interviewing, and the use of mobile health technology, among others.

A recently published (2014) systematic review of studies involving task-shifting for the management of NCD reported two studies from South Africa<sup>212</sup>. One of these, which was published in 1998, showed that task-shifting of chronic clinical care to nurses enabled scale-up and decentralisation of chronic diseases’ services while improving adherence<sup>213</sup>. This nurse-led service for non-communicable diseases was introduced into all primary care clinics in KwaZulu-Natal resulting in nurses clinically managing 68% of clients with hypertension, 82% of those with type 2 diabetes, and 84% of those with asthma while significantly improving adherence to treatment. After two years of implementation, client reported adherence to treatment increased from 79% to 87% ( $p < 0.05$ ). In a more recent

study<sup>214</sup>, 60 clients with moderate to severe depression received interpersonal therapy support through community health workers. This strategy significantly reduced depressive symptoms among participants at the completion of the intervention as well as 24 weeks post baseline compared to standard of care, through improved social support, enhanced individual coping skills and improved personal agency.<sup>214</sup>

The majority of the literature around adherence interventions and chronic diseases has so far been carried out in high-income countries, mostly the US. A recent systematic review (2014) of RCT and quasi-experimental studies investigating the impact of interventions on medication adherence in type 2 diabetic populations found no studies conducted in sub-Saharan Africa; three-quarters of all trials had been conducted in USA, Europe and Australia<sup>215</sup>. Of the included studies in this review, over half (55%; 15/27) reported on one-on-one counselling, with 13 out of 15 studies being significant for changes in medication adherence and/or HbA1c. Like for HIV, several studies also used self-monitoring as a tool to improve adherence. Eight studies used self-monitoring data, such as home blood glucose reading, to try to improve adherence. Of these, half showed statistically significant improved adherence to medication and/or lower (HbA1c. Fourteen studies assessed the use of telehealth/telemedicine, with ten of these studies showing significance for differences in medication adherence and/or HbA1c: mobile phones, such as using phones to provide adherence support and integrative coaching sessions (3/4 studies were significant), telephones, to, for example, receive educational sessions (7/9 studies were significant), and the internet (one study that provided education about depression and diabetes online), which did not show any significant differences between intervention and control). New technology that makes use of a contact lens to monitor glucose levels in tear fluid is currently in prototype form with hopes to have a product ready for market within five years<sup>216</sup>.

As with hypertension and other chronic conditions, the majority of controlled interventions to improve adherence have been carried out in high-income countries. A recent large review synthesising the evidence regarding the efficacy and effectiveness of different interventions to improve medication adherence among adults across a broad array of chronic conditions was carried out in the US—with African American populations being “reasonably well covered”. Strongest evidence for improving adherence was found through reduction of co-pays across different clinical conditions, self-management of asthma (improved short-term outcomes), and collaborative care or case management<sup>t</sup> for depression<sup>217</sup>. Other consistent evidence for adherence in chronic conditions included interventions such as education, reminders, and pharmacist-led multicomponent interventions.

In conclusion, South Africa is currently facing a growing chronic diseases’ epidemic. More and more people are developing one or multiple chronic conditions resulting in increased demands on an over-stretched healthcare and pharmacy system, resulting in poor services

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<sup>t</sup> Case management involves proactively identifying clients who are not likely to adhere to complex treatment regimens.

and leading to poor adherence and retention in care. While there are differences in how HIV and other chronic diseases are clinically managed, approaches to service provision and adherence promotion are similar for HIV and other chronic diseases, with a potential to “cross-fertilise” present care models of HIV with other chronic diseases.<sup>218</sup> This includes task-shifting and decentralisation, simplification of treatment, education and counselling, encouragement of self-management and the use of mobile technology. As such, the South Africa adherence strategy encompasses not just HIV/AIDS but other chronic diseases also<sup>4</sup>.

The strengths of this evaluation include the fact that it incorporates clients’ perspectives. In order to address the issue of adherence and retention, we must listen to the voices of our clients. They, more than anyone else, understand their needs. Furthermore, the team interviewed more than 170 key informants in five out of nine provinces, chosen to provide a range of contexts. These key informants came from a wide range of backgrounds including government representatives from the national, provincial and district departments of health, academics, public and NGO programme managers, physicians, nurses, pharmacists, counsellors, community health care workers, support group facilitators, and data capturers. A concomitant literature review helped provide evidence supporting our key findings. The primary limitation to the evaluation is the limited timeframe for the study. The team had to analyse and report the findings in three weeks after completion of interviews.

## Chapter 10. Conclusions and recommendations

This chapter outlines the main conclusions and recommendations based on the first phase of the evaluation, highlighting possible intervention models and strategies with regards to improving ART adherence and retention in care in South Africa. It also provides reflections on the wider adherence and retention issues in chronic diseases in South Africa, which are relevant to the development of the South Africa Adherence Strategy, entitled 'A stepwise approach to linkage to care, retention in care and adherence to treatment of chronic diseases'. Conclusions and recommendations are presented according to four broad characteristics of well-designed interventions to improve adherence across all stages of the care cascade:

### AREA 1 | Improving clients' understanding of their treatment

**Based on evidence reviewed in Phase 1, we conclude that:**

- Clients living with HIV may not have sufficient knowledge about the risks of non-adherence to ART and of delaying ART initiation once ART eligibility is confirmed.
- Nurses and counsellors often don't have the time to comprehensively answer client questions.
- Counsellors' training has been focused on HCT and not on ART adherence, and this shows in client perceptions of the services they receive.
- It was apparent that many people are not familiar with the National AIDS Helpline 0800 012 322.
- Client knowledge and understanding of their treatment is an essential ingredient for medication adherence in chronic diseases. Internationally, increased knowledge has been found to help clients understand the importance of treatment regimens and treatment monitoring - treatment effects can be better appreciated, the reasons why adherence is important for the client's health better understood, and prescribed behaviour followed.
- International good practice in chronic diseases' management shows that for clients to adhere to any treatment intervention over time, it is prerequisite to determine clients' knowledge and perceptions, and to address their uncertainties. The educational content needs to be matched to the client's level of health and treatment literacy and their age group, and put into the appropriate context. Also, the education should be aligned with the client's readiness to make a behavioural change and build on existing knowledge. The information should be reinforced by others in the provider team and messaging should be clear and harmonised.

## Recommendations for future treatment adherence models:

**1 Information provided to clients must be focused on the individual needs of the client as well as on the understanding of “client typologies” (Table 3) (different types of clients having different information and support needs).** Information must be conveyed in the most time-efficient way and the way it is conveyed should be validated. For example, tests on knowledge could be carried out pre- and post-educational sessions on selected participants to see if clients understand the information in the way that is delivered, which can then be refined accordingly.

**2 Clients must be able to access and exchange information anonymously and at convenient times and places.** This includes the use of e-technology, which is already being harnessed albeit at a small scale (Facebook, WhatsApp Messenger app, chat rooms, health forums etc.). The Internet generation is accustomed to receive peer support and socially network via virtual forums, and there is scope to further harness such technology for certain chronic disease client groups.

**3 Clients must obtain information on what to expect to happen from a specific scheduled appointment, and what services they have a right on.** This includes diagnostic tests, potential referrals to other services, ancillary treatment like IPT, and linked follow-up services. MomConnect is already implementing such an approach through text message alerts to pregnant women, an appointment service, and information sharing on services the client is entitled to receive.

**4 The National AIDS Helpline can be better utilised to support client education, and could be complemented by a mobile application, which could also have a broader application to chronic diseases’ management and treatment adherence.** Such an app and/or extension of the helpline service should be of high quality and represent a client-oriented source of advice and information. The current services offered may need to be reviewed in terms of the nature of the queries received, whether adequate training of phone operators is in place, and the different channels that can be used for better market the service. The helpline should provide rapid responses by phone, text message and e-mail and cover all diagnosis/testing-related questions of HIV (including viral load and interpretation of HIV self-test) and other chronic diseases, drug interactions, medication for opportunistic infections, drug availability, adherence support, questions on disclosure, and employee protection from unfair discrimination, among others.

Note that in future apps could fulfil a key role in client education and information (see also Box 1 on mHealth above). A first-of-its kind app for health care professionals has just been launched by Metropolitan Health, the largest administrator of medical schemes in South Africa<sup>u</sup>. The app covers all aspects of HIV care and decision-making. For instance, the toxicity and

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<sup>u</sup> News South Africa: New HIV Mobile App Guides Treatment of Patient. <http://ehealthnews.co.za/news/new-hiv-mobile-app-guides-treatment-patients/>, 29 September 2014



adverse reaction pathology calculator determines whether a client should remain on a specific treatment or switch.

## AREA 2 | Provide focused counselling and grow accountability

**Based on evidence reviewed in Phase 1, we conclude that:**

- Client-oriented counselling is important at all stages of the treatment and care cascade.
- Satisfied clients feel empowered from counselling sessions. Clients that do not receive the counselling support they need, specific to their circumstances, may default from treatment as a consequence.
- The timing, length, session composition and delivery characteristics of counselling sessions are perceived as important by practitioners and clients. Interestingly, a recent randomised controlled trial in South Africa did not find that motivational counselling was superior over classic didactic methods.<sup>136</sup>
- When preparing ART eligible clients for ART initiation, it is beneficial to extend counselling into the ART consolidation phase to reduce delays in ART initiation.
- As the ART programme grows in scale, there is a danger that health staff-to-client ratios decrease and extended face-to-face counselling may not be feasible.
- There is an urgent need to make counselling for ART and other long-term treatment adherence as efficient as possible. It has been reported internationally from medication adherence research that supportive counselling helps clients become and remain engaged in their health, build clients' self-efficacy in their medication taking behaviours and helps them embrace accountability for their treatment. Such counselling interventions can be delivered in a variety of forms, including by peers and volunteers.

### Recommendations for future treatment adherence models:

**5 Standardise adherence counselling approaches to have a predictable offer for clients, simplify service delivery, and facilitate quality assurance.** The type of counselling and education that is offered for ART preparation—and for other chronic diseases—currently differs significantly across facilities and programmes in South Africa.

- Standardising the content, schedule and delivery tools of counselling sessions with reference to standard operating procedures (SOP) will help with much needed quality assurance of adherence counselling - this is of particular importance in the context of task-shifting of counselling responsibility to lay persons.
- But: standardised tools should allow a degree of flexibility to ensure a client-centred approach is utilised. Specific and tailored counselling for **adolescents, pregnant women**

**and TB clients** is recommended, to ensure that the content and delivery of sessions is appropriate to the needs of, and acceptable by, the target population.

- The benefits of technologically based tools, such as their potential to deliver interactive sessions and to monitor client progress, should be balanced by 'reality checks', such as the need for computer literacy, power, and device maintenance.

**6 Revision of the ART preparation counselling model based on lessons learnt.** Counselling and education, along with the use of SMS messaging, were shown to have the strongest evidence for promoting ART adherence and retention in care in a recent review, with evidence from RCTs and observational studies carried out in several different contexts<sup>101</sup>. While the research team did not observe a 'perfect' model, several elements of models were highlighted to be potentially good practice. For instance, shifting some of the ART preparation counselling sessions to post-ART initiation (MSF ART initiation counselling model) prevents unnecessary delays in ART initiation. Good quality pre-ART sessions with verification of client understanding and readiness to initiate treatment prior to ART initiation remain important. Also, training counsellors specifically on adherence and non-adherence problems is crucial since most counsellors were trained primarily on pre- and post-test counselling.

**7 Identification of clients at risk of treatment failure early, through the use of viral load testing.** Although South Africa is the largest purchaser of VL tests in the world<sup>82</sup>, currently only around a third of ART clients receive VL testing in South Africa<sup>10</sup>. The relatively high cost of VL tests has been one barrier to scale-up. A new Global Access Program, launched by global partners and Roche Diagnostics, announced on 25 September 2014, is expected to reduce the price of VL tests by more than 40% in low- and middle-income countries, including in South Africa<sup>v</sup>. With this price-reducing initiative, scale-up of VL testing becomes a more realistic option. Innovative strategies, including those from other sub-Saharan countries, which reduce the costs associated with VL testing and therefore facilitate scale-up should be further explored for potential application. Logistical barriers to VL testing scale-up, such as transportation of samples and limited human resources, can be overcome by future VL POC technology. In addition, treatment sites could more effectively utilise their viral load data to: monitor facility success in achieving viral load suppression; target adherence strategies to those clients who need more support; and to ensure that clients are informed of their viral load status, ensuring they understand what their result means.

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<sup>v</sup> <http://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2014/september/20140925prviralload/>

**8 Improve data quality and systems across providers and facilities, thereby strengthening accountability.** Multiple registers, inconsistent recording by health care staff, work overload for data capturers, non-networked health databases and the absence of a unique client identifier code were highlighted as barriers to a well-functioning programme and client monitoring.

- An integrated data platform with the planned unique identifier system will reduce misclassification of clients as lost to follow-up.
- The streamlining and integration of registers is recommended.
- Initiatives to reduce the workload of data capturers should be explored, including the use of mobile technology to record client data at point of care, task-shifting strategies, and improving the efficiency of data capturers through capacity building.
- Network reliance could potentially slow down data capturing and needs careful evaluation.
- Staff should be provided with further training to ensure that recording of information is consistent.
- Procedures for officially transferring between facilities should be revised, to help minimise clients self-transferring between facilities, which results in unnecessary additional investigations to be carried out as well as misclassification errors.
- The MomConnect model provides great learning opportunities for understanding data systems, which include targeted client contacting and feedback loops, thereby strengthening accountability of providers.

## AREA 3 | Ensuring that there are tools and strategies to assist client self-monitoring

**Based on evidence reviewed in Phase 1, we conclude that:**

- There is much scope for increased self-monitoring by clients along the treatment and care cascade of HIV and other chronic diseases. The ICDM model promotes “assisted” self-support and management of clients.
- Increased self-monitoring will support ART programme expansion and the scale-up of other chronic disease programmes, in which decongestion of facilities and decentralisation of care functions are regarded as essential.
- The deployment of community health workers can facilitate self-monitoring by clients, and further technical development on data carriers and shared data platforms will contribute to initiatives for increased self-monitoring.
- The concept of self-monitoring also fits with calls for empowerment of clients and makes people accountable for their health and medication-taking behaviours.

- Self-monitoring is especially promising in client populations who are stable on their treatment regimen (HIV and other chronic conditions) and are treatment literate.
- The international literature regards self-monitoring as an essential tool to improve adherence and also to inform health providers about client behaviours and health needs. The collection of client data is a rapidly developing field, and encompasses several metrics of which some can be collected remotely, depending on the chronic condition of interest and availability of technology. Medication adherence data such as prescription renewal and medication diaries are promising, as are NCD indicators such as blood pressure or glucose levels. Self-monitoring of TB medication taking has been piloted in South Africa with the smart pill cap SIMpill (see Box 1).
- Data collected through self-monitoring gives clients direct feedback and it can be shared with health providers. Importantly, the data can also be reported to health care systems for client tracking and incorporation into the electronic health record.

### Recommendations for future treatment adherence models:

**9 Use self-monitoring approaches in a model specifically designed for the needs of “healthy feeling” people: those who are diagnosed early who are not yet eligible for ART; those initiated early on ART; those who are stable and well on ART; those with chronic conditions and who are asymptomatic such as those with hypertension, for example.** This model would include the collection of some vital parameters (like body weight, body temperature, blood pressure) either at a decentralised/community level or—once technology allows—via clients’ own monitoring. Clients would have access to diverse channels of information provision. They would be linked to a semi-automated drug refill system resulting in more convenient and anonymous delivery of medication to participating pharmacies or sites, for example. Such a model would serve primarily stable clients on long-term medication.

- With the advent of telemedicine platforms, such a model could use an app allowing clients to click through various options or menus to respond to over the phone similar to a checklist that would be used during a clinic visit.
- Such an app, for example, would give clients several results for next steps: ‘green’ (drug refill); ‘yellow’ (needs additional assessment, i.e. laboratory test); ‘red’ (needs to see a health care provider).
- Data would be entered into a database similar to mobile banking. The main aim of such a model would be to make medication use more convenient for clients, and free up the health facilities to serve clients who are less well and who are struggling with medication adherence.
- Clients would continue to have access to adherence or chronic clubs, which fulfil a need to exchange with peers. It is thought that such a model facilitates medication adherence in

clients who want to stay anonymous, who are unable to spend time at health facilities due to working hours or migration, and who suffer from discrimination and stigma.

**10 Data systems that can link self-monitoring data and health service data and allow bi-directional data exchange.** Obvious applications of mHealth are the use of mobile phones for linking up with clients after undergoing diagnostic tests (including HIV tests, VL assessments, etc.). Box 1 on mHealth provides further concrete examples how future models could harness mobile technology for strengthening and expanding data systems and monitoring capacity in different client populations of interest. Other mHealth initiatives that provide clients with information about their condition as well as providing them with channels to communicate their experiences, such as MomConnect, are excellent tools with the potential to empower clients and create demand for services. Such mHealth platforms should be further explored for potential scale-up not just among pregnant women.

## AREA 4 | Reducing barriers to diagnosis, treatment and care

**Based on evidence reviewed in Phase 1, we conclude that:**

- There are barriers to access to services across the treatment and care continuum, from testing and linkage to care and treatment to the stable management of a chronic condition. Although there are clinical differences between diseases, barriers to care—such as long queues and poor education-, and managing and overcoming barriers to care - such as the need to reduce client opportunity costs and to provide adherence support -, for HIV and other communicable diseases are similar to non-communicable chronic diseases.
- In ART, some barriers are mounting as the programme expands in scale, for instance through increased opportunity costs of clinic visits due to waiting times.
- Models must be designed to mitigate barriers to testing, treatment and chronic care, as stigma persists and client volumes rise.
- Decentralisation, integration of HIV and chronic disease care and self-management of conditions are important measures. The Integrated Chronic Disease Model (ICDM), for example, aims to provide client-centred care in an integrated manner and promote self-management of chronic diseases. It is important to bear in mind that although decentralisation of services is key to improving scale-up and coverage, decentralised services must not be disconnected from facility-based services, potentially leading to parallel services. Decentralised services (and the associated data) must be a continuum or arm of the whole service delivery package.
- Even in the well-established PMTCT programme there are barriers; late ANC booking was highlighted as a major factor in late HIV testing and ART initiation for PMTCT for pregnant women. Initiatives that promote women empowerment, such as community dialogues,

mentoring and mHealth platforms like MomConnect, seem well placed to help address barriers.

## Recommendations for future treatment adherence models:

**11 Better ‘diagnosis’ of non-adherence and ‘prescribe’ individualised ‘treatment’ of non-adherence.** This addresses the observation that often the wrong prescription is made for an adherence problem (e.g. more facility visits for a client struggling with regular attendance of facility-based services). This is also highly relevant if the new ART eligibility criteria are operationalised with an “opt-out” approach to ART initiation. ART eligible clients refusing ART will need a careful diagnosis of their barriers to treatment acceptance, and an individualised approach to consider enrolment in the ART programme when they are treatment-ready.

**12 HIV self-testing as a low-threshold method and an integral part of the ART scale-up model.** Self-testing requires a clear regulatory environment in South Africa, a (social) marketing strategy and accessible counselling and information services (see reference to Helpline and app above). Self-testing is an innovative method of promoting HIV testing especially among hard to reach adult populations. Considerations must be given to the packaging of the test, appropriate distribution channels and counselling/psychological support, through client and market research. With insufficient linkage to care of newly diagnosed PLHIV, the HIV self-test model should include an identifier which qualifies new HIV cases for receiving care and opt-out ART when treatment eligible.

**13 Point-of-care technology as a means to increase convenience of testing for clients and reduce barriers to biological monitoring.** The use of point-of-care CD4 technology was shown to improve linkage to care and ART initiation, including among special populations such as adolescents. By increasing the number of clients who are assessed for ART eligibility, it will enable the health provider to initiate ART if eligible, or initiate the agreed package of care if not yet eligible (according to 2013 guidelines this is: 1) transfer to a wellness programme for regular follow-up and repeat CD4 testing 6-monthly; 2) advice on prevention of onward HIV transmission; 3) initiation of IPT if asymptomatic for TB; and iv) counselling on nutrition and contraception and annual pap smear). **However, it is important to consider that scaling up such POC CD4 technology may not be the best investment in the long term**, particularly as the current climate suggests a move to universal testing and treatment may be a reality in the future, which would render CD4 testing unnecessary.

Developing models which combine elements of the above - improving clients’ understanding of their treatments, providing focused counselling and nurturing accountability, making tools available which empower clients to self-monitor, and reducing barriers across the HIV cascade — is one step towards maintaining and potentially increasing ART adherence in South Africa. Models that can provide synergistic effects across different conditions and diseases will be

especially valuable for public health aims and for ART as a public good. Components of the models must be personalised to the clients' situations—even in a very large ART programme. The intensity of resources and technology used should be scaled to meet an individual client's needs. Some clients will require intensive, individualised in-person counselling, others may respond just as well or better with infrequent face to face contact and instead with reminders via mobile phone. Matching intervention delivery and intensity with clients' needs is the goal for South Africa's adherence programmes, which must be scalable and sustainable.



# Outlook: Phases 2 and 3 of the impact evaluation

## Phase 2

The second phase of the evaluation will consist of two separate analyses:

### **A. Secondary analysis of laboratory test data to determine HIV treatment outcomes in geographic and demographic strata of ART clients to guide Phase 3 focus**

This secondary analysis of existing ART monitoring data will include VL and CD4 recovery rate data. The work will be conducted over three months in partnership with the National Health Laboratory Service (NHLS) and the National Institute for Communicable Diseases (NICD). The NHLS laboratory database (“Corporate Data Warehouse”) contains VL and CD4 test results from public sector ART sites from 2004 (around 4 million VL test results and well over 16 million CD4 tests results). The areas the joint analysis covers are:

- **Spatial distribution of VL data with the ART facility being the lowest unit of analysis** – understanding the spatial distribution and any potential clustering will help to select and match districts and facilities in Phase 3
- **Temporal, geographic and sub-population distribution analysis of CD4 recovery rates (including by facility)** – this will further help to identify which of the PLHIV sub-population strata the evaluation should focus on (this is on-going work at NHLS but needs to be fast-tracked to be useful for Phase 3)
- **Temporal, geographic and sub-population distribution analysis of the HIV care cascade** – understanding such patterns would be useful for the evaluation in that it would help identify which of the PLHIV sub-population strata the evaluation should focus on (this is on-going work at NHLS but needs to be fast-tracked to be useful for Phase 3)

The above, in conjunction with the data dashboards that provide monthly information on the number of VL and CD4 tests carried out their results by district, will help pinpoint which geographic areas and sub-populations Phase 3 should focus on.

### **B. Micro-costing of four major adherence counselling models**

The Phase 1 key informant interviews and review of the evidence have identified four adherence counselling models with high potential for strengthening ART adherence and medication adherence for other chronic conditions. The NDOH has requested for these four models to be micro-costed as an activity that complements The Health Economics and Epidemiology Research Office’s (HE2RO) work on the overall costing of the proposed South

Africa Adherence Strategy. The costing will be led by the World Bank team and be done over 2–3 months. Some of the costs will have to be estimated due to the limited time-frame.

The following four models will be costed:

1. I ACT model (for newly diagnosed)
2. MSF ART initiation counselling model (ART preparation)
3. ART adherence club model (for those who are stable and adherent)
4. MSF enhanced adherence counselling model (for non-adherent clients)

Phases 1 and 2 will help pinpoint which ART adherence and retention interventions should be tested in which ART facilities and demographics in Phase 3.

## Phase 3

**This phase consists of prospectively evaluating adherence interventions to improve ART outcomes in specific types of clients, and to learn what works more generally in supporting medication adherence.**

It builds on the learning and identification of good practices in the previous phases, and the on-going discussions with South African partners and colleagues to continuously ensure that priority evaluation questions are being addressed through this effort. Phase 3 will be conducted over 12 months and involve all collaborating key partners of the impact evaluation. It takes place as ART adherence interventions are being implemented. Using the capacity of the NHLS Corporate Data Warehouse, continued analysis of client outcome data will help assess the impact of adherence interventions on viral suppression and immune recovery. Survey activities at ART facilities and community levels will help to elucidate any changes in ART outcomes in clients. Additional VL and CD4 test data will be collected from non-adherent ART clients who were initiated on but are now defaulting from treatment.

Phase 1 has shown that different ART client types need different support and adherence interventions. Phase 3 should generate knowledge on what works, for instance, in: 1) New ART clients at CD4 count  $<350$  cells/mm<sup>3</sup>; 2) New ART clients at CD4  $>350$  cells/mm<sup>3</sup>; 3) Stable ART clients on ART for  $> 1$  year; 4) Unstable ART clients. Figure 16 below presents these broad categories of ART clients and the possible interventions that could be evaluated, suited to meet clients' support needs and preferences.

Figure 16. Potential interventions for evaluation according to different ART client typologies

	mHealth linked to HIV self- testing	Needs-based counselling and treatment initiation	ART adherence clubs	Decentralise ART delivery
New clients at CD4 counts <350	✓	✓	✓	✓
New clients at CD4 counts >350	✓	✓	✓	✓
Stable clients on ART for >1 year			✓	✓
Unstable clients*		✓	✓	✓

Phase 1 has also shown that in-depth reflection and review is required as to whether specific ART adherence interventions can suit the broader needs of supporting medication adherence in chronic disease.

Preliminary discussions suggest the following interventions to be evaluated for impact in Phase 3:

**A. Prospective impact evaluation of selected strategies to improve ART adherence and retention in care**

This evaluation is being designed currently. It will use evidence from the Phase 2 micro-costing activity and the Phase 2 laboratory data analysis, as well as Phase 1 insights into the available adherence counselling and club options for different client categories and their specific ART support needs. It is likely to include a combination of approaches in adherence counselling and support via clubs, decentralised drug delivery, staff training for better client experiences, and availability of VL data for client monitoring and clinic management purposes.

**B. The impact of a mHealth intervention on ART adherence and retention in care of adolescents/youths who have been enrolled in the ART programme**

This evaluation will focus on younger ART clients, a group known to have a problem of low ART adherence (but high levels of use of electronic media and mobile technology). This age group has generally high levels of sexual activity and partner change and makes this a priority population for improving ART adherence for treatment and prevention alike. The exact intervention is currently being discussed, but one element will be the communication of test results via mobile technology. This is based on the hypothesis that giving ART clients with a smartphone their blood results as an easy-to-review ID number-protected file, with some explanatory notes, will lead to higher client satisfaction, better knowledge of CD4 and viral load results, health care worker requests for results, decreased additional blood tests, and better viral suppression. The intervention would be a tailored app that allows downloading of all prior test results, as well as new results, in a format that is easy to interpret (results with date, normal values and a short explanation of what the test measures). Clients would be

randomised to receive the app or not, after consent/randomisation; a counsellor will assist them to download the app, and explain how to access the data. Depending on the target age group, parental consent may need to be obtained for participation in the trial. Such evaluations would respond to several criteria identified in the previous section:

- B.1. Client knowledge and understanding
- B.2. Targeting individualised adherence effort where it is needed
- B.3. Harnessing mHealth technology and strengthening bi-directional communication
- B.4. Client self-monitoring and empowerment, growing accountability

**C. Case study and programme evaluation to understand the Integrated Chronic Disease Management model and its scope to address and improve medication adherence**

In Phase 3, the evaluation team may also write up a case study of the Integrated Chronic Disease Management (ICDM) model, which has been piloted in 42 health facilities in three select districts<sup>219</sup>. This would involve costing activities and participatory review of the model, the implementation experience and what can be learnt from it for South Africa's National Adherence Strategy.

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# Annex 1. Key Informant Interview Guide 1

## Programme managers and other knowledgeable persons of HIV adherence strategies in South Africa

**All interviews should be started with:**

- Thanking informant for taking their time to speak to you
- Introduction of interviewer(s) (who you are)
- Brief background to project (why you are there)

As you may know, the Government of South Africa wishes to undertake a prospective evaluation of different strategies through which to improve ART adherence and retention in public sector health facilities and community-based organisations providing ART.

In order to do so, they need to identify programmatic gaps and promising practices in client adherence support and retention. This is the first phase of the evaluation. The objective of this first phase is to define the spectrum of ART programmes and identify best practice (either here or elsewhere in sub-Saharan Africa).

We are therefore interested in finding out more about ART programmes and ART adherence initiatives in South Africa and/or elsewhere at all stages of the HIV treatment cascade.

- Assurance of confidentiality
- Provide a letter of introduction from the Department of Health (DOH) that shows the permission granted by the DOH for undertaking the study

**Information needed for each key informant (see coversheet below, which also needs to be filled in)**

- Full name
- Gender, age of informant
- Name of organisation
- Role in organisation
- Date and time of interview

**Can you tell me a bit about what your organisation does in South Africa, particularly with ART, ART adherence and ART retention?**

- ART, ART adherence and ART retention efforts in South Africa
- Geographic areas (health districts) where the organisation that the person works for, operates in (for ART service delivery or ART adherence)
- Funding, if applicable

**Can you tell me a bit about your experience in South Africa, particularly with ART, ART adherence and ART retention?**

- What does your role entail?
- How long have you worked with your organisation in South Africa?
- Have you worked for other organisations in South Africa? What did these previous roles entail? How long were you with these organisations?
- Geographic areas (health districts) where the person has worked in South Africa

**The following questions should be used to guide the rest of the interview. It is important to note that not all questions will be relevant to each key informant. Therefore, the interview should be tailored appropriately.**

**Strategies implemented in South Africa to improve adherence to HIV care, at all stages of the treatment cascade**

- What initiatives/strategies have you been involved in implementing with your organisation in South Africa—technological, facility, community and/or home-based—among children, youth and/or adults in an attempt to:

*(Note that these should be asked in turn, with each relevant strategy further probed using the question guide below, before moving to the next stage of the HIV treatment cascade)*

- Increase HIV testing
- Improve linkages to HIV care for those testing positive for HIV
- Improve clinical grading, including CD4 and VL testing, of those testing positive
- Improve initiation of ART for those who are HIV positive and eligible for treatment
- Improve adherence to ART drug regimens and care instructions
- Improve retention in care (post-ART)

**The following question guide should be followed, as appropriate, for each strategy/initiative, at all stages of the HIV treatment cascade, as described above.**

- Can you describe what this strategy/initiative entails?
- When was this strategy/initiative implemented and why?
- Where was it implemented? Urban, rural, or peri-urban/rural areas, or both? Facility based, community based or home based, or a combination of these? If facility based, what types of facilities (hospital, clinic, private, government, NGO)? Geographical coverage?
- Were any specific population or sub-population targeted?
- How many people are targeted with this initiative? How many people are covered?
- How often are people reached with this initiative?
- How do you measure adherence? How do you monitor adherence?
- Has this initiative been successful in improving adherence in the area where it was implemented?
- As far as you know, have there been any studies, published or unpublished, elsewhere in sub-Saharan Africa, where the impact of this initiative was formally evaluated? If so, how was impact assessed? What are the key findings?
- What are the major challenges of implementing such an initiative? Do you think this initiative threatens quality of care? What are the advantages of this approach?
- Do you think this can be replicated elsewhere in South Africa (or among a different population)? Based on your experience, where or in what context do you think the initiative would be particularly successful and where would it be more difficult to implement? Are there any specifics of the initiative that may or may not make it suitable for certain populations e.g., age or gender specific
- Do you know how much this initiative costs, say per person?
- Do you think this initiative is sustainable in South Africa?
- Can this initiative be improved?

### **Barriers to adherence**

- Based on your experience, what are the major barriers to adherence to HIV treatment in South Africa?
  - Client factors (e.g., are there certain populations among whom adherence to the treatment cascade is particularly poor in South Africa)? Who doesn't test? Who isn't linked to care? Who doesn't initiate ART? Who doesn't adhere to ART regimen? Who defaults from post-ART care?



- System factors e.g. are there particular types of programmes or clinics where adherence is particularly poor in South Africa)? Why do people adhere to treatment cascade in some facilities/programmes and not others?
- Structural factors. What are the community factors that hinder adherence to treatment cascade in South Africa that you have come across?
- Is there a particular stage(s) in the HIV treatment cascade where adherence is particularly challenging in South Africa? If so, is there a known reason for this?

#### **Facilitating factors to adherence**

- Based on your experience, what are the major facilitators to adherence to HIV treatment in South Africa?
  - Client factors (e.g., are there certain populations among whom adherence is particularly good in South Africa)? (as above)
  - System factors (e.g., are there particular types of programmes or clinics where adherence is particularly good or which clients prefer in South Africa)? (as above)
  - Structural factors (what sort of environment in South Africa enables adherence)? (as above)
- Is there a particular stage(s) in the HIV treatment cascade where adherence is particularly good in South Africa? If so, is there a known reason for this?

#### **Promising and/or innovative strategies/initiatives that have been implemented elsewhere in South Africa**

- Do you know of any other relevant strategy/initiative—technological, facility, community or home-based—that has been implemented elsewhere in South Africa by others that you think could have a significant impact on improving adherence to HIV care in South Africa if expanded (at any stage of the cascade)?
- Who implemented this initiative? Civil society, private sector, DOH, or health clinics etc.?
- How do these strategies/initiatives address the barriers to adherence that you mentioned?
- Why do you think it would work elsewhere in South Africa?
- Are there any challenges that you can foresee of expanding such a strategy/initiative in South Africa?
- Who would be the best person to speak to for more information on this initiative?

#### **Promising and/or innovative strategies/initiatives that have been implemented elsewhere in sub-Saharan Africa**

- Do you know of any other relevant strategy/initiative—technological, facility, community or home-based—that has been implemented elsewhere in sub-Saharan Africa that you think

could have a significant impact on improving adherence to HIV care in South Africa (at any stage of the cascade)?

- Who implemented this initiative? Civil society, private sector, DOH, or health clinics etc.?
- How do these strategies/initiatives address the barriers to adherence that you mentioned?
- Why do you think it would work in South Africa?
- Are there any challenges that you can foresee of implementing such a strategy/initiative in South Africa?

**Promising and/or innovative strategies/initiatives that have been yet to be tried and tested**

- From your experience, what kind of initiative(s) do you think needs to be tried in South Africa that has not yet been tried in sub-Saharan Africa?
- How would these strategies/initiatives address the barriers to adherence that you mentioned?
- Why do you think it would work in South Africa?
- Are there any challenges that you can foresee of implementing such a strategy/initiative in South Africa?

**Challenges with measuring and monitoring ART adherence and retention**

- What are the main challenges you come across in your work in South Africa in measuring and monitoring adherence, at all stages of the treatment cascade?
- What do you think needs to be done to overcome these challenges?

**Additional information**

- Is there anyone (else) that you think would be a good person for us to speak to for more information on some of the initiatives that have been implemented in South Africa and/or potential initiatives to implement/expand in South Africa to improve adherence to the HIV treatment cascade?
- Do you have any published or unpublished reports and/or data that you think are useful that you can share with us?

**MAKE SURE TO THANK THE KEY INFORMANT AT THE END OF THE INTERVIEW FOR TAKING THE TIME TO SPEAK TO YOU.**

## Annex 2. Key Informant Interview Guide 2

### Facility managers

**All interviews should be started with:**

- Thanking informant for taking their time to speak to you
- Introduction of interviewer(s) (who you are)
- Brief background to project (why you are there)

As you may know, the Government of South Africa wishes to undertake a prospective evaluation of different strategies through which to improve ART adherence and retention in public sector health facilities and community-based organisations providing ART.

In order to do so, they need to identify programmatic gaps and promising practices in client adherence support and retention. This is the first phase of the evaluation. The objective of this first phase is to define the spectrum of ART programmes in South Africa and identify best practice.

We are therefore interested in finding out more about HIV services and programmes in South Africa, focusing on the factors that motivate and discourage people to test for HIV, initiate ART, adhere to ART, and continue with lifelong ART care. We are also interested in finding out about different strategies or initiatives that have been implemented in South Africa to improve adherence to HIV care at all stages of the HIV treatment cascade.

- Assurance of confidentiality
- Provide a letter of introduction from the Department of Health (DOH) that shows the permission granted by the DOH for undertaking the study

**Information needed for each key informant (see coversheet below, which also needs to be filled in)**

- Full name
- Gender, age of informant
- Name of facility
- Role in facility
- Facility type (e.g., hospital, clinic)
- Location of facility
- Operating authority (e.g., government, private, NGO)

- Funding source, if applicable
- Date and time of interview

**Can you tell me a little bit about your facility?**

- Population served
- Client volume
- HIV facilities offered (NB. If certain ART services are not provided, probe later to find out who does provide this and how the overall system is coordinated between different service providers)
- Staffing (levels, skills, motivation, task-shifting)
- Facility opening days and hours

**The following questions should be used to guide the rest of the interview. It is important to note that not all questions will be relevant to each key informant and/or each facility. Therefore, the interview should be tailored appropriately according to the previous responses.**

**A. HIV testing and diagnosis**

- Does your facility (or its community programme arm) provide HIV testing?
- If yes, who is being tested? Who is doing the testing? Is counselling provided? How frequently are they tested? Types of tests? Same-day results? Cost of testing?
- If not, where do people get tested? How do they come to you?
- From your experience, who doesn't get tested? Who doesn't return for their results? Why do you think this is? (client, system and community factors)
- Has the facility tried to address any of these barriers to testing that you have mentioned? Tell me more about that.
- Based on your experience, what do you think needs to be done to improve the level of testing in your facility or in your community?

**B. Linked to care**

- What happens to those who test positive? Are they referred? Tell me more about that process.
- Who is referred and who isn't referred? Who attends and who doesn't attend? What do you think the reason is that some people are not referred/ do not attend? (client, system, community factors)
- Has the facility tried to address any of these barriers to linkages to care that you have mentioned? How has the facility improved quality of care? Tell me more about that.

- Based on your experience, what do you think needs to be done to improve linkages to HIV care in your facility or in your community?

### **C. Clinically staged**

- Do you provide CD4 and VL testing in your facility? Tell me more about that process. If not, where are these tests carried out? How many sites? Distance to sites?
- What happens to those who are eligible for treatment? What happens to those who are ineligible for treatment?
- What do you think motivates people to undergo these tests and what hinders them from undergoing these tests? (client, system and community factors)
- Has the facility tried to address any of these barriers to staging that you have mentioned? How has the facility improved quality of care?
- Based on your experience, what do you think needs to be done to improve clinical grading in your facility or in your community?

### **D. ART initiation**

- What are the eligibility criteria that you use here to initiate clients on ART? Is it in line with national guidelines? Do you have local facility guidelines?
- Who prescribes ART? How does this person (or other person if applicable) assess if the client is ready to initiate treatment? What information is given to the client? Is this provided in written form such as leaflets?
- What regimen is prescribed? Are clients given a choice of regimen? If so, what is this choice based on?
- Where is ART dispensed? Is there a pharmacy at the same facility? Do people have to travel to the pharmacy? How far do they have to travel?
- Is ART always available in the pharmacy? If no, why not? How does that affect your clients?
- Do people pay for ART? If so, who pays and how much? Do you come across cases where people cannot afford to initiate ART? What happens to these people?
- How much ART is supplied at initiation? And then thereafter?
- Based on your experience, what motivates people to initiate ART? What prevents them from initiating? (client, system and community factors)
- Has the facility tried to address any of the barriers that you have mentioned? How has the facility improved quality of care? Tell me more about that.
- Based on your experience, what do you think needs to be done to improve ART initiation?

### **E. Adhere to ART drug regimens and care instructions**

- Is there someone here who advises clients on how their ART regimen should be taken? What do they tell clients? Is written information provided? Are clients advised of the consequences of not taking their ART regimen appropriately? What are they told? Is written information provided?
- Are clients given any incentives to take their ART regimen?
- Do you measure (and monitor) client adherence to ART in your facility?
- If so, how do you measure and validate this (and how frequently)? Client self-report, Pill counts, Pharmacy data, VL testing
- What challenges have you come across in measuring client adherence in your facility?
- Based on your experience, what motivates people to adhere to their ART regimen? What prevents them from adhering to their treatment? (client, system and community factors)
- I understand that South Africa has recently switched to a once a day fixed dose drug regimen. What has been your experience with this in your facility? Do you think this has helped adherence?
- Has the facility tried to address any of the barriers that you have mentioned? Tell me about that.
- Any recommendations for improving adherence to ART regimen?

### **F. Retention in care (post-ART)**

- How do you measure retention in care in this facility? What challenges have you come across in measuring post-ART retention?
- Tell me about the client appointment schedules and how they work.
- Based on your experience, who doesn't come to their appointments? Why do you think they miss their appointments or do not return? Do we know what happens to them?
- What encourages people to come for follow-up? How frequent are follow-up appointments?
- Has the facility tried to address any of the barriers that you have mentioned? Tell me more about that.
- Any recommendations for improving post-ART retention in care?

**Additional information**

- Is there anyone (else) that you think would be a good person for us to speak to for more information
- Do you have any published or unpublished reports and/or data that you think are useful that you can share with us?

**MAKE SURE TO THANK THE KEY INFORMANT AT THE END OF THE INTERVIEW FOR TAKING THE TIME TO SPEAK TO YOU**



