ADHERENCE GUIDELINES for HIV, TB and NCDs

Policy and service delivery guidelines for linkage to care, adherence to treatment and retention in care

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CONTENTS

Page 3 Foreword
Page 4 Acknowledgements
Page 5 Acronyms
Page 6 Definitions
Page 7 Executive summary

PART 1: STRATEGIC DOCUMENT

Page 11 1. Introduction
Page 13 2. Barriers to linkage, adherence and retention in care
Page 15 3. Stepwise approach to adherence across the continuum of care
Page 19 4. Evidence-based models and interventions: General
Page 29 5. Evidence-based interventions: Vulnerable populations
Page 35 6. Selected interventions

PART 2: IMPLEMENTATION GUIDE

Page 38 7. Description of interventions for implementers
Page 50 8. Resource implications and coordination of activities
Page 64 9. Monitoring, Evaluation and Reporting

APPENDIXES (DETAILED GUIDELINES)

Page 67 Appendix 1: Fast Track Initiation Counselling
Page 85 Appendix 2: Enhanced Adherence Counselling
Page 87 Appendix 3: Spaced and Fast Lane Appointment system
Page 89 Appendix 4: Adherence Clubs
Page 94 Appendix 5: Central Chronic Medicine Dispensing and Distribution
Page 97 Appendix 6: Tracing and Retention in Care
Page 105 Appendix 7: Child and Adolescent Disclosure (for HIV)
Page 111 Appendix 8: Mental Health Assessment
Page 114 Appendix 9: Integrated Access to Care and Treatment (I ACT)
Page 117 References

FOREWORD

It gives me great pleasure to introduce these National Adherence Guidelines for Chronic Diseases including HIV, tuberculosis (TB) and Non-Communicable Diseases (NCDs). The South African National Department of Health (NDoH) shows itself ahead of the curve – the first on the continent – in its willingness to tackle these emerging issues of adherence to treatment.

The aim of the guidelines is to work towards the achievement of South Africa's 2030 National Development Plan, which calls us to:

- Increase average male and female life expectancy from birth to 70 years
- Progressively improve TB prevention and cure
- Reduce maternal, infant and child mortality
- Significantly reduce prevalence and impact of uncontrolled non-communicable chronic diseases.

South Africa has the largest number of people on ART living with HIV in the world and the comorbidity of HIV, TB and other chronic conditions, including mental illness, place a heavy burden on society and the health system. As people live longer, we are facing a growing burden of Non-Communicable Diseases (NCDs). As the number of patients accessing treatment for HIV, TB and NCDs grows, adherence becomes an increasing challenge for us to address. New strategies are needed to support adherence to life-saving care and treatment.

This National Department of Health guideline aims to strengthen access to appropriate services and interventions in order to improve clinical outcomes. The guidelines also assist service providers to ensure that people with chronic diseases are linked to care, retained in care and supported in adhering to treatment.

As a custodian of Health Care in South Africa, I wish to invite all government departments, Development Partners and civil society organisations, as well as the private sector, to collaborate with us in implementing this guideline for the future health of our country.

Dr A P MOTSOALEDI
MINISTER OF HEALTH

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ACRONYMS

AC	Adherence Club
AGL	Adherence Guidelines for HIV, TB and NCDs
ANC	Antenatal Care
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral Therapy
ASSA	Actuarial Society of South Africa
BP	Blood Pressure
CADC	Child and Adolescent Disclosure Counselling
CBO	Community Based Organisation
CCG	Community Care Giver
CCMDD	Central Chronic Medicine Dispensing and Distribution
CHW	Community Health Worker
DAART	Directly Administered Antiretroviral Therapy
EAC	Enhanced Adherence Counselling
FBC	Full Blood Count
FBO	Faith Based Organisation
FTIC	Fast Track Initiation Counselling
FPG	Fasting Plasma Glucose
HAART	Highly Active Antiretroviral Therapy
HbA1c	Haemoglobin Adult type 1c
HBC	Home Based Care
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
I ACT	Integrated Access to Care and Treatment
ICDM	Integrated Chronic Disease Model
IEC	Information, Education and Communication
ID	Identity Document
LTFU	Lost to Follow Up
M	Month
MDR-TB	Multi Drug Resistant TB
MSM	Men who have Sex with Men
NCD	Non-Communicable Disease
TB	Tuberculosis
OI	Opportunistic Infections
PCR	Polymerase Chain Reaction
PHC	Primary Health Care
PICT	Provider Initiated Counselling and Testing
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission of HIV
PN	Professional Nurse
PuP	Pick-up Point
RIC	Retention in Care
RPCS	Repeat Prescription Collection Strategies
SFLA	Spaced and Fast Lane Appointment system
SRQ20	Self-Reporting Questionnaire 20
STI	Sexually Transmitted Infection
TRiC	Tracing and Retention in Care
VL	Viral Load
WBOT	Ward Based Outreach Teams
XDR-TB	Extensively Drug Resistant TB

DEFINITIONS

Adherence	The extent to which a person's behaviour corresponds with agreed recommendations from a health care provider in respect of taking medication, following a diet and/or implementing lifestyle changes.
Attrition	Discontinuation of active engagement in care for any reason including death.
Chronic diseases	Diseases of long duration that may require long-term management or treatment.
Continuum of care	Continuum of care refers to a comprehensive package of prevention, diagnosis, treatment and support services provided to patients and their families ranging across: initial diagnosis and linkage to care; management of the disease and co-morbidities; initiating, maintaining and monitoring medical treatment; switching from first- to second- and third-line therapy as necessary; and palliative care.
Clinical outcomes	The end results of a medical intervention, such as survival or improved health.
Drug resistance	Drug resistance refers to the ability of a pathogenic organism to replicate in the presence of drugs that usually suppress its replication.
First-line drugs	The preferred standard or first choice of treatment for a disease when there is no evidence of a complication that warrants the use of an alternative treatment regimen.
Linkage to care	The process of engaging a person with a disease to appropriate prevention, treatment, care, and support services.
Lost to follow-up	Patients who are lost from the continuum of care with unknown outcomes. The time lapse for one to be considered lost to follow-up may vary across chronic diseases.
Mental health	A state of well-being in which every individual realises his or her own potential and can positively cope with the normal stresses of life.
Multi-drug resistant TB	A strain of Mycobacterium tuberculosis (MTB) that is resistant to Isoniazid and Rifampicin, with or without resistance to other first-line drugs (FLD)
Non-communicable disease	A medical condition or disease that may be chronic or of long duration and is not transmitted from person to person (e.g. hypertension; asthma; diabetes; cardiovascular insufficiency; mental disorders).
One-on-one adherence support	One-on-one adherence support. The provision of assistance and guidance in preventing and resolving adherence problems. This includes motivational interview, problem solving and other counselling techniques.
Retention in care	Continuous, regular engagement of a patient, from the time of diagnosis, in an on-going comprehensive package of follow-up assessment, prevention, treatment, care and support services.
Stigma	Refers to the concept of people being 'marked' as different, specifically in a negative manner, based on some characteristics and circumstances.
Screening	Screening is the presumptive identification of unrecognised disease or defects by means of diagnostic tests, through clinical assessment or other diagnostic medical procedures.
Testing	A procedure performed on an individual to determine if he or she has a specific disease or health condition.

EXECUTIVE SUMMARY

It is estimated that there will be a total of 12.3 million people being treated for chronic diseases or living with HIV and receiving antiretroviral treatment (ART) by 2025 in South Africa (ASSA 2013). The massive expansion of the ART programme in recent years and the rising burden of NCDs in South Africa is placing considerable strain on health care services, which presents challenges of maintaining high quality public services. Adherence to HIV, TB and NCD treatments is an increasing challenge and non-adherence to long-term therapies results in poor health outcomes and increases overall health care costs.

The challenge of non-adherence is multifaceted, with patients facing barriers to adherence as a result of both supply- and demand-side factors. Circumstances that negatively affect linkage, adherence and retention in care vary between individuals and across populations.

Patient-related barriers to linkage, adherence and retention in care are:

- The lack of knowledge and understanding about disease(s) and treatments
- The perception and beliefs in relation to disease management
- Affective factors (depression, anxiety, shame, etc.)
- Behavioural factors (e.g. missed appointments)
- Factors related to treatment burden and an adverse drug event (treatment fatigue, side effects)
- Socio-economic and demographic factors (disease-related stigma, transport, age, etc.)
- The lack of support (e.g. social support)

Health system-related barriers can include:

- Poor quality interventions (lack of health education, assessment, communication, tracing systems, etc.)
- Lack of appropriate health care providers' skills and attitude
- Organisational barriers (waiting time, distance, lack of integration, etc.)

In considering what strengthening adherence means, it is also important to define the following seven steps in the continuum of care or 'treatment cascade'. Adherence can be compromised (or strengthened) at different steps of the treatment cascade and linkage, adherence, and retention in care are key indicators in evaluating programmes.

Linkage to care

Step 1 – Screening to testing

Step 2 – Testing to enrolment in care

Retention in Care and Adherence to Treatment

Step 3 – Enrolment in care to eligibility for treatment
Step 4 – Eligibility for treatment to treatment initiation
Step 5 – Treatment initiation to treatment stabilisation (intensive phase)
Step 6 – Regular reviews for stable patients on treatment (consolidation and maintenance)
Step 7 – Review adherence and treatment for unstable patients on treatment

The longer we delay to trace patients whoare lost to follow-up (LTFU), the higher the risk of adverse patient and health service outcomes. There are also distinct opportunities at several steps to facilitate and maximise the effective transition of people into the next stage of care. These guidelines outline strategies to decrease the health care burden for stable patients (time and cost related) and improve health service congestion, based on available evidence and resources.

Much of the evidence comes from HIV/TB models of care but is applicable to other disease categories as well. International evidence is also drawn upon in assessing strategies for NCDs, given the lack of local evidence. It is important to implement an integrated approach in this way (treating multiple diseases rather than one at a time), since this is more convenient for patients and thus represents a patient-centred health system approach. Newly initiated and unstable patients should be provided with complete information about their conditions and encouraged to identify strategies to overcome treatment adherence barriers.

While **Section 1** of this document presents the conceptual framing and evidence base used to develop the adherence strategy guidelines, **Section 2** presents a minimum package of interventions to support linkage, adherence and retention in care that should be implemented in all health facilities of South Africa. The minimum package was arrived at after considering interventions that a) are proven to increase linkage, adherence and retention in care, particularly in the unique South African context; and b) feasible to implement in terms of cost implications. Provinces and districts are expected to build these interventions into their business plans or district health plans (DHPs) and partner with local stakeholders to implement and monitor them.

The 'minimum package' of interventions to support linkage, adherence and retention in care includes:

- Standardised education sessions and counselling approach for initiation on treatment, for unstable patients and for child and adolescent disclosure (see Appendices 1, 2 and 7).
- Repeat prescription collection strategies for stable patients allowing less frequent clinical consultations and shorter waiting times at the health facility (see Appendices 3 to 5).
- A patient tracing system to limit losses from care (see Appendix 6).
- An integrated model for co-infected patients with HIV, TB and/or NCDs to rationalise frequency of clinical consultations and facility visits to pick up medication.

A number of additional interventions are presented for provinces to consider, and could be implemented according to available resources and the context- and patient-specific needs:

- Peer support (including peer education)
- mHealth technologies
- Community Adherence (ART) Groups
- Adaptation of services to specific populations and contexts

Provinces are encouraged to prioritise interventions applicable to them and to include them in their service packages, provide sufficient training, mentoring, and to adjust job descriptions for all staff involved in implementing them in the particular service area. In order to effectively implement the recommendations of these guidelines, discussions on Adherence should be integrated in the agenda of existing platforms to plan for the recommended changes and monitor their progress.

District support partners, civil society and non-governmental organisations (NGOs) must support government to implement and monitor performance of the proposed Adherence Guidelines interventions.

PART 1:
STRATEGIC DOCUMENT

[Audience: Policymakers and Administrators]

1. INTRODUCTION

1.1 BACKGROUND

South Africa is facing a quadruple burden of communicable, non-communicable, perinatal and maternal, and injury-related disorders.[1] The country has the largest ART programme in the world, with 2.5 million people on treatment in 2014.[2] The country also carries the third largest burden of tuberculosis (TB), drug resistant (DR-TB) and multidrug resistant tuberculosis (MDR-TB) in the world.[3] The incidence of TB increased from 300 per 100 000 in 1990 to 950 per 100 000 in 2012.[4] Furthermore, diabetes increases the risk of TB while hypertension increases pregnancy risks.[5]

As a result of ART, people with HIV are living longer and therefore are developing non-HIV-related chronic conditions similar to the rest of the population.[6] In addition, inflammatory cardiac conditions are becoming more common in HIV positive individuals. Many risk factors for Non Communicable Diseases (NCDs) have increased substantially during the past two decades.[7] The Actuarial Society of South Africa (ASSA) 2008 model estimated that there will be a total of 12.3 million people being treated for chronic disease or living with HIV and receiving ART by 2025.[8]

Neuropsychiatric problems are ranked third as a category, following HIV/AIDS and other infectious diseases, in their contribution to the overall burden of disease in South Africa.[9] The burden of mental illness is also felt through its co-morbidity with other illnesses including HIV.[10] The prevalence of chronic communicable diseases and NCDs, coupled with an ageing population, will place an increasing burden of long term care and treatment on public and private health care services.[11] Studies conducted in South Africa have indicated that poor retention in care is one of the challenges threatening the gains made by the national ART programme.

Retention in care rates of ART clients are deteriorating in South Africa. Following the increase in size of the cohort of clients initiated on ART, there is an observed decline in the number of HIV positive clients remaining on treatment.[27] The National Department of Health indicator update reports low rates of adherence to ART among adults, with 35% of the total virally suppressed at 48 months.[12]

According to the World Health Organization (WHO), the degree of non-adherence to treatment is pervasive internationally, and the consequences are of such concern that more people worldwide would benefit from efforts to improve adherence than the development of new medical treatments.[13]

The consequences of non-adherence to long-term therapies are poor health outcomes, impacting morbidity and mortality, and increased health care costs due to compromised treatment effectiveness. In HIV and TB, the long term risks of developing drug resistance to first line regimens due to poor adherence is a major public health concern. The prevention of transmission of HIV and TB primarily benefits from patients adhering to the prescribed ART, TB and DR-TB regimens.

Importantly, treatment adherence has been identified as a major driver of the overall cost-effectiveness of an ART programme.[14] South African data suggest that if the quality of the ART programme increases, the average cost to produce quality-adjusted outputs (patients on ART and responding) fall and therefore cost-effectiveness and value for money increase.[15]

1.2 STRUCTURE

The document is divided into 2 parts:

1. Strategic document outlining a stepwise approach model to inform the national and provincial level about evidence-based interventions that overcome barriers to linkage, adherence and retention in care for HIV, TB and NCDs.
2. Implementation guide providing recommendations to provincial, district and facility managers on the interventions to be implemented throughout the continuum of care based on the approach described in Part 1.

The appendices provide further details for implementing the recommendations.

1.3 OBJECTIVES

- To identify the most common barriers to linkage, adherence and retention in care.
- To highlight evidence-based models and interventions across the continuum of care to strengthen linkage, adherence and retention in care.
- To outline an implementation guide providing recommendations and guidance on strategies to overcome the barriers to adherence and promote interventions that will improve clinical outcomes.

2. BARRIERS TO LINKAGE, ADHERENCE AND RETENTION IN CARE

This section covers the identified barriers to linkage to care, adherence and retention in care for people living with chronic diseases including HIV, TB, NCDs and chronic mental health diseases. It identifies the gaps in the demand for health care delivery by the patient (Table 1) and the supply or provider aspects (Table 2). Factors that negatively affect linkage, adherence and retention in care are complex and vary between individuals and across different populations.

2.1 DEMAND PERSPECTIVE

Table 1: Patient-related barriers to linkage, adherence and retention in care

Cognitive	Knowledge and understanding of the result, the disease, the treatment options, the importance of care, the potential side effects, the relationship between adherence and the disease progression and the consequences of discontinuing treatment[17, 18] Perceptions and beliefs about the health system, the health care providers, the efficacy of treatment, alternative/traditional medicines and risky behaviour[18]
Affective	Depression, anxiety, denial, lack of motivation, reduction of self-worth, fear of violence, stigma and/or abandonment[19]
Behavioural	Forgetfulness[17] Alcohol and drug consumption[17] Experience with medication and side effects[17] Missed appointments (this could be for a number of reasons, including stigma, disinterest, denial, financial constraints, transport issues etc.)[17]
Medical	Pill burden and regimen complexity[17] Treatment adverse effects[17] Medication toxicities or cross-interaction with other drugs[17] Medication palatability[17]
Socio-demographic	Age (younger), sex (male)[17] Socio-economic status (employment status, level of education, available income for transport, lost wages when attending the clinic, etc.)[17] Stigma and non-disclosure of status (own or offspring)[18]
Family/social support	Lack of social support[18] Lack of community involvement in treatment programmes[18] Dependency on partner[18]

2.2 SUPPLY PERSPECTIVE

Table 2: Provider-related and structural barriers to linkage, adherence and retention in care

Provider-related	
Intervention quality	Poor patient–provider communication[20] Inadequate health education Lack of assessment and understanding of the patient's reasons for non-adherence Weaknesses in measuring adherence or identifying patients at risk Inadequate consultation or contact-time[21] Poor management of pain, symptoms and medication side effects
Behavioural	Attitude of healthcare providers towards patients[65] Level of engagement and empathy towards patients
Training	Inadequate training of staff in breaking bad news, educating and supporting patients in adherence (delivery of test result and explanation of significance) Limited capacity to screen and identify mental illnesses[21]
Structural	
Organisa-tional	Distance to the clinic[18] Long waiting time[17, 18] Lack of integration and of coordination between services[18] Medicine shortages and lack of stock[17, 18] Inflexible clinic hours[19]
Intervention quality	Lack of tools to guide the healthcare workers on ways to support patients' adherence Lack of confidentiality[18] Inconvenient linkage to care[22] Delayed treatment initiation[22] Inadequate assessment of treatment adaption needed Poor tracing system Inadequate resources and laboratory services[18] Poor management and support of healthcare workers

Note: The categories are not mutually exclusive. They can also be shared across supply and demand. The classification above is only meant to provide guidance for identifying strategies to improve retention.

3. STEPWISE APPROACH TO ADHERENCE ACROSS THE CONTINUUM OF CARE

For the purposes of this document, the continuum of care is defined as the composition of the following seven steps to ensuring linkage, adherence and retention in care.

Linkage to care

Step 1 – Screening to testing
Step 2 – Testing to enrolment in care

Retention in Care and Adherence to Treatment

Step 3 – Enrolment in care to eligibility for treatment
Step 4 – Eligibility for treatment to treatment initiation
Step 5 – Treatment initiation to treatment stabilisation (intensive phase)
Step 6 – Regular reviews for stable patients on treatment (consolidation and maintenance)
Step 7 – Review adherence and treatment for unstable patients on treatment

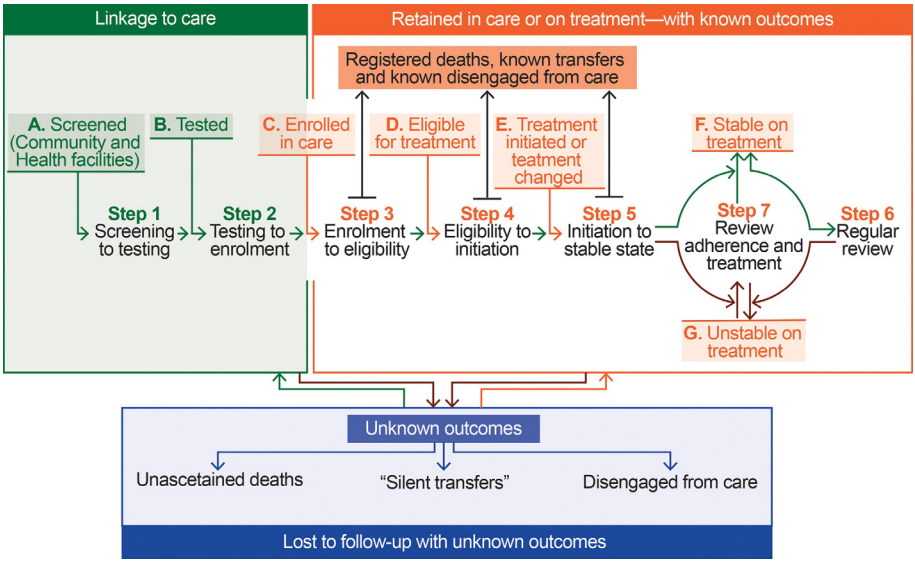
The following figure (Figure 1) defines the steps patients go through as they progress from screening and/or testing (diagnosis) and enter the continuum of care.

An individual may not necessarily go through all the stages in different chronic conditions, or go through them sequentially. Some patients may pass rapidly through the first five steps in one consultation and start treatment on the first visit. Others may take weeks or months for each transition depending on patient- and service delivery-related factors. The pathway from screening to stable on treatment may not be linear in reality. Clients may engage, disengage, and re-engage in treatment and care, a behaviour which is sometimes referred to as 'churning'.[23]

The role of the health sector is to ensure smooth transition of an individual from one stage to the next, as clinically indicated. With each transition or step between these stages there is a chance that clients will be lost to follow-up, with an increased risk of adverse outcomes over time.

There are distinct opportunities at each step to facilitate and maximise the effective transition of people into the next stage of the continuum of care, as their disease progression dictates. The section below elaborates on the steps and how they can be utilised to try to ensure retention in care and minimise loss to follow-up.

Figure 1: Stepwise approach to support linkage, adherence and retention in care



3.1 LINKAGE TO CARE

Step 1 – Screening to testing

Screening interventions are designed to identify diseases early, thus enabling earlier intervention to reduce mortality and morbidity.

Types of screening:

- **Universal screening** involves screening of all individuals in a certain category (for example, screening for hypertension through routine PHC screening for all patients > 18 years)
- **Case finding (high risk/selective)** involves screening a smaller group of people based on the presence of risk factors (for example, TB contact screening, high BMI, smoking)
- **Multiphase screening** is the application of two or more screening tests to a large population at one time, instead of carrying out separate screening tests for single diseases

Screening and testing is not always carried out consistently in South Africa. A recent study found that across all 9 provinces, screening rates for diabetes (23.8%), cholesterol (20.1%) and HIV (8.2%) were very low in the medically insured population.[24]

Step 2 – Testing to enrolment in care

Patients with confirmed positive results after screening or diagnosis require referral for further investigations or entry into treatment, care and support. A high number of patients who tested positive fail to link to care.

There is an urgent need for programmes to ensure that increased access to testing is accompanied by improved linkage to care.[19]

3.2 RETENTION IN CARE AND ADHERENCE TO TREATMENT

Step 3 – Enrolment in care to eligibility for treatment – Pre-treatment Care

Pre-treatment is an important stage in the continuum of care and starts immediately after diagnosis and before eligibility to start treatment (for some diseases). Some diagnosed patients may not be ready to start treatment due to non-eligibility or because they are not psychologically ready to adhere to long-term or lifelong treatment. Significant patient attrition occurs at this stage.

Once patients link to care, education and peer support can empower them to start treatment at the time they meet eligibility criteria.

Step 4 – Eligibility for treatment to treatment initiation

Once eligibility is established, patients should start treatment as soon as possible. Chronic disease treatment initiation marks the beginning of long-term or lifelong treatment, care and health monitoring. Delaying initiation of treatment increases attrition rates.

Special attention should be provided to patients who start treatment late in the course of their illness, who may also have some complications (e.g. opportunistic infections in HIV).

Treatment should be offered to all patients as soon as they are eligible, to reduce LTFU. Education and counselling empowers patients to deal with the reality of life on treatment.

Step 5 – Treatment initiation to treatment stabilisation – Intensive phase

Following initiation, patients may face a range of challenges – both physical (side effects) and psychological (discouragement, negative thoughts attached to the treatment, etc.).

If managed properly, retention in care and treatment adherence results in better clinical outcomes and lower healthcare costs by minimising the long term complications of chronic diseases. For TB and HIV, non-adherence to treatment increases the risk of drug resistance, poor treatment outcomes, and increased infectiousness. Monitoring of patients as per clinical guidelines plays an important role during this phase in evaluating patient adherence to treatment.

Early investment in adherence counselling and support are effective ways to maximise long term treatment success.[25]

Step 6 – Stable on Treatment – Consolidation and Maintenance phase

Once the patient is stable (as per clinical guideline monitoring recommendations), after a designated period of time, the healthcare provider must reinforce strategies to maintain the patient at a stable level, through the decentralised treatment and community support strategies. Taking treatment and clinical follow-up must be made as convenient as possible for such patients to minimise LTFU.

Strategies decreasing the potential burden of care for patients (time and cost related) and health services congestion should be proposed to stable patients.

Step 7 – Unstable on Treatment

Patients with poor clinical outcomes, adherence problems (interruption or inconsistency in taking the treatment), those who failed to come for their clinical check and/or treatment collection can be referred to as patients unstable on treatment. These patients are at risk of treatment failure, and require specialised and intensified support.

Unstable patients should be provided with complete information about their condition (explanation of result of lab test, other diagnostic test and clinical assessment); support in identifying barriers to adherence and strategies to overcome them. Specific support should include the timely switch to 2nd line regimens where applicable..

4. EVIDENCE-BASED MODELS AND INTERVENTIONS: GENERAL REVIEW

This section briefly presents available models and provides the rationale and evidence base for consideration of their effectiveness in improving linkage, adherence and retention in care.

Note that many of the implementation approaches developed for HIV programmes have the potential to contribute to the framework addressing NCDs, and can offer effective models and interventions that can be emulated and adapted.[26] The majority of the literature around adherence interventions for chronic diseases (excluding HIV) is from high-income countries, especially the US.[27] While there are differences in how HIV and other chronic diseases are clinically managed, approaches to service provision and adherence promotion are often similar for HIV and other chronic diseases, with a potential to "cross-fertilise" present models of HIV care with other chronic diseases.[28]

Bärnighausen *et al*.[29], Thompson *et al*.[56] and Chaiyachati *et al*.[30], provide recommendations on strategies to improve adherence in two systematic reviews, and one guideline, respectively. The WHO report on Adherence to Long-Term therapies (2003) is more comprehensive and provides recommendations for NCDs, TB and HIV. The main recommendations of this literature appear in Table 3 which evaluates the quality of the body of evidence related to adherence.

Table 3: Recommended interventions from three large-scale reviews of antiretroviral adherence literature and the WHO report on Adherence to long-term therapies

Monitor entry and retention	**Systematic monitoring of linkage** for all diagnosed **Systematic monitoring of retention** is recommended for all patients	High level of evidence Recommended for all patients
Adherence monitoring	**Self-reported adherence** should be obtained routinely in all patients **Self-monitoring strategies** WHO recommends VL monitoring for HIV	High level of evidence Recommended for all patients
ART strategies	For regimens of similar efficacy and tolerability, **once-daily regimens** are recommended for treatment-naïve patients beginning ART For regimens of equal efficacy and safety, **fixed-dose combinations** are recommended to decrease pill burden	High level of evidence Recommended for most patients Medium level of evidence

Counselling and education	Individual ART **education** is recommended/ can be done in group (based on individual circumstances) WHO recommends education on the use of medication for all NCDs, TB and HIV Providing **one-on-one adherence support** to patients through adherence counselling is recommended	High level of evidence Recommended for all patients
Peer support	Offering **peer / treatment support** may be considered	Medium level of evidence Optional
Interactive reminder devices	**Reminder devices** (e.g. pillboxes) and the use of **communication technologies** with an interactive component are recommended (weekly messaging, interactive component for patients with poor adherence)	Excellent level of evidence Optional

4.1 EVIDENCE-BASED INTERVENTIONS TO INCREASE LINKAGE TO CARE

Systematic monitoring of linkage to care through referral forms and logbooks

Existing evidence shows that successful interventions to improve linkage include the use of referral forms and patient tracking logbooks, coupled with interventions to bring those lost to follow-up back into care through SMS, phone calls or home visits.[31]

Stakeholders consulted for these guidelines confirmed the importance of referral forms, in particular when testing is performed outside of a healthcare facility or in settings where treatment is unavailable. Logbooks were also found important for tracking individuals testing positive to determine whether they are linked to care, and to monitoring performance across time and facilities and intervene appropriately.[32]

Registers allow recording of this information and referral forms should be comprehensive, harmonised and simplified. Both should be simple enough for lay workers to use.

Strengthen post-test and linkage to care interventions through enhanced counselling

Enhanced post-test counselling has been found to increase linkage to care.[16] A randomised control trial conducted in Uganda showed that intensified post-test counselling and monthly visits by a peer support worker almost doubled linkage to HIV care.[19]

A model being implemented in Nelson Mandela District in the Eastern Cape shows that providing scheduled appointments (a set day and time) for return facility visits can increase linkage to care as it allows patients to access a given service without requiring lengthy queuing. This model also simplifies tracking patients and alleviates the backlog that facilities face during peak working times, as those living close to facilities could be allocated appointments after the early morning rush.[32]

In a factorial randomised study in a Ugandan hospital, patients were randomly allocated to receive common HCT or 'abbreviated' HCT (without risk assessment) and **enhanced linkage to care counselling**. The enhanced linkage to care intervention included: (1) counselling to reduce barriers to linkage to care, (2) assisted disclosure of HIV status to people who could provide social support, (3) introduction to the referral service at the Hospital, (4) a reminder via telephone or home visit 1 week before the scheduled appointment. If the appointment was missed, phone call reminders or home visits were conducted. The study concluded that abbreviated HCT did not adversely affect risk behaviour and that a linkage to care intervention decreases time to enrolment in care.[3]

Integrated Access to Care and Treatment (I ACT) for HIV clients

Integrated Access to Care and Treatment (I ACT) started in 2009 and has since been adopted by Free State Department of Health. The programme involves six group education sessions for newly diagnosed and pre-ART patients. Sessions can also include HIV negative people (open group) and patients already on ART.

A study conducted on 280 patients who enrolled in I ACT support groups showed a significant increase in HIV knowledge and the feeling of social support. Despite the fact that many patients recruited did not meet the programme criteria, retention in care was higher than expected for pre-ART participants: 77% of pre-ART patients with the medical record available had a clinical visit that occurred 6 months or more after the study enrolment.[1] A recent prospective analysis conducted on the I ACT programme in Free State found knowledge on HIV improved significantly ($p<0.05$).[27]

Point of Care (POC) testing

Several studies have found that offering same-day point of care (POC) CD4 testing improves linkage to HIV care, both in facility settings and testing done outside of facilities.[35-36] However,

benefits of purchasing CD4 POC technology must be weighed against South Africa's plans to move to "Test and Treat" in the ART programme which would render the technology redundant.

A study conducted in South Africa showed that POC Xpert is an effective method of diagnosing smear-negative TB. Data-driven studies are needed to determine its cost-effectiveness in resource-poor settings with diverse diagnostic practices.[37]

4.2 EVIDENCE-BASED INTERVENTIONS TO SUPPORT INTIATION ON TREATMENT

ART strategies: Once daily and Fixed Dose Combination (FDC) regimens

Among regimens of similar efficacy and tolerability, once-daily-regimens are recommended for treatment naïve patients beginning ART, for patient convenience and in order to reduce LTFU. Among regimens of equal efficacy and safety, FDCs are recommended to decrease the pill burden.[56]

Counselling and education to support treatment initiation

ART education and adherence interventions positively influence adherence outcomes.[29, 30, 56] One study from South Africa found that HIV patients receiving Community-Based Adherence Support (CBAS) had significantly better ART outcomes in an observational, multi-cohort study of adults enrolling for ART between 2004 and 2010 across 57 sites. 19,668 patients received CBAS. After 5 years, patient retention was 79.1% in CBAS patients versus 73.6% in the control group.[38]

While patient education and adherence counselling are recommended to improve long-term adherence,[56] lengthy processes before starting ART cause delays that contribute to high LTFU.[39]

Fast track initiation counselling

When the HIV comprehensive care, management and treatment (CCMT) programme was first introduced in South Africa, patients were expected to undergo 3 sessions prior to ART initiation. In 2012, the National Department of Health released a circular recommending fast tracking patients onto ART without unnecessary delay. Some facilities now provide minimal ART preparation counselling and others continue to require attendance at multiple sessions, causing ART initiation delays and thereby creating a potential for increased LTFU.

Model for Fast-Tracking initiation counselling

Kuyasa Clinic in Khayelitsha experimented with a revised ART/TB preparation counselling model that limits pre-initiation counselling to one session, provides one session on the subsequent day of initiation, and strengthens post-initiation with two counselling sessions focused on adherence. LTFU prior to ART initiation, before the clinic implemented this model, were estimated at 35%. In the first nine months of implementation, only 3.6% of ART eligible patients were lost, ART enrolment rates increased, short term retention in care was not compromised (98% at 1 month, 86% at 6 months), and high rates of viral load suppression were achieved. All City Health clinics in Khayelitsha have now implemented the same model. The model also allows for adaptations for patients who are co-infected with TB and need to initiate ART shortly after TB treatment, and for pregnant women who initiate on the same day as HCT. Adherence messaging focused on planning around the most common barriers to adherence, including migratory travel and misperceptions about taking treatment when consuming alcohol.[32]

4.3 EVIDENCE-BASED INTERVENTIONS TO SUPPORT MAINTENANCE TREATMENT AND RETENTION IN CARE

Adherence clubs

In adherence clubs, stable patients are grouped together voluntarily for routine check-ups and repeat prescription collections are managed by a lay healthcare worker (task shifting). Clubs can take place at the health facility or in the community to save patients time and money. Patients discuss their questions and concerns openly with peers in the clubs and receive basic health education. Members receive spaced appointment dates without having to queue and support one another emotionally. Club membership is also conditional on remaining stable – an incentive to remain in care.

Doctors Without Borders, in partnership with local government, began with a pilot of 20 ART adherence clubs at Ubuntu Clinic in Khayelitsha in 2007. A retrospective observational evaluation found that retention in clinic care after one year was 97% for club patients compared to 85% for those who qualified for clubs, but continued to be managed at the clinic outside of the club model.[1] The cost was also found to be significantly lower with fewer missed appointments and shorter waiting times.[2] Better adherence in clubs was shown, with club patients being 67% less likely to experience virological rebound compared to those in mainstream care. [40]

Other repeat collection prescription strategies

Reduced frequency of clinical consultations and repeat prescription collections

Allowing a reduced frequency of clinical appointments and longer supply of medicines for healthy and stable patients can help reduce the burden on health workers and patients. Separating medicine pick-up from clinical assessments was found to benefit patients in a range of settings.[45]

In a study in Malawi, patients received medication refills every 3 months with 6 monthly clinical visits. After 36 months, 94.3% of the patients enrolled in the system were retained in care, compared to 83% retention for patients eligible for, but not enrolled in the spaced appointment system.[42] The Clinton Health Access Initiative (CHAI) similarly found that one of the main ways of reducing cost and boosting retention on ART in South Africa was through spaced appointments.[43]

Fast lane appointments and Chronic Medication Delivery

Fast lane appointments allow stable patients to collect their medication at the pharmacy without waiting. This reduces patients' waiting times and helps reduce congestion at health facilities. Many facilities make use of private service providers (through the CCMDD) for the fast-tracking of clients and the delivery of chronic medications to stable clients in the community. To be eligible for fast lane appointment and/or medication delivery, clients must be stable on treatment and able to provide blood results from the past 6 months. Clients are then fast-tracked to receive medication through the programme. Clients receive monthly reminders about medicine pick-up dates. According to qualitative key informants, the use of this service has helped bring down client waiting time in the facility to about five minutes only.[27]

Community adherence group / patient led clubs

Patient empowerment can potentially contribute to a broader impact in the community, changing patients' identity and role from being ignored or excluded to being considered as part of the health system.[44] Community repeat prescription collection strategies, giving individuals responsibility to collect medication for other group members can be useful in rural areas, especially to reduce patient load.

Community Adherence (ART) Groups (CAGs) started in Tete province in Mozambique in 2008. Stable patients living in the same area organised themselves into groups of 6, taking turns to collect treatment every month for group members. Each member visits the clinic every 6 months for medical check-up (and blood test as needed) and to collect treatment for all group members. In case of problems, patients go back to the clinic (either self-referred or referred by other group members).[45] A retrospective cohort study between February 2008 and December 2012 found that out of 5,729 CAG members, mortality and loss to follow-up rates were 2.1 and 0.1 per 100 person-years respectively. Retention was 91.8 % at 48 months.[46] CAGs reduced the cost and the time burden on patients and care providers and may be a particularly effective strategy in rural areas where clinics are far away.

4.4 EVIDENCE-BASED INTERVENTIONS FOR UNSTABLE PATIENTS

Adherence monitoring

There is an increasing appreciation for the benefits of routine viral load monitoring to provide early indication of treatment failure and to reinforce ART adherence. The clear trend of re-suppression following viral load testing and adherence support demonstrates the utility of viral load tests as a tool to identify patients in need of enhanced adherence support.[47] The same could be said of culture results in the case of TB, HbA1c results for diabetes, blood pressure results for Hypertension, and so on as per programme-specific recommendations. Specific interventions should target patients with any result raising suspicion of non-adherence or treatment failure. The WHO also recommends the use of self-monitoring strategies for NCDs.

Enhanced Adherence Counselling (EAC)

Enhanced Adherence Counselling (EAC) focuses on supporting patients presenting with adherence issues or a poor treatment response (and signs of treatment failure for HIV and TB). The main principle of EAC is to provide information to the patients about their condition, to correct mis-conceptions, and to allow flexibility around the most common barriers to adherence (such as alcohol/ drug consumption, forgetting doses due to rigid schedule, etc.). EAC helps patients to develop adherence strategies to overcome common barriers in treatment adherence.[48]

In KwaZulu-Natal, an Enhanced Adherence Counselling intervention conducted with 352 patients with a Viral Load result above a 1000 copies resulted in an overall re-suppression rate of 58%.[48]

Where access to routine viral load monitoring and second line ART is available, integrated, clinician-led adherence support combined with appropriate switching achieves high rates of virologic re-suppression.[49]

4.5 EVIDENCE-BASED INTERVENTIONS ACROSS THE CONTINUUM OF CARE

Integrated approach for HIV, TB and NCDs: The Integrated Chronic Disease Model (ICDM)

ICDM is an approach that strengthens the health system providing integrated prevention, treatment and care for clients with chronic conditions at the PHC level, in order to ensure a seamless transition to 'assisted' self-management within the community. ICDM is based on an approach that aims to help the patient take responsibility and ownership for their health, while at the same time intervening at the community, population and health service level across the continuum of care. The ICDM model addresses chronic communicable diseases, including HIV, TB and MDR-TB, as well as NCDs including hypertension, diabetes, asthma and mental health illnesses.

ICDM is designed to help with early detection of chronic conditions and their appropriate management. The ICDM resonates with the UNAIDS 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 should be adherent with the desired clinical benefits

If successfully implemented, such a strategy would result in almost three-quarters of people with a chronic condition (73%) attaining full treatment benefits.

Early missed appointment tracing

Patient tracing can help retain patients in HIV, TB and NCD programmes. Early active follow-up of patients missing appointments reduces the proportion of patients classified as LTFU.[1] Electronic medical record systems such as Tier.net and ETR.net facilitate the identification of missed appointments. Modes of patient tracing are described in several studies and include telephone calls or SMS, letters, outreach teams and home visits.[51]

In facilities providing ART in Malawi, patients who missed appointments for more than 3 weeks were identified and traced. **Between** 2006 and 2009, of 1,580 patients LTFU available for interview, 74% came back to their ART clinic.[52]

Mobile Health (mHealth)

mHealth (the practice of medicine and public health supported by mobile devices) has been identified as a potential tool to transform and support the achievement of health objectives along the treatment cascade. One randomised control trial[1] demonstrated the benefit of SMS technology to improve adherence and virological suppression. Other studies suggest SMSs improve linkage.[54-55]

mHealth interventions are highly adaptable. Their success is based on a number of factors including: inherent value derived by the patient; project follow-up; the design of the intervention for a specific context; and consideration of the frequency, wording and content of SMSs.

WhatsApp adherence support can be established for newly diagnosed and stable patients who opt for repeat prescription collection strategies such as spaced and fast lane appointment system, adherence clubs and decentralised medicine delivery. WhatsApp adherence support has a potential to support patients in their treatment journey and to keep patients connected to clinicians, non-clinicians and peer support.

Decentralised care and treatment delivery

There is a growing body of evidence to support the contention that community and home-based care, including symptom relief, supportive and palliative care, are generally associated with better ART adherence and retention in care.[16,26] Home-based care programmes provide holistic support to patients and their caregivers. They are ideally situated to screen for comorbidity, monitor adherence and motivate for the maintenance of health-seeking behaviours.

The South African government is actually working in partnerships with private enterprise in the distribution of medication to increase access. This is achieved by drawing on the distribution resources of the private sector to deliver essential chronic medication closer to clients..

The PHC re-engineering programme, launched in 2010, incorporates Ward-Based PHC Outreach Teams (WBOTs). The strategy prioritises NCDs and WBOT teams provide preventative, promotive, curative and rehabilitative service to families in the community.[27]

Peer support strategies

Support Groups

The evidence base for the use of peer support shows mixed outcomes.[56] Support Groups have existed for many years as a mechanism for bringing individuals together to provide group counselling, to share life experiences and support each other in overcoming barriers to adherence. The capacity to carry out such interventions is likely to affect final outcomes.

In a study observing factors influencing TB adherence in South Africa, co-infected patients (with TB and HIV) perceived the Support Group as valuable because it provided a forum for disclosure as well as social support, acceptance and education. This was perceived to help adherence.[57]

Buddy system or peer mentors

A research study in America showed that 6 months intervention of peer mentors significantly improved glucose control in diabetic patients with persistently poor baseline levels.[58] In a multicentre cohort study conducted by Kheth'Impilo in South Africa, client retention (after 5 years) was 79.1% in clients who received adherence support versus 73.6% in clients who didn't.[38]

5. EVIDENCE-BASED INTERVENTIONS: VULNERABLE POPULATIONS

The following outlines some of the challenges related to linkage, adherence and retention in care faced by distinct groups of people with different support needs. Several of the interventions proposed above are relevant for these populations. In addition, this section presents tailored interventions to help improve linkage, adherence and retention in care for these groups.

5.1 OLDER PERSONS

A systematic review of barriers to medication adherence in the elderly[80] provides the following information:

Barriers to adherence

- Impaired physical and cognitive abilities
- Mental health conditions
- Poverty
- Complex medication regimen

Recommended Interventions

- Information should be adapted according to their inabilities, e.g. adapt visual material and ways to address old persons (repeat and talk loader if needed)
- Include a family member or caregiver when providing information to older persons with a mental health condition
- In cases of complex medication regimen, take time to explain while providing information, repeat the information often and include a family member or caregiver when providing information

5.2 PERSONS WITH DISABILITIES

Barriers to adherence

- Stigma
- Physical barriers (including difficulty in swallowing medication and accessing services)
- Limited access to written material
- Lack of training of health workers to support persons with disabilities

Recommended interventions

- Health workers should be equipped with a basic understanding of managing persons with disabilities
- Major health campaigns should target persons with disabilities as well, and include them in the planning and execution of campaigns
- Ensure that communication material is available in accessible formats such as Braille
- Involve the family in adherence support

5.3 MENTAL HEALTH AND SUBSTANCE USE DISORDERS

Patients with mental health disorders are less likely to adhere to chronic treatments.[68]

Barriers to adherence

- Stigma
- Non-attendance at medical appointments
- Limited number of health workers trained on mental health conditions

Recommended interventions

- Screening, management, and treatment for psychosocial stress, depression and other mental illnesses should be integrated into management of chronic diseases.[69]
- Cognitive–behavioural therapy for depression and psychosocial stress combined with ART adherence counselling improves ART adherence and reduces depressive symptoms,[70] though this may be difficult under current resource constraints.
- Providing treatment for depression improves ART adherence and treatment outcomes.[71]

Substance use disorders

Alcohol and substance use increases the risk of poor retention in care, poor adherence, and poor treatment outcomes with HIV and TB, if not other chronic conditions.[73]

- Screening for substance use and appropriate referral should be integrated into the management of chronic conditions
- Integration of DAART into methadone maintenance treatment for opioid-dependent patients is critical.

5.4 PREGNANT AND LACTATING WOMEN

There is evidence that adherence to ART and retention in care is particularly challenging for women initiated on PMTCT.[64]

Barriers to adherence

- Lack of knowledge about PMTCT[65]
- Stigma and heightened fear of disclosure of status to family and friends[66]
- Pregnancy-related issues: morning sickness, postpartum depression
- Childcare challenges, long waiting times and multiple visits for diverse services

Recommended interventions

- **HIV testing should be offered repeatedly** to women (tested negative or never tested previously) during pregnancy. All women living with HIV should be encouraged to start ART for PMTCT and lifelong thereafter.[67]
- **PMTCT education and counselling:** studies in South Africa reveal the need for improving the provision of information on PMTCT within and outside health settings. Counselling strategies for PMTCT should address disclosure and help women identify strategies for ART adherence if unable or unwilling to disclose.[65]
- **Integrated care:** HIV, TB and NCD services should be integrated with other maternal and child health services to maximise efficiency for the patient, service delivery and confidentiality (e.g. same day ANC and ART appointment).
- **Community based-support:** The use of a home-based care provider or the use of mobile phones can enhance adherence to treatment and care.[65]

MomConnect uses SMSs to remind pregnant women of critical appointments for tests and check-ups, and to deliver health and childcare information. Messages arrive through pregnancy and until the baby is 18 months. The flow of information is bi-directional and also allows women to report on the quality of care they receive.

5.5 CHILDREN AND ADOLESCENTS

Children with long-term treatment needs face unique challenges and require support to ensure optimal adherence. Strategies for children and adolescents must be reviewed and adapted to individuals' changing needs as they mature. The transition from childhood to adolescence is frequently associated with deterioration in adherence and worse outcomes than adults.[59]

Barriers to adherence

Children:

- Lack of support[60]
- Difficulty swallowing pills, limited choice of paediatric formulations, bad taste of medication and difficulty timing medication administration around meals

- Potentially large pill burden[61]
- Lack of information about their own disease and treatment[3]
- Stigma[62]
- Delays and sub-optimum disclosure of HIV status[62]
- Lack of training among health staff to deal with children

Adolescents:

- Stigma[62]
- Desire to conform with peers[62]
- Lack of training among health staff to deal with complex needs as children mature[62]
- Inconsistent daily routine[60]

Recommended interventions:

Child and Adolescent Disclosure Counselling

- Children do well when they are equipped to understand their illness. Practical disclosure strategies enable children to learn about their disease, their responsibilities and the skills to manage the social consequences.[62]
- These strategies need to be integrated into medical care, with healthcare workers better trained in child progressive disclosure and adherence.[62]
- Visual material can help children better understand their illness and treatment.

Adolescent and youth-focused strategies:

- **Assisting in the development of support networks** for adolescents and youth can improve entry into and retention in care, and helps to address specific needs such as sexual and reproductive health education. This is particularly in light of significant stigma faced by young people living with HIV.[62]
- **'Youth clubs'** grouping pre-ART, newly initiated and stable youth on ART, show signs of improving retention in care.[63]

B-WIZE is an mHealth App that aims to assist youth make informed decisions about their health.

5.6 MEN WHO HAVE SEX WITH MEN

Heterosexual transmission is the dominant mode of HIV transmission, but evidence suggests that men who have sex with men (MSM) behaviour plays an important part in the South African HIV

epidemic. A Human Sciences Research Council population-based survey found that 3.2% of men self-reported MSM behaviour; of these, an estimated 10% were HIV-infected.74 Patterns of same-sex behaviour in rural areas are not well researched,[75] but evidence from two studies in KwaZulu-Natal and Eastern Cape indicate that male to male sexual behaviour is strongly associated with concurrent heterosexual relationships and with higher levels of gender violence perpetration, including male to female and male to male rape.[76,77] Issues around stigma and discrimination deter MSM from receiving education on prevention that is tailored to their sexual behaviour and from accessing HIV/TB treatment and care services.[78] Socio-cultural and institutional barriers influence MSM uptake of sexual disinhibition and, ultimately, their HIV transmission and HIV-related morbidity rates.

Barriers to adherence

- Severe stigmatisation
- Lack of appropriate training for healthcare providers to deliver tailored services to MSM
- Limited education on HIV prevention

Recommended interventions

- Create MSM-friendly services
- Train health staff in supporting MSM living with HIV, TB and/or NCDs in adhering to their treatment
- Inclusion in information, education and communication materials for the general population on prevention technologies (including use of water-based lubricant) and on transmission routes (including anal sex)
- Examination of gender-based violence events and referral to appropriate services

5.7 SEX WORKERS

Barriers to adherence

With a very high risk of HIV infection, poor access to prevention and treatment services and often severe stigmatisation, sex workers are a highly vulnerable group that can contribute significantly to HIV transmission in any community.

Recommended interventions

Outreach interventions to propose a comprehensive package of care and the use of peer educators can ensure accessibility of care and treatment services to sex workers.[79] The lessons from MSM around tackling stigma and population-specific services also apply to sex workers.

Several studies in South Africa and internationally have shown that Pre-Exposure Prophylaxis (PrEP) when taken regularly by HIV negative people with ongoing HIV risk exposure such as key populations can significantly reduce a person's risk of acquiring HIV. PrEP has been shown to be effective notably for key populations such as Men having Sex with Men and Sex Workers.

PrEP can be offered as an option during Universal Test and Treat for clients who test HIV negative and are at ongoing HIV risk exposure. PrEP as an option should be tailored to address specific risks, and must be provided as part of a package of combination prevention options inclusive of biomedical and psychosocial or behaviour change interventions.

PrEP usage requires commitment from both the provider and the user to ensure success. Adherence to PrEP is critical for PrEP to be effective. PrEP does not need to be taken for a lifetime, however should be taken only for as long as the HIV-negative client remains at high risk for HIV.This could be for only a few months or it could be for years. If PrEP is not taken routinely, around the same time, every day, it is much less effective. Since PrEP is not 100% effective, it is recommended that people still use condoms when they have sex, even if they are taking PrEP, for the best protection against HIV. PrEP does not provide any protection against pregnancy and most STIs.

Emphasis on linkage to care, adherence and retention in care must underpin all the education and counselling provided during PrEP counselling sessions in order for PrEP to be effective. Adherence interventions for clients may include i) fast track initiation counselling including laboratory monitoring with regular HIV tests as per schedule, ii) enhanced adherence counselling for clients struggling with adherence, iii) repeat prescription collection strategies for clients stable on PrEP such as spaced and fast lane appointment and adherence club options, iv) Peer support such as support groups, WhatsApp adherence and remote communication support v) adaptation of services and specific tailored sessions for PrEP clients and vi) Tracing and Retention In Care for clients who miss their scheduled PrEP appointments, if known to have ongoing HIV risk exposure.

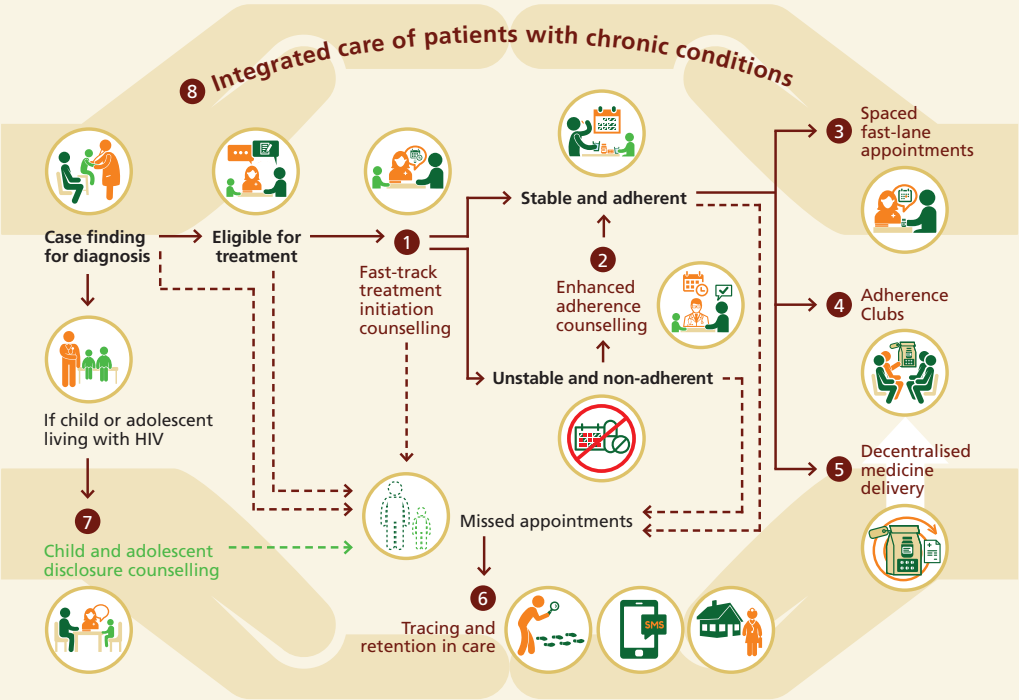
6. SELECTED INTERVENTIONS

Some interventions appear to be the most likely to enhance linkage, adherence and retention in care. Amongst these, a minimum package is recommended as compulsory to be implemented in all facilities providing long-term therapies in the South African context. This minimum package of intervention to support linkage, adherence and retention in care has been selected based on the quality of evidence in the literature and the actual South African context, requiring cost effective strategies to minimise congestion at health facilities while supporting patients to overcome barriers to adherence.

Table 4: Minimum package of interventions to support linkage, adherence and RIC

Education and counselling	Standardised, updated counselling approach for: – Fast track initiation counselling: education and support, focusing on potential barriers to adherence – Enhanced Adherence Counselling: adherence monitoring and targeted intervention for unstable patients – Child and adolescent disclosure counselling for children living with HIV
Rrepeat prescription collection strategies	One or more of the following strategies based on context: – Adherence clubs – Spaced, fast lane appointments system – Decentralised medication delivery (e.g. CCMDD)
Patient tracing	– Monitoring of linkage and retention – Early tracing of all missed appointments
An integrated model for patients co-infected with HIV, TB and/or NCDs	– Integrated Chronic Disease Management (including WBOT) – Rationalisation of the frequency of the clinical consultations, facility visits for Repeat Prescription Collection and counselling sessions

The minimum package of interventions to support linkage, adherence and retention in care



In addition to this core package, some additional interventions may need to be selected according to the context and population needs. The additional interventions include standardised education sessions by peer educators (I ACT), support groups, buddy systems, youth-focused strategies, the use of mHealth strategies, Community Adherence (ART) groups (CAG), collaboration with traditional healers authorities and the use of Directly Observed Treatment (DOT) for specific populations.

PART 2: IMPLEMENTATION GUIDE

[Audience: Policy implementers]

7. DESCRIPTION OF INTERVENTIONS FOR IMPLEMENTERS

Based on the evidence presented in Part 1, this section details a minimum package of interventions to be implemented in all health facilities to increase linkage to care, retention in care and adherence to treatment in South Africa. It also recommends a number of additional interventions to be implemented according to available resources. The latter are generally more expensive or less well proven. Detailed information and instructions regarding the recommended interventions are provided in the appendices and the standard operating procedures while an overview of the interventions, with roles and responsibilities of key players, is provided in this section.

7.1 MINIMUM PACKAGE OF INTERVENTIONS TO SUPPORT LINKAGE, ADHERENCE AND RETENTION IN CARE (RIC)

Table 4, reproduced from Part 1, summarises a minimum package of interventions to support linkage, adherence and retention in care nationwide. Figure 2 shows at which steps of the continuum of care patients should receive these interventions.

Table 4: Minimum package of intervention to support linkage, adherence and RIC

Education and counselling	Standardised, updated counselling approach for: – Fast track initiation counselling: education and support, focusing on potential barriers to adherence – Enhanced Adherence Counselling: adherence monitoring and targeted intervention for unstable patients – Child and adolescent disclosure for children living with HIV
Alternative repeat prescription collection strategies	One or more of the following strategies based on context: – Adherence clubs – Spaced, fast lane appointments system – Decentralised medication delivery (e.g. CCMDD)
Patient tracing	– Monitoring of linkage and retention – Early tracing of all missed appointments
An integrated model for patients co-infected with HIV, TB and/or NCDs	– Integrated Chronic Disease Management (including WBOT) – Rationalisation of the frequency of the clinical consultations, the facility visits for Repeat Prescription Collection and the counselling sessions

Figure 2: Minimum package of services to support linkage, adherence and retention in care by stage in the continuum of care

Education and Counselling

Education and counselling must be provided from the time of eligibility without delaying initiation on treatment for patients who are ready. Adherence should be monitored as recommended by the guidelines for ART, TB and NCD treatments (viral load, sputum samples, blood pressure, etc.). Actions should be taken for patients with poor clinical outcomes and training must be provided to staff on how to do so. Enhanced Adherence Counselling is recommended for patients unstable on treatment. For Children with HIV, disclosure of HIV status (often lacking due to stigma-related issues) should happen progressively and all children should be fully disclosed before the age of 12 years.

The following models provide education and support to initiate treatment and enhance patient adherence:

Fast Track Initiation Counselling (FTIC)

Fast track initiation counselling should focus on:

- Providing education and support to the patient without delaying initiation on treatment. HIV positive patients should be initiated onto treatment within a week of confirming eligibility
- Ensuring pre- and post-initiation support, with particular focus on adherence support
- Problem solving around the most common barriers to adherence (including mental health issues, drug use issues, misperceptions, etc. – see Section 2 in Part 1)
- An individualised adherence plan should be developed
- Clear treatment milestones, including an undetectable viral load for HIV infected patients, smear negative or sputum conversion for TB patients, blood pressure target for hypertensive patients, and blood sugar level for diabetics
- Comprehensive support for pregnant/lactating woman on ART or HIV/TB co-infected patients

Initiation models with these aspects are currently used in different settings to address HIV/TB and hypertension. They can be adapted for most chronic illnesses and are described in Appendix 1.

Enhanced Adherence Counselling (EAC)

Enhance Adherence Counselling focuses on:

- Finding patients with less optimal outcomes (high viral load for HIV, high blood pressure, etc.) and/or adherence problems and referring them for support as soon as possible
- Providing education on the outcome of their latest clinical assessment
- Assessing the barriers to adherence (including misconceptions and fears linked to taking medication in case of alcohol or substance consumption or forgetting doses)

- Discussing effective strategies to overcome barriers to adherence
- Setting new objectives according to the next treatment steps
- Providing additional, individual support in case of switching to another regimen

This model can be adapted for TB and most chronic illnesses. It is described in detail in Appendix 2.

Child and Adolescent Disclosure Counselling (CADC)

Child disclosure focuses on the following and applies to HIV:

- A step by step approach to disclosure, providing education on HIV and ART in adapted language respecting the needs of the child. As a first step, children are taught about a special germ that enters the body, and treatment to keep the germ asleep. This is termed 'partial disclosure'. The second stage involves explaining to children they are HIV positive and educating them about transmission ('full disclosure').
- A pro-active and routine support to disclosure initiated by the health worker.
- Educating caregivers on the importance and the advantages of progressive disclosure, and, very importantly, involving them in the process.
- Start partial disclosure from the ages of 3 and ensure full disclosure by the age of 10.

In case the health care workers encounter adolescents from the age of 10 who have not been disclosed to yet, it is very important to proceed to full disclosure through the disclosure stepwise process by providing the information on the child and adolescent disclosure counselling model. See Appendix 7 for more details on the child and adolescent disclosure counselling model.

Repeat prescription collection strategies

Repeat prescription collection strategies should be proposed to all stable patients to decrease waiting time and transport costs associated with facility visits. A clinician defines stability based on patient clinical outcomes. At least one of the following strategies should be implemented in each health facility to reduce the load on clinical services while increasing convenience and thus lowering likelihood of defaulting treatment:

Adherence Clubs (AC)

The following are key aspects of the model. The model has been tested in the area of HIV; it may apply to other diseases but it may be difficult to integrate with other diseases given complications of conflicting script timing:

- An adherence club consists of a group of no more than 30 clients stable on treatment. Groups meet every 2 months for approximately 1 hour at the facility or in the community (and can be linked with WBOT or other monthly community activities).
- Clubs are managed by a lay counsellor, home based carer, community care giver, enrolled nursing assistant or equivalent
- At each club visit, members can have a basic clinical assessment, sometimes participate in a group support/education activity and are issued with 2 months pre-dispensed, pre-packed medication.
- Clinical monitoring and bloods are performed for all club members at a health facility once per year.
- In case of a problem, club members are referred by the designated official for an individual with a professional nurse consultation. Club members are re-scripted for drug supply purposes every six months when coming to the health facility.
- Clubs offer peer support and increase patient participation and empowerment.

For more detailed recommendations for implementing the AC model see Appendix 4.

Spaced / fast lane appointment (SFLA)

Allowing a reduced frequency of clinical appointments and longer supply of drugs for healthy and stable patients on treatment can help decongest health facilities and reduce the burden on health workers and patients.

- In the spaced appointment system, clinically stable patients are requested to attend the clinic once a year for clinical assessment and drawing of blood (instead of every 1 or 2 months).
- Patients receive 6 months' prescription for their medication. When patients come for the second 3 months refill, another prescription should be prepared in advance and handed over to them for the next refill.
- Each time they visit the health facility, stable patients should be allowed to collect at least 2 months of treatment.
- Patients should be allowed to go through a fast lane system, meaning direct and quick access to the pharmacy or the HCW distributing pre-packed medication.
- In case of health problems or pregnancy, patients return to regular care..

For more detailed recommendations for implementing the SFLA model see Appendix 3.

Treatment delivery or collection closer to home: options for drug delivery

The NDOH is phasing in the Central Chronic Medicine Dispensing and Distribution (CCMDD) for medicine delivery to stable patients. Service providers such as pharmacies or private companies

are contracted to pack the treatments and deliver them to collection points where the patient or a delegated individual can collect them on a 1 to 2 monthly basis.

In this programme, patients have to come for clinical visits every 6 months. When they come, a 6-month repeat prescription is issued. Patients receive their initial supply of medicines (1st issue) from the facility and the 5 remaining repeats are dispensed by the CCMDD service provider and collected from the contracted private pick-up point a designated health care facility or NGO.

The patient registration form and prescription is submitted to the CCMDD service provider. Pick-up-point notifies the CCMDD service provider if patients fail to collect the package 2 days after the scheduled pick-up date, which will trigger a patient tracing process. This programme shows promise due to making access of chronic medication more convenient for patients.

For more detailed recommendations for implementing the CCMDD model see Appendix 5.

Patient Tracing and Retention in Care system (TRIC)

The following activities should be integrated into the strategy to track and trace patients throughout the continuum of care.

Asking consent to be traced

- Informing all patients of the need to stay on long term treatment and in care, and the possibility that at a certain time in their life they may disengage from care and how to handle that
- Asking for patient consent to allow tracing and agreeing on the best way to trace them (through home visits, by phone or SMS) if necessary
- Asking for the address and contact number of the patient and reassessing at each consultation if there are any changes regarding these.
- Liaise with CHWs and use telephone calls to trace patients

Making an active referral for a specific time and date:

- Making an active referral is one in which the official referring the patient makes an appointment for the patient or accompanies the patient to an appointment, including for co-located services, and enrolment into linkage into care.
- Provide an appointment date (based on convenient date and time for the patient)
- Patients not yet linked to care are supported to identify a convenient place and date to link to care
- Patients in care know when they have to come back to the facility
- The appointment date is recorded in a database or log book

- The waiting time for patients is decreased by providing a specific time for the appointment
- Share appointment information related to patients who are supposed to link into care with the receiving facility/service

A national unique patient identifier

The use of unique patient identifiers should allow tracking linkage and movements of patients from one facility to another. The Patient Unique Identifier (PUI) should identity document number, passport number or ayslum seeking permit or an ID document should be provided with another unique patient identifier number from the facility.

Identifying patients who miss their appointments

- Identifying patients who missed their appointment through the facility appointment book
- Issuing a list of patients who have missed their appointments 14 days ago through an electronic database (such as Tier.net or ETR.net) or paper-based diary
- Transferring this list to the person responsible for tracing patients, e.g. WBOT leader.

Tracing of missed appointments

- The facility manager must sign off the list for tracing
- Tracing patients as soon as the list is issued
- Using SMS/phone to contact patient and involving CHWs to trace patients when they cannot be reached by phone or do not come back to the health facility
- Recording of the information about the patients to be traced with the outcomes on standardised tracing forms
- Provide support to patients that return late (as part of the referral system)

For more detailed recommendations for implementing the TRIC model see Appendix 6.

Integrated care for HIV co-infected patients with TB and/or NCDs

In order to decrease the waiting time and the number of consultations at health facilities, clinicians should provide care and treatment for different health conditions at the same time. Once the patient has received the education sessions relevant to different conditions separately, the counsellor should address adherence to different treatments together simultenously.

Provincial strategies to integrate care should focus on:

- The ICDM model offering 'one-stop shop' approach for all chronic conditions

- Training clinical staff to offer integrated consultations to patients with co-morbidities or diverse medical conditions
- Using an integrated counselling model adapted for different conditions to ensure an integrated chronic and services delivery model (Appendix 1).

The Ward Based Outreach Team (WBOT) programme should allow for the continuation of these integrated services at the community level and support the different adherence strategies proposed in the minimum package of interventions.

7.2 ADDITIONAL RECOMMENDED INTERVENTIONS THROUGHOUT THE CONTINUUM OF CARE

Table 5 provides additional recommendations that can be implemented in the health facilities depending on the context, the specificity of the population and the available resources.

Table 5: Additional interventions to support adherence and RIC

Peer support and education	– Integrated Access to Care and Treatment (I ACT) – Support groups – Youth clubs – Buddy systems – Collaboration with traditional authorities and healers
mHealth	SMS encouraging adherence and appointment reminders
CAGs	Community Adherence (ART) groups
Adaptation of services to specific populations and contexts	– Outreach services (WBOT and CHW) – After hours services and MSM, LGBTI and sex worker-friendly clinics

Peer support

It is important to encourage patients to identify a support system within or outside the household. Despite the fact that having a support system can enhance adherence and retention in care, having a treatment 'buddy' or being part of a support group should never be a condition to initiate treatment or receive care. The following models can be used to offer peer support and education to patients who are willing to join such a group.

Education by peer educators

The **Integrated Access to Care and Treatment (I ACT)** is a programme that aims to empower PLHIV and others who are otherwise affected by HIV to confidently lead healthy lives. The programme is designed to follow well-defined steps covering topics such as education on illness and treatment, acceptance of status, healthy living principles and planning for the future.

- Educational sessions are offered in locations where people might need help, including the waiting rooms of local clinics, churches, taxi and bus ranks, and community centres.
- Closed support groups are exclusive to PLHIV. After the first session, no new participants are allowed to join. Closed support group participants commit to attend six sessions, not only to cover the complete programme content, but also to foster personal support networks.
- Open support groups cover the same six content areas but serve both PLHIV and others who are impacted by HIV. "Open" groups allow people to drop in for the sessions they are most interested in; there is no obligation to attend all sessions. This format helps participants address gaps in knowledge and learn about specific areas within the curriculum. Importantly, open groups do not require disclosure of status.

Support Groups

Support groups have been in existence for many years around the world as a mechanism for bringing individuals together to provide group support, to share life experiences and support each other collectively. Support groups should create opportunities to form adherence clubs and reduce the burden on patients by providing medication to clinically stable members.

Youth-focused strategies

The Hlanganani Programme for HIV-positive adolescent showed measurable improvement in a group of youth aged from 16 to 24 years. The programme proposes a structured support group for HIV-infected adolescents. It consists in three structured support group sessions of 2 hours, which are held once a week and are facilitated by a lay worker. The 3 main themes are: coping and support (session 1), HIV health (session 2); and positive prevention (session 3). Each session opens with a role play and is followed by group reflection on the issues raised and relaxation exercises. At the end of each session, participants set achievable goals related to the topic discussed, such as getting one's CD4 count, disclosing one's status, etc. Linkage to care was 100% for all participants compare to 58% in those who did not attend any sessions.

MSF youth clubs group pre-ART, newly initiated and stable youth on ART. Youth-specific topics are discussed during the club sessions such as safe sex, unwanted/youth pregnancy amongst other topics. The Youth Clubs create peer support among youth living with HIV and have been shown to improve retention in care. They also provide socialising opportunities. Youth who are on treatment recieve their medication refill through the club, which decrease waiting time at the health facility.

Buddy systems

Self-identified buddy: Health care workers can encourage the patient to identify someone living in the same household or area to support them in taking treatment and coming to the facility. Choosing a buddy is an individual choice and should not be imposed as a condition to initiate treatment.

Buddy facilitated by the health facility: Health workers can provide buddy options. The buddy could be a CHW, an expert patient or a peer from a support group who has been on treatment for some time. Peer mentors can significantly improve clinical outcomes in patients with NCDs. Patient Advocates can also support linkage to care and accompany patients who have just tested HIV positive.

Buddy systems can help patients to remember the time to take their treatment, remind them when they have to come for follow up and/or accompany them to the facility. Once the patient is stable on treatment, the buddy can collect medication for the patient at the health facility or in the club, as long as the patient comes when due for a clinical visit or according to alternative refill strategy requirements.

Collaboration with traditional authorities

Traditional healers and leaders should be involved and empowered to identify and refer patients for HCT, TB and NCDs screening and testing. The Health sector should explore measures to use them to support treatment adherence practices during consultations and provide them with appropriate training.

mHealth

In addition to the use of mobile phones to trace patients, interventions can also involve sending text messages before the person's appointment to remind them about their appointments or requesting them to report at facilities for follow ups. This was shown to have a positive impact on attendance. The use of weekly messages may also improve adherence to treatment but requires further testing.

The use of technologies such as SMSs and Apps to get information and share experience can raise interest and discussions among youth. mHealth can also provide an opportunity to educate and empower patients to take care of their own health and may be worth considering for key populations.

Community Adherence (ART) Group (CAG)

CAGs currently exist for HIV but can be created for different chronic disease programmes. CAGs are self-formed groups of patients who take turns attending clinical assessment and monitoring tests at the health facility, whilst collecting medication for themselves and the other members of the group. The CAG provides a means of accessing ART for the group members and a source of social support. CAGs are particularly applicable in rural areas where there are significant distances to clinics.

On a monthly basis the following steps are repeated:

Step 1: CAG meeting in the community before collection of ART by the group representative

Patients meet at the home of one of the CAG members or another community venue to report on their adherence and health and discuss day to day issues. During that meeting, the members choose a representative (1 member of the group who is due for annual blood test and/or clinical consultation) to go and collect drugs for all the group members at the clinic.

Step 2: CAG representative reports to the health facility

The CAG representative reports to the clinic for a clinical consultation and blood tests. The representative reports on the adherence and health of other members to the clinic and collects drugs for all group members.

Step 3: CAG meeting after ART collection upon the return of group representative

The group meets on the same day of the ART refill date at the home of a member or another Community venue, where the group representative distributes the repeat prescription medicine parcels to each CAG member.

Community ART groups (CAGs) facilitate access to medicine for patients by reducing financial and time costs associated with frequent clinic visits. CAGs encourage peer support at the community level, improving social ties between patients, and reducing perceived stigma. They create a stronger engagement of the community in HIV care with patients taking up critical roles in the delivery of ART in their communities. In addition organised patient groups can form an accountability mechanism towards the health system, calling for adequate and quality services.

CAGs reduce the workload of overburdened health care workers by reducing the number of patients individually attending the clinics whilst achieving good health outcomes for the patients. The CAG model also fosters patient self-management and independence from the health-service.

Adaptation of services to specific populations

Outreach services (WBOT and CHW)

To face a growing population on ART, TB and NCD medications, decentralising access to testing, treatment and counselling activities can reduce and has already reduced the burden on health workers and patients and improves retention in care. Community-based services that involve the use of Ward Based Outreach (WBOT) teams and CHWs can take services to communities and decongest health facilities. This model supports the principles of a PHC and patient-focused approach.

Outreach strategies could also involve the support of monitoring strategies by CHWs for stable patients. Decentralising a comprehensive package of care (including treatment) can be an effective way to ensure that highly stigmatised populations such as sex workers can access care. At the same time, clubs mixing stable and less stable patients for vulnerable groups, such as youth clubs (see above) can enhance peer dynamic and retention.

After hours services and MSM, Transgender and Sex Worker-friendly clinics

Offering health care out of working hours allows patients (often men) who are busy during the day and/or who prefer to visit health services out of working hours to access care and treatment. Training staff through specialised organisation to deal with MSM, Transgender and Sex Workers in a respectful way can also help to decrease stigma and fear amongst these vulnerable populations to access care.

8. RESOURCE IMPLICATIONS AND COORDINATION OF ACTIVITIES

8.1 AGL ROLL OUT RESOURCE IMPLICATIONS

All the AGL minimum package models have been costed to guide Department of Health planning at national, provincial and district level.

The principles of costing the AGL focuses on investing in repeat prescription collection strategies to support clients stable on chronic treatment in order to decongest facilities. Decongesting facilities will allow health care service providers to a) focus on unstable clients who struggle with adherence, and b) initiate more clients in need of chronic treatment for HIV, TB and NCDs. Overall, the scale up of the minimum package models will lead to better linkage to care, treatment uptake, adherence and retention in care, hence better clinical outcomes for HIV, TB and NCDs clients.

In order for the AGL to be rolled out, it will be necessary to incur a number of initial setup and training costs associated with starting the programme. This includes training of trainers, trainers' time, venues and catering, transport, accommodation, training materials, as well as materials for health facilities, health care providers, clients and caregivers.

In the cost estimation of the AGL scale-up, it has been assumed that existing staff and facilities are sufficient, as the AGL models are expected to free up staff and decongest facilities. The estimated 'incremental costs' of implementing the AGL models therefore mainly consist of those for mentorship, training and educational materials, but not additional human or infrastructural resources.

There are three options for phased roll-out of the Adherence Guidelines for HIV, TB and NCD clients. The three options focus either on the country as a whole, on the provinces or the districts as units in which the roll-out is phased. **All three options use TROA as a proxy for chronic client volume, acknowledging that many of the chronic clients in facilities are HIV clients.**

Option 1: Roll out by facility TROA for national coverage

This option focuses on central planning for national coverage. In this option, all public sector facilities in the country are ranked by TROA to decide on the phasing of the AGL roll-out across the country. High HIV burden areas with many large ART facilities would be prioritised in the early phase. The speed or roll-out to reach full national coverage of the AGL models could be:

– Roll out over 3 years
– Roll out over 4 years
– Roll out over 5 years

Illustrative example for national coverage, fast roll-out over 3 years and TROA bands >1000, 500-1000 and <500:

- If all facilities with TROA of at least 1000 clients were targeted in year 1, it would involve about 860 ART facilities (23% of all in public sector). It would already address 67% of all ART clients and also include over half of ART clients who struggle with viral suppression.
- In year 2, facilities with TROA between 500 and 1000 could be added to the scale-up (about 740 facilities), addressing a further 18% of all TROA and 20% of clients struggling with viral suppression.
- In year 3, the many remaining smaller ART clinics (about 2000) would join the roll-out, and this would address the final 15% of TROA and another quarter of clients with unsuppressed viral loads.

Option 2: Roll out by facility TROA per province priorities

This option focuses on provinces as units of planning for AGL roll-out. Provinces would set priorities within each province separately by defining their own TROA bands for annual roll-out to take into account province-specific conditions (some provinces have many large ART facilities, some provinces have many small ART facilities, and province-specific TROA bands would cater for this).

Option 3: Roll out by facility TROA per district priorities

This option focuses on districts as units of planning and directly links to the district-specific DIP processes. Districts could prioritise facilities to roll out minimum package models based on their specific DIP targets, using DHIS and NHLS data for decision-making.

It is important that at national, province and district level, key role players from the Department of Health, Development Partner Organisations, and District Support Partners meet regularly to mobilise resources and plan local approaches to cost-share implementation of the Adherence Guidelines minimum package models.

8.2 COORDINATION-LEVEL IMPLEMENTATION ACTIVITIES

The following tables indicate the roles and responsibilities of key players as well as the resource implications for the interventions above. The roles and responsibilities below provide an outline of the activities for particular programmes that would lead to effective implementation of the strategy. Programmes are encouraged to take these activities and include them in their service package, training and job descriptions of staff providing services in the particular service area.

Table 6: Activities to be implemented at coordination levels:

Coordination level	Activities	Resource implications
National coordination	• Develop/review and disseminate adherence models as standard recognised models for implementation • Develop supervision and monitoring tools • Develop standardised training modules • Monitor, support and evaluate the implementation of adherence models • Finalise and disseminate mHealth policy for Health • Roll out unique patient identifier nationwide	• Budget for the creation, the printing and the distribution of Counselling material, IEC material, Adherence plans, Flow charts etc. • Budget for set up and training cost for AGL minimum package • Budget allocation to districts • Allocation to support intermediate care for chronic conditions including tuberculosis • Infrastructure to implement • mHealth and SMS technology
Provincial coordination	• Disseminate guidelines and policies • Develop and disseminate adherence tools (such as adherence plans, registers and logbook), supervision and monitoring tools • Disseminate training modules	• Build capacity to implement the AGL • Re-alignment of resources and services • Budget for adherence support by counsellors in Annual Performance Plans and as part of budget bids process

Provincial coordination (Cont.)	• Allocate financial resources to Districts to roll-out and strengthen adherence to treatment and facilitate linkage to care • Add the topic of adherence in the agenda of existing forums to measure progress of the implementation of the minimum package of interventions	• Re-organise services to support implementation of the AGL and the tools to support adherence
District/ Sub-district Managers/ Supervisors	• Integrate the implementation of the AGL into DHPs • Mobilise health workers for training • Establish clinical forums in each sub district for sharing of information, including putting adherence on the agenda during war rooms and Imbizos • Support facilities in establishing all recommended interventions • Support facilities and community based organisations with language appropriate counselling and distribution of IEC material for all diseases • Supervise the new implemented models with appropriate supervision tools	• Re-align services provided by NGOs, CBOs and development partners with AGL recommendations • Recruitment and training costs • District partners to provide technical support and financial resources • Translation of IEC material to local language
Provincial/ District Development Partners	• Provide technical support to districts and Sub district on strengthening and monitoring adherence interventions in facilities.	• Human, logistic and financial resources to implement the recommended interventions

Coordination level	Activities	Resource implications
Provincial/ District Development Partners (Cont.)	This may include training, assisting with the implementation of the education and counselling models, the establishment of alternative repeat prescription collection strategies and tracing strategies • Develop supervision and monitoring tools	
Facility Managers	• Ensure all staff is trained on the latest programme guidelines and strategies • Define staff responsibilities in the implementation of the adherence strategies – enforce organograms • Supervise implementation and appropriate use of the AGL and related tools. • Employ data capture/allocate data capturing responsibility • Use electronic database (Tier. net or ETR.net) for capturing patient HIV programme data, capturing appointments and monitoring clinic attendance • Implement an integrated approach to adherence support for TB, ART and other chronic disease medication involving the facility-based counsellors • Fast track treatment of chronic diseases, implement appointments system, screen for HIV, TB and NCDs for patients upon arrival in health facility	• Computer to record patient information, medical records, and data • Health education and counselling material (sessions guide, adherence plans and visual material) • Communication, including landline phone and cell phones • Create an enabling work enviroment and working station for staff • Implement the health care standards

Facility Managers (Cont.)	• Establish systems to implement enhanced Adherence counselling for unstable patients • Establish Repeat Prescription Collection Strategies • Adherence clubs and other peer support strategies such as I ACT • Ensure tracking and tracing of all patients being referred from testing			

8.3 FACILITY-LEVEL IMPLEMENTATION ACTIVITIES

Table 7 (below) presents the role of each specific cadre to enhance linkage, adherence and retention in care at each step of the continuum of care.

Table 7: Health facility level implementation of activities

Step 1: Screening to testing				
Recommended intervention	**Clinician's role (nurse, doctor or pharmacist)**	**Non-clinician's role**	**Patient's role**	**Follow up Definition of LTFU**
Education and promotion of HCT TB screening: All HIV + Symptoms TB contact Routine PHC screening for all patients ≥ 18 years ICDM	• PICT • Identify need for TB screening (HIV, contact or symptoms) • Screen for co-morbidi-ties • Identify TB contact • Identify previous TB • Identification of patients at risk	• Health promotion/ Education • Pre-test counselling (including HCT) • Provide education on HIV, TB and NCDs • Get consent for patient tracing	• Accept HCT, TB and NCD screening service • Identification of TB contacts • Awareness of the risk of untreated HIV, TB and NCDs and comorbidities	Follow up: • For HCT, If patient agree, proceed to testing • If patient refuses, provide counselling on the advantages of testing and encourage to come for testing when ready

Recommended intervention	Clinician's role (nurse, doctor or pharmacist)	Non-clinician's role	Patient's role	Follow up Definition of LTFU
(Step 1 cont.)	• Assess need for testing according to symptoms • Pregnant patients managed according to ANC guide-lines			• For TB, refer patients in need for Xpert testing and/or Xray according to the clinical guidelines • For NCDs, refer for follow up tests if the patient screen positive to routine PHC screening • Share the list of referred patients with referral service/facility
Step 2: Testing to Enrolment				
Post-Test counselling (HCT) Linkage to care ICDM Systematic monitoring of linkage Tracing of early missed appointment	• Post-test counselling (if PICT) • Confirm diagnosis based on national testing algorithm • Follow up according to HIV/TB/NCDs guidelines (staging, prophylaxis, FBC, etc.) • Refer for linkage to care • Share list of referred patients with referral service/facility	• Post-test counselling (HCT) • If tested positive, focus on: • acceptance of status • Support system • Education on illness and treatment • Provide an appointment for further care and share the list of referred patients with the referral service/facility • Link to peer support	• Discuss and agree on referral plan with the provider (place, time to link) • Voice concerns and questions • Identify support and consider disclosure • Act responsibly to avoid transmission • Assist to identify possible TB contacts • Link with peer support	Follow up: • Follow up on result and assess clinically as recom-mended in guidelines. • Share the list of referred patients with referral service / facility • Compare referral list versus the patients attending the service

Recommended intervention	Clinician's role (nurse, doctor or pharmacist)	Non-clinician's role	Patient's role	Follow up Definition of LTFU
(Step 2 cont.)	• Record patient's ID / passport, asylum permit number • Register patients in appropriate register (or logbook) and provide an appointment date and a referral slip for further care • Inform the patient about tracing	• Register patients in appropriate register / logbook and provide an appointment for care • Inform about tracing and ask for contact number/ address	• Attend health facility according to agreed plan	Missed appointment: • Failure to attend the health facility on the set appointment date LTFU: • Failure to attend the health facility within 90 days following the set appoint-ment date Additional interventions: I ACT /CHW / Support groups/ mHealth strategies, etc.
Step 3: Enrolment to eligibility				
Education Systematic monitoring of linkage ICDM Tracing of early missed appointment	• Assess as recommended in guidelines: CD4, BP, sputum... • Register patient result/ stage • Assess TB, HIV, STIs, family planning needs, pregnancy • Provide prophylaxis / treatment	• Education and support: • Disease literacy • Acceptance of status/ diagnosis • Disclosure • Health seeking behaviour • Importance of regular review • Importance of starting treat-ment as soon as eligible	• Attend for follow up visits • Act responsibly to prevent transmission • Identify support • Share concerns and questions • Agree on care plan • Inform provider if unable to present , if move or change of contact details	Follow up: • Reinforce need to return for medical check up • Share the list of referred patients with referral service • Compare referral list versus the patients attending the service

Recommended intervention	Clinician's role (nurse, doctor or pharmacist)	Non-clinician's role	Patient's role	Follow up Definition of LTFU
(Step 3 cont.)	• Inform the patient about tracing • Record patient's ID / passport / asylum permit number and contacts	• Inform and agree about tracing system • Referral for social assistance if indicated	• Report worsening of health	• Call those who miss the appointment date. **Missed appointment:** • Failure to return on agreed appointment date. **LTFU:** • Failure to attend the health facility within 90 days following the set appoint-ment date **Additional interventions:** I ACT / CHW / Support groups/ mHealth strategies, etc.
Step 4: Eligibility to initiation				
Fast Track Initiation Counseling Model ICDM Tracing of early missed appointment	• Screen and provide treatment based on guidelines • Emphasise importance of treatment continuation • Screen for mental and substance use disorders	• Education on illness, treatment, adherence, side effects and risk of non-adherence • Creation of an adherence plan helping to identify: • motivation to start treatment • support system	• Understand the importance of starting treatment • Identify a support system • Take the decision to start treatment • Voice concerns and ask questions	**Follow up:** • Treatment to be started • Monthly review visits during first 4 months on treatment (intensive phase) **Missed appointment:** • Failure to return on agreed

Recommended intervention	Clinician's role (nurse, doctor or pharmacist)	Non-clinician's role	Patient's role	Follow up Definition of LTFU
(Step 4 cont.)	• Record patient's ID / passport / asylum permit number • Inform the patient about tracing	• plan for appointments • assess readiness to start	• Agree on goals and care plan with provider	appointment date. • Call or home visit for those who miss the appointment date. **LTFU:** • Failure to attend the health facility within 90 days following the set appoint-ment date **Additional interventions:** I ACT / CHW / Support groups/ mHealth strategies, etc.
Step 5: Treatment initiation to stabilisation (intensive phase)				
Fast Track Initiation Counseling Model ICDM Tracing of early missed appointment	• Screen and provide treatment based on guidelines • Emphasise importance of treatment continuation • Prepare for effective management of medication side effects • Manage side effects swiftly • Provide next appointment as per guidelines	Continuation of the adherence plan to: • Create a medication schedule • Deal with missed doses • Identify reminders • Identify where to store medication • Deal with side effects • Know what to do in case travel	• Elaborate an adherence plan with the counsellor to identify the best time to take treatment, reminders, place to store medication, etc. • Knowing how to adhere in case of alcohol / substance use • Come back for appoint-ments	**Follow up:** • Monthly during the first 6 months • As recom-mended in guidelines (Viral Load at 6 months, Sputum's at 2 month on treatment, BP, etc.) **Missed appointment:** • Failure to return on agreed appointment

Recommended intervention	Clinician's role (nurse, doctor or pharmacist)	Non-clinician's role	Patient's role	Follow up Definition of LTFU
(Step 5 cont.)	• Invite the patient to express side effects or other concern and support (with treatment if appropriate)	• Take medication in case of substance or alcohol use • Educate on the future steps on treatment (VL, sputum, etc.) • Set goals (undetectable VL, complete TB treatment, BP< 140/90, controlled sugar level, etc. as recommended per guidelines)	• Take treatment to reach goals.	• Use Facility appointment book and electronic register to identified patient who missed appointment (≥2weeks) • Call or home visit those who miss appointment date. LTFU: • Failure to attend the health facility within 90 days following the set appointment date Additional interventions: I ACT / CHW / Support groups/ mHealth strategies, etc.
Step 6: Stabilisation on treatment				
CLUBs Spaced/fast lane appointment / CCMDD ICDM Tracing of early missed appointment	• Screen and provide treatment based on guidelines • Clinical review every 6M, or yearly depending on the condition, or as recommended per clinical GL	• Propose to join a Club, spaced /fast lane appointment system or CCMDD • Adherence monitoring yearly through the revision of the adherence plan	• Apply adherence plan and take responsibility of own health and adherence • Collect medication • Come for medical follow up visits to nurse/doctor	Follow up: • 6 monthly or yearly review • medication collection as agreed with the patient • Viral load every 12 months / BP/ etc.

Recommended intervention	Clinician's role (nurse, doctor or pharmacist)	Non-clinician's role	Patient's role	Follow up Definition of LTFU
(Step 6 cont.)	• Assess side effects and manage swiftly: provide (or adapt) treat-ment if appropriate • Emphasise importance of treatment continuation • Record any changes in patient's contact	• Emphasise importance of treatment continuation • Check client's contact number and address	and for viral load/blood pressure/ sugar level	Missed appointment: • Failure to return on agreed appointment date for drug collection or clinical visit. • Use facility appointment book and electronic register to identified patient who missed appointment • Call or home visit those who miss appoint-ment date. LTFU: • Failure to attend the facility or distribution point (club or CCMDD) within 90 days following the set appointment
Step 7: Unstable on treatment (Regular review– if patient become stable return to 6 if unstable progress to 5)				
Enhance adherence counselling Integrated care	• Explain result to the patient • Careful review of adherence history.	• Education on result and common cause for treatment failure • Assess barriers to adherence	• Express barriers to adherence and potential reason for treatment failure	Follow up: • Come back for next check/ test (VL in 2 months, hyper-tension monthly or

Recommended intervention	Clinician's role (nurse, doctor or pharmacist)	Non-clinician's role	Patient's role	Follow up Definition of LTFU
(Step 6 cont.) Tracing of early missed appointment	• Assess and manage side effects swiftly • Screen and provide treatment based on guidelines • Emphasise importance of treatment continuation • Consider switching to alternate regimen as per national guidelines recommenda-tions	• Assess misconceptions and beliefs about treatment • Support to elaborate strategies to overcome barriers (taking treatment even if use alcohol, etc.) • Set new goals for next test/ check (VL, blood pressure, sputum, etc.) • Encourage adherence to influence next result • Adopt a non-judgmental and support-ive attitude	• Review and adapt adherence plan • Set new objectives • Adhere to treatment • Come for next appointment and inform in case of change of contact number or address or if travelling	sputum when recommended) • 2nd Viral load after 2 months and switch in 2nd line in case of 2nd high VL **Missed appointment:** • Failure to return on agreed appointment date • Use facility appointment book and electronic register to identified patient who missed appointment • Call or home visits those who miss appointment date. **LTFU:** • Failure to attend the health facility within 90 days following the set appoint-ment date

Vulnerable populations				
Recommended intervention	**Clinician's role (nurse, doctor or pharmacist)**	**Non-clinician's role**	**Patient's role**	**Follow up Definition of LTFU**
Pregnant woman: PMTCTB+ Tracing mHealth Peer support	Treat as recommended by guidelines for PMTCT	• Education on PMTCT • Facilitate the Fast Track Initiation Counselling Model • Develop and adherence plan adding specific adherence steps on PMTCT	(see table for initiation)	ANC follow up
Children: Child disclosure Tracing Peer support	Treat as recommended by guidelines	• Support caregiver and child with progressive disclosure from 6 to 9 year and full disclosure form 9 to 12 year	Caregiver (supported by the counsellor) to disclose to the child	Come for refill and clinical follow up (as tables above recommend)
MSM and Sex workers: Decentralise care Peer support	Treat MSM and sex workers with respect and adapt a non-judgmental attitude	• Treat MSM and sex workers with respect and adopt a non-judgmental attitude	(see table for initiation)	Come for refill and clinical follow up (as table above recommend)

9. MONITORING AND EVALUATION (M&E)

The National Department of Health recognises that the success of this adherence strategy relies heavily on the comprehensive and on-going implementation of the proposed interventions. Monitoring and evaluating the implementation process is therefore of particular importance to the success of this strategy to improve linkage to care, adherence to treatment and retention in care. The monitoring and evaluation of the implementation of this adherence guideline requires several strategies:

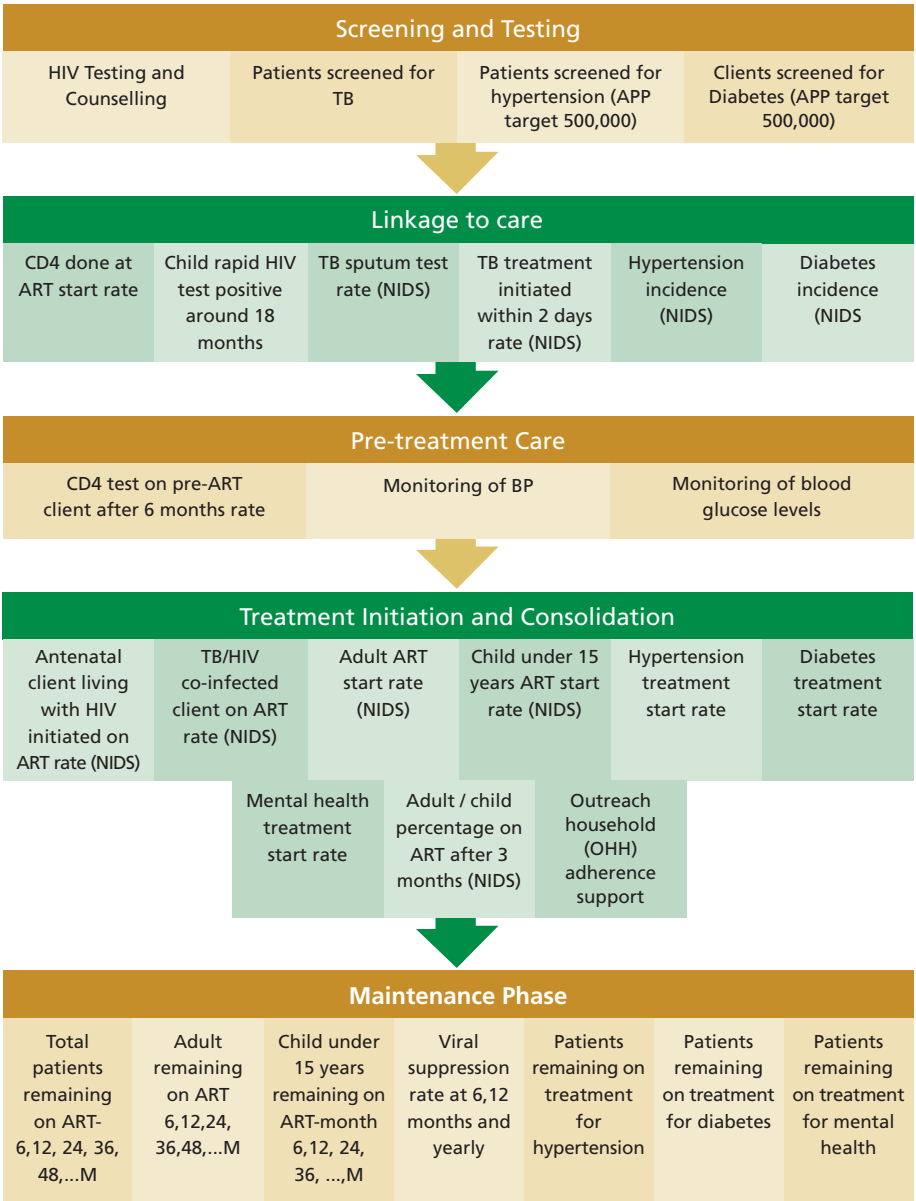
- Each disease programme (HIV, TB, NCD) will continue to monitor their patients using existing indicators. Additional indicators to be considered at provincial and district level include:
  1. number of patients completing the fast track initiation counselling sessions
  2. total patients traced after defaulting
  3. number of patients in alternative RPCS
  4. number of patients referred for enhanced adherence counselling, the re-suppression rate and the number of patient switched to second line treatment
  5. number of patients eligible for treatment who linked to care within 30 days and
  6. number of clubs per facility.
- NDOH has planned for a unique patient identifier which will aid patient tracing.
- It is important to ensure consistency of reporting and standardised reporting tools across the continuum of care.

The following Reports that are usefull and can be used to monitor implementation of guidelines

- Reports tracking defaulters:
  - Report on patient supposed to link into care (appointment book/list)
  - **Early** Missed Appointment List
  - **Late** Missed Appointment List
  - Report on tracing activities (number of patient traced and outcomes)
- Reports that help with patient management:
  - **Viral Load** report
  - TB conversion report

The monitoring and evaluation of programmes remains important at National, Provincial, District and Facility levels. The adherence programme should be measured through existing M&E systems like DHIS, Tier.net and ETR.net. Data collection tools should be modified, where feasible to measure the minimum package of interventions proposed in these guidelines. It is also recommended that Districts should identify Adherence champions to ensure that issues of linkage to care, adherence and retention in care are discussed during District management team meetings and war rooms. The following figure depicts useful indicators to monitor linkage, adherence and retention in care.

Figure 4: Indicators at each stage useful for the tracking of adherence along the treatment continuum



APPENDICES
DETAILED GUIDANCE

APPENDIX 1: FAST TRACK INITIATION COUNSELLING

Session 1: Day of eligibility

Depending on the condition(s) of the patient, the appropriate content should be facilitated before/on the day of initiation on treatment. All content needs to be covered in one session.

Explain to the patients that you will assist them to create a plan to help them take their treatment correctly. It is recommended that you have a document to record the plan elaborated by the patient. It can either be a standardised adherence plan (see the last page of this appendix) or written in the file.

The first step of the adherence plan is education on illness and treatment:

STEP 1: Education on illness and treatment (can be done in group or individually)

- Provide education on illness and treatment depending on the condition(s) as below.
- Use flip file with images or drawing to help the patients understand the explanations.

A. EDUCATION ON TB

To be facilitated on the day of TB screening/diagnosis/treatment initiation (in group or individual session).

Content:

What is TB?

- TB is an infectious disease caused by Mycobacterium Tuberculosis that you breathe in and can make you sick in a few weeks, months or even after years.
- TB mainly damages the lungs by growing and causing local destruction. This form is called pulmonary TB and is infectious to others.
- TB can also occur in some parts of the body outside of the lungs. These forms are called extra-pulmonary TB, and are not infectious to others.

How is TB spread?

- TB is spread in the air when people who have active TB are coughing, sneezing or singing. Then other people can breathe in the Mycobacterium TB and may get sick sooner or later.
- This happens more in crowded spaces
- Children and people with a weak immune system are most at risk of getting TB
- TB cannot be spread by shaking hands, sharing cups or sharing eating utensils

How can you prevent passing TB on to others?

- Cover your mouth with a tissue or your sleeve when you cough or sneeze
- Let sunshine and fresh air in: open windows and doors in your house, cars, taxis, etc.
- Wear a mask
- Avoid close contact with others until you have completed 2 weeks of treatment (if possible sleep in a room on your own during this time).
- The best way to avoid spreading TB is to complete your treatment.

What are the symptoms of TB?

- Anyone experiencing a cough for more than 2 weeks, unexplained loss of weight, drenching night sweats or persistent fever for more than 2 weeks needs to go to the clinic for a sputum test.
- Other symptoms can be specific to the part of the body where the TB bacteria are growing.
- All children under 5 living with you should be taken to the clinic for a TB test and preventive treatment.

What is the link between TB and HIV?

- TB is the most common serious opportunistic infection among people living with HIV/AIDS (PLHIV).
- HIV attacks the soldiers (CD4 cells) of the immune system that protect the body from infection. As the immune system of PLHIV is weak, TB easily develops in the body.
- TB can be treated and be cured. HIV can be treated but cannot be cured.
- TB and HIV are spread in different ways: TB bacteria are breathed in and HIV is most commonly spread through unsafe sex.
- When you have HIV and TB at the same time, you should start ARVs 2 weeks after starting your TB treatment.
- Starting both treatments at the right time will help you to heal from TB better and faster, because ARVs will help make your immune system stronger.

What is the link between Diabetes and TB?

- Diabetes increases the risk of developing TB. Consequently, rates of TB are higher in people with diabetes than in the rest of the population.
- TB infection may progress at a faster rate in people with diabetes than in those without diabetes.

- Diabetes can delay TB treatment response and reduce the likelihood of a good outcome, increasing the risk of relapse or death.
- TB may trigger the onset of diabetes, and worsen glycaemic control in existing diabetes.
- It is important to screen people with diabetes for TB and all TB patients for diabetes.

How does TB treatment work?

- There are medicines to fight against TB. We need a combination of at least 4 medicines to fight TB. They are often put together in one tablet (a fixed dose combination or FDC).
- Some TB hides deep in the lungs and since TB grows slowly, it takes at least 6 months to kill all the TB bacteria.

How to adhere to your TB treatment?

- During the entire 6 months, TB medicines need to be taken every single day.
- When you miss a dose, you should take the forgotten dose as soon as you remember and then get back to your usual medication schedule.
- Medicines should be kept in a safe, dry place that is not too hot.

The risk of poor adherence:

- If you stop before 6 months or do not take TB treatment regularly, you may develop Drug Resistant TB (DR TB). You will have to take treatment for longer to get rid of the DR TB treatment takes up to 2 years, with 6 months intensive phase (with daily injections) and a continuation phase of 18 months.
- If you are taking contraception, the TB medicines could affect their effectiveness. Talk about it with the doctor or nurse.

Side effects

- Most people do not get side effects. Some people could experience mild side effects like heartburn, nausea, rash, painful feet or urine turning orange.
- A few people may experience serious side effects like yellow skin/eyes, severe abdominal pain, bruising or problems with sight and hearing. If you have any of these serious side effects, come straight away to see your doctor or nurse.

Alcohol and TB treatment

- It is better not to drink any alcohol in the period that you are taking TB treatment. This combination will have a bad effect on your liver and your nerves. If you experience difficulty in reducing alcohol consumption, do not stop the treatment but seek help.

B. EDUCATION ON HIV/ART

To be discussed and explained on the day of HIV screening, diagnosis or treatment initiation (in groups or individual sessions).

Content:

What has HIV done to my body so far?

- CD4 cells are cells that live inside the blood and protect the body against disease. They are like the 'soldiers' of your body and they fight against diseases. All CD4 cells together are the 'army' of the body which we call the immune system.
- HIV is a virus that enters your body. This virus is clever, it makes more and more HIV when it enters the body and attacks our CD4 cells, destroying the immune system (our body's soldiers).
- The blood test you took is called a CD4 count, which measures the strength of your immune system. The CD4 test helps in the decision about when you need to start treatment.
- When the HIV kills your CD4 cells (your body's soldiers) diseases can enter into the body and make you sick. We call these opportunistic infections (the infection is taking the opportunity to spread). The most frequent opportunistic infections are tuberculosis, diarrhoea, skin diseases and others.
- The best time to start taking ARV treatment is when your CD4 has reached 500. Below 500 you are at a higher risk of getting infections like TB. The earlier you start ARV's, the faster your CD4 count will return to normal and the smaller the chance that you will get sick.
- We used to only start patients on ART when their CD4 was less than 350, but after years of putting patients on ART, we now know it is better for patients to start before they get too sick.
- For pregnant or breastfeeding women it is important to start ART early, at any CD4 count. Taking ART protects the baby from getting HIV and keeps you healthy.

How taking ARVs can help you

- ARVs are a treatment that stops the multiplication of HIV. When HIV stops multiplying in our bodies, our CD4 cells grow strong again, helping our immune system to fight off diseases. ARVs do not kill all HIV in the body but they kill enough to keep us healthy.
- We need to take 3 different ARVs every day for the rest of our lives to keep our HIV under control. Most of the time, these 3 ARVs are combined in one tablet. It is the combination of the 3 that works to fight HIV.
- Some of the ARVs need to be taken once a day and others need to be taken twice a day. Your doctor or nurse will decide which treatment is right for you.
- ARVs need to be taken for life and should not be stopped and started again and again. The better you are at taking your treatment, the longer you will stay healthy.

How to keep taking your ARV treatment

- ARVs are to be taken every day as close to the same time as possible.
- Most patients will need to take their treatment once a day, a few will still need to take their treatment in the morning and evening, meaning every 12 hours.
- You should choose the best time according to your daily habits: wake up time, work, school, etc.
- When you miss a dose, you should take the forgotten dose as soon as you remember and then get back to your usual medication schedule.
- Learning a new habit like adhering to treatment takes time and practice. It is normal for you to forget a dose or to take a dose late, but we will work with you to help you become good at taking your medication at the same time every day. With time, taking your ARVs will become easier.

Risks of poor adherence

- Poor adherence occurs when we keep taking our pills too late, when we forget to take a dose, when we do not take all of our pills, or when we stop the treatment because we are feeling better.
- If you do not take your ARVs every day you will not have enough ARVs in your blood to fight the HIV. So the HIV will multiply and destroy the CD4, which means you will get sick.
- Another consequence of not taking medicine properly is resistance. If the HIV virus encounters few ARVs in the blood, and multiplies, it can transform itself, and become able to resist the ARV attacks meaning that your ARVs will no longer work to kill your HIV.

Side effects of ARVs

- All patients will probably have some minor side effects at the start of their treatment. It is normal to experience some nausea, headache, dizziness, diarrhoea. They mostly disappear within a few weeks after starting treatment. It is important to continue to take your treatment even if you experience these side effects, or talk to your doctor or nurse if you think there is a problem.
- Some patients may experience vomiting when they take their ARVs, especially in the beginning when the body is still adapting to the medication. If you do vomit in the hour following the time you have taken your medication, then you must take another dose (all of them). If you are having problems with this it is best to talk to your doctor or nurse.
- Only a few patients will experience serious symptoms. If this happens to you, you should not stop taking your treatment, but come to the health facility as soon as possible to find out what the problem is. The problem could be due to side effects, but could also be related to HIV itself or something else completely. Your local clinic is there to help.

C. EDUCATION ON PrEP

To be discussed and explained on the day of eligibility for treatment (in groups or individual sessions).

Content:

What is PrEP?

- Pre-exposure prophylaxis, also known as PrEP, is a new HIV combination prevention option for HIV negative women and men with ongoing HIV risk exposure.
- PrEP cannot be taken by everyone. PrEP is for HIV negative people who are at ongoing high risk of HIV infection; for example, if you cannot always have protected sex with partners who you do not know the status of, or who are HIV positive, if you are not always able to negotiate condom use or if you find it difficult to control the risk of being infected with HIV.

How does PrEP work?

- PrEP combines some types of ARV medicines in one tablet. These are the same ARV medicine that are commonly used as part of ARV group of medicines to treat HIV infection in HIV-positive people.
- When you take PrEP, it makes a shield around your soldiers (CD4). It takes some time for the shield to be built. It takes approximately 3 weeks for your shield to be well built and protect you well against HIV. When HIV comes in your body, HIV cannot attack the CD4 cells. HIV does not survive the battle with the shield and dies.
- When you stop taking PrEP your shield around your soldiers will become weaker and eventually disappear.

Why is adherence to PrEP important?

- If taken daily around the same time, every day, PrEP gives you a high chance to remain HIV negative.
- PrEP needs to be taken regularly, even on days when you do not have sex.
- People do not need to take PrEP for the rest of their lives. You need to take PrEP during periods in your life when you think you may be at high risk of getting HIV, this can be several months to many years.
- If you are taking PrEP, you need to attend the facility periodically for laboratory monitoring including scheduled HIV tests and adherence support.
- If you want to stop taking PrEP because you feel you are not at risk of getting HIV, you should still take PrEP for one month following the last time you had unprotected sex or risky behaviour.

- If you decide to stop taking PrEP, you must inform the health care worker, so that you can be advised about other HIV prevention options. Most people who take PrEP do not experience side effects from the tablets.
- If you experience side-effects, it is important to keep taking your PrEP and come to the health facility to inform the health care woker about your experience when taking PrEP to find appropriate support.
- If PrEP is not taken routinely, around the same time, every day, it is much less effective. Since PrEP is not 100% effective at preventing HIV infection, it is recommended that people still use other combination prevention methods, such as consistent and correct use of condoms when they have sex, even if they are taking PrEP, for the best protection against HIV. PrEP does not provide any protection against pregnancy and most STIs.

D. EDUCATION ON HYPERTENSION

To be discussed and explained on the day of screening, diagnosis or treatment (in groups or individual sessions).

Content:

What is high blood pressure?

- High blood pressure is a condition you have for life.
- High blood pressure often has no symptoms and can cause serious disease and serious complications such as a stroke, a heart attack or death.
- Early detection and good blood pressure control lowers the chance of having a stroke, heart attack and death.
- High blood pressure has no cure, but it can be controlled through lifestyle changes and often through taking medication.

How does our heart and blood work?

- Our heart works like a pump and makes the blood circulate around the body. With every heart beat blood is pushed through the veins and sent through the body carrying oxygen and nutrition.

What is blood pressure and how is it measured?

- Blood pressure is the force of blood as it flows through your veins.
- Two numbers are used to describe blood pressure: the upper number measures the blood pressure when your heart pumps, the lower number measures when your heart is at rest.
- Blood pressure is measured with a blood pressure cuff, ideally at the health facility.
- A normal blood pressure is less than 140 over 90.

How is high blood pressure diagnosed?

- Blood pressure can be variable over time; therefore several readings need to be done to properly diagnose high blood pressure.
- You must have blood pressure readings when you are not ill or stressed.
- When blood pressure remains high, meaning above 140 over 90 after several tests taken on different days, the doctor diagnoses high blood pressure.
- The only way to detect hypertension (high blood pressure) early enough to prevent getting sick is by checking your blood pressure regularly. Even if totally healthy you should go to the clinic every year.

Who is at risk for high blood pressure?

- High blood pressure can be caused by multiple factors. Some factors can be controlled and some cannot.
- Factors that can be controlled by making lifestyle changes include: smoking, being overweight, eating a lot of salt and fat, drinking a lot of alcohol, being much stressed, and not getting exercise. Doing these things will increase your risk of high blood pressure.
- Other factors cannot be controlled.
- The following people are more likely to have high blood pressure:
  - People who have heart or kidney diseases, as well as people who have had a stroke
  - People who have a history of high blood pressure in the family
  - People with another chronic condition like diabetes or HIV
  - The older you are, the higher risk
- Though some people are at a higher risk of developing high blood pressure, anyone at any age and background can develop it.
- People who are at risk for hypertension should get their blood pressured measured on a regular basis.

How can high blood pressure hurt your body?

- Due to high blood pressure, blood vessels can break if pressure is too high.
- In other cases, vessels can be blocked so that the blood can no longer pass.
- The rupture or blockage can lead to a stroke, blindness, heart attack, heart failure, kidney failure and even death.
- The higher your blood pressure is over time, the greater the risk of complication or death.
- When you have high blood pressure and you do nothing to lower your blood pressure, your chances will be high to develop complications.

How to lower high blood pressure

- Controlling high blood pressure means a lifelong change of some eating and lifestyle habits for all people with high blood pressure:

- Lose weight if overweight
- Do not smoke
- No excessive alcohol use
- Reduce stress
- Eat less salt and fats
- Exercise 30 minutes a day or more by walking, dancing, or playing a sport
- **Medications may also be necessary to bring high blood pressure back to normal for some people with high blood pressure.**

How to eat well

- Here are some steps to ensure a healthy diet:
  - Reduce salt intake to <1 teaspoon/day by avoiding food that is rich in salt and not adding salt
  - Drink plenty of water daily and reduce intake of coffee, tea and drinking chocolate
  - Reduce alcohol (men ≤ 2 drinks/day, women ≤ 1 drink/day)
  - Reduce fat intake by avoiding fried food and fatty meat. Cook with vegetable oil and use low fat milk
  - Increase fruit and vegetables to 5 servings per day

When and how to take medicines for high blood pressure?

- When lifestyle changes alone do not help to control blood pressure enough, the clinician may prescribe medications. Lifestyle changes will need to continue however since them also help.
- The clinician will choose the treatment for you depending on your blood pressure and medical history. This means you might take different drugs from those somebody with the same condition takes. Some people need just one medication to control their blood pressure, others need three or more.
- It is very important to take your medication as prescribed. Medication should not be taken just when you feel sick, but should be continued even if blood pressure is well controlled. Interrupting or stopping treatment can be dangerous and should be discussed with your doctor or nurse first.

What are side effects of medication for high blood pressure?

- Some medications may have side effects. If you have unpleasant side effects, rather than getting discouraged and stopping the medication on your own, consult with your doctor who may be able to change your medication or adjust your dosage to decrease the side effects.
- Possible side effects may include (explain only side effects related to specifi c treatment):
  - Dizziness
  - Cough
  - Swelling
  - Increased urination

- Sexual dysfunction
- Muscle cramps

How often should I go to the clinic?

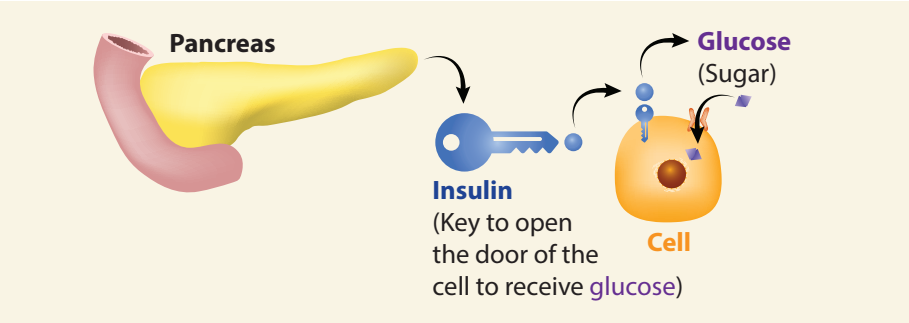
- For patients who are not on medication:
  - You should have your blood pressure checked every 3-6 months and see the doctor once a year for a check-up.
- For patients who are on medication:
  - Regular check-ups with the doctor in the clinic are important to determine the effectiveness of the medications by checking your blood pressure and to have a physical examination.
  - At the start of your treatment we will help you to make a plan on how to adapt your lifestyle and adhere to your medication.

E. EDUCATION ON DIABETES

To be discussed and explained on the day ofscreening, diagnosis or treatment (in groups or individual sessions).

Content:

What is diabetes?



Diabetes is a chronic disease which increases the level of the sugar in your blood above normal. Your cells need sugar to work. Diabetes is when you lack the insulin (key) to open the door of your cells which means that the sugar cannot enter the cells. The sugar will keep on going around in your blood, all around the body, and this circulating sugar will destroy blood vessels and nerves to your legs, eyes, heart, kidneys and general circulation. This may result in blindness, kidney failure, heart disease, stroke, and limb amputations.

What are the symptoms?

There are 3 types of diabetes.

- The 1st type develops in children: they will lose weight, feel very thirsty and urinate more than normal.
- The 2nd type will develop in adults, usually over 30 years old, and often overweight. In the beginning, the high sugar in the blood will not cause any symptoms, so we need to SCREEN for this high sugar in people who are at risk for diabetes (for example, overweight people, people with high blood pressure, or people who have had a stroke in the past).

The following symptoms can appear: frequent urination, excessive thirst, unexplained weight loss, extreme hunger, sudden vision changes (e.g. blurred vision), tingling or numbness in hands or feet, feeling very tired much of the time, very dry skin, sores that are slow to heal, erectile dysfunction and persistent vaginal thrush and urinary tract infections.

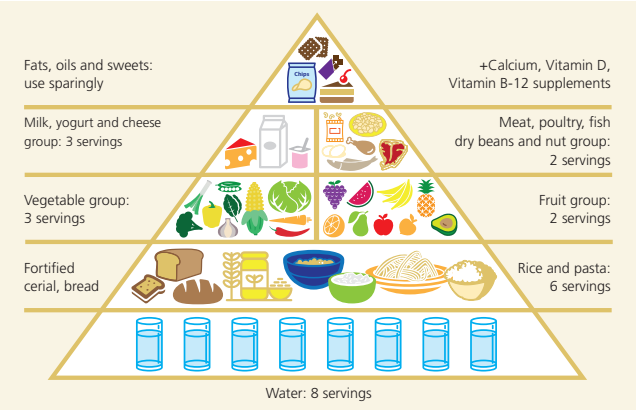
The 3rd type is the Gestational diabetes: this diabetes occurs during pregnancy due to hormonal changes in the body. It is important to be screened for Diabetes throughout your pregnancy but especially from week 24 of your pregnancy. Gestational Diabetes in most women goes away after birth, however, if a healthy lifestyle is not maintained, the woman can develop Type 2 Diabetes later in life.

How can we prevent diabetes?

The 1st type of diabetes, in children, cannot be prevented. It is genetic, so we have to diagnose it as early as possible, when the symptoms above are present.

The 2nd type can be prevented with lifestyle changes: by keeping your correct weight, with regular physical exercise (30min/day), and with a balanced diet.

See the Food Triangle to understand what a basic, healthy diet is made up of. It is recommended that you eat most of the products that are at the base of the triangle, and the least of the products on top. Drinking a lot of water (or tea without sugar) is important.



How can we treat and prevent complications?

It is important to know that diabetes is not a death sentence. Diabetes can be managed effectively with education, lifestyle changes and medication. There are many people living with Diabetes who have a good quality of life and have very little to no complications.

Healthy eating, physical activity, insulin injections and regular blood glucose testing are the best treatment for Type 1 diabetes.

Healthy eating, physical activity and blood glucose testing are the basic treatment for Type 2 diabetes. In addition, many people with Type 2 diabetes require oral medication, insulin, or both to control their blood glucose levels.

Most people with Type 2 Diabetes will have to inject insulin to control their blood glucose levels at some point in their lives because the pancreas continues to produce less insulin over the years and eventually produces no insulin at all.

If you don't keep the level of sugar controlled, this sugar will go round and destroy blood vessels and nerves.

It is important:

- To lose weight if you are overweight.
- FEET care: ask your relative to check your feet for small wounds (because of destroyed nerves you won't feel them and because of damaged vessels they won't heal properly).
- To stop smoking and to have your blood pressure checked regularly (as both increase the risk of heart infarct and stroke, just like diabetes).
- Have your eyes checked, as uncontrolled diabetes can make you blind. Take the recommended dosage and avoid taking traditional medication for this.

What is the link between Diabetes and TB?

- Diabetes triples the risk of developing TB. Consequently, rates of TB are higher in people with diabetes than in other people.
- TB infection may progress at a faster rate in people with diabetes than in those without diabetes.
- It is important to screen people with diabetes for TB.

Continuation of the adherence plan:

STEP 2: Identify life goals

- Ask the patient to think about the things that make him/her want to stay healthy and alive.
- Ask them to think about the important people in their lives, what projects or goals they have in the future, etc. Ask them to think about 3 things. e.g.: getting married, school or work, taking care of my family, etc.

STEP 3: Identify Support system

- Who could support you in taking your treatment?
- Would you agree to have a Community Health Worker visiting you at home or to be contacted by phone?

STEP 4: Plan for future appointments

- How will you come to your appointments?
- What will you do if something prevents you from coming to your appointment (such as no money for transport, raining when you usually walk, taxi strike or a sick child, or any other reason)?

STEP 5: Assess the readiness of the patient to start treatment

- Do you feel ready to start treatment as soon as possible? If not, stay supportive.

Invite patient to express beliefs or concerns that may interfere with the initiation of the treatment. Correct misconceptions (avoiding judgments).

For patients who are reluctant to start treatment, propose that they meet a peer (from a support group or a peer educator) to hear about their experience on treatment.

Repeat the life goals with the patient and remind them that starting treatment will be the best way to achieve their goals. Invite them to choose a moment to think about the goals every day if they can, for example when waking up or waiting for transport.

Session 2: day of initiation

- Continue the adherence plan.
- Ask the patient to remember the 3 reasons to stay healthy from the previous session, and then facilitate the following steps:

STEP 6: Medication schedule

- According to your schedule, what would be the best time for you to take your treatment?

STEP 7: Managing missed dose

- What will you do in case you forget to take a dose?

Advise them to take the treatment as soon as they remember (except for hypertension).

STEP 8: Reminders

- What difficulties have you faced in remembering to take medication when a treatment was prescribed to you in the past?
- What could you use to remind you to take your medication?

Help the patient to think about what they do at this time of the day to identify reminders that can fit into their environment (e.g. alarm, someone to remind them, when "Generations" is starting on TV, etc.)

STEP 9: Storing medication and extra dose

- Do you worry about people seeing your treatment?
- Which safe place could you identify to store your treatment?
- In case you don't have access to your treatment at the time you are supposed to take it, how can you always carry 1 or 2 doses with you?

STEP 10: Dealing with side effects

- What will you do if you are experiencing side effects?

Encourage them to make a plan, explaining that:
Side effects such as dizziness, nausea, headache or diarrhoea can happen when starting treatment. Most side effects go away after a few weeks. If you vomit up to one hour after taking the medication, take your treatment again. Severe side effects are rare. If you don't feel well, it is important you don't stop your treatment and come to the clinic.

Session 3: After 1 month on treatment (on medication collection day)

- Finalise the last steps of the adherence plan.
- Assess how the first weeks on treatment have been and if the patient managed to apply the adherence steps agreed upon last time.
- The following steps should be addressed during this session:

STEP 11: Plan for travels

- Do you plan to travel in the coming weeks or months?
- What would you do to make sure you can continue your treatment if you go away?
- What could you do in case you have an unplanned trip and can't come to the clinic before leaving (e.g. funeral or wedding)?

Inform patients that:
The best plan would be to come to the health facility before travelling to inform them how long/where you are going and to receive a referral letter and enough treatment.

If the trip is not planned and you cannot come to the health facility, it is important to go to the nearest health facility in the travel area as soon as you arrive to make sure you access treatment there. It is important that you carry evidence of your condition and evidence of the treatment you are taking.

STEP 12: Dealing with substance use

Explain that:
Ideally, it is better to moderate alcohol or substance consumption when you are on treatment (especially TB treatment). But if you have difficulties in limiting your consumption to 1 or 2 drinks, it is still important to make sure that you do not forget to take your treatment (judgment is unhelpful).

- In case you are going to drink alcohol or use drugs, what could you do to make sure you remember to take your treatment?

Support the patient in making a plan, assessing if someone could make sure they take their medication when they use drugs/alcohol or if they should rather take it at another time (when they are less likely to be intoxicated).

Encourage patients to think about their 3 reasons to stay healthy (from the first session) to re-motivate them when they experience difficulty in taking their treatment. If there are treatment options available, make them known to the client.

Session 4: After 2 months on treatment (on medication collection day)

Education and Goals

Provide explanation on the further test that will be performed:

For HIV:
- To know if your treatment is working, we will do a Viral Load test. The Viral Load test measures the amount of HIV virus in your blood. It is taken after 6 months on treatment.
- Explain the possible result and its meaning (undetectable vs high viral load, in terms of the number of copies in the blood)

For TB:

- Explain that a sputum test will be done at 2 months on treatment
- Explain the continuation phase (treatment changed in case sputum is positive)
- Explain the importance of continuing and adhering to treatment till the end (6 months/8 months for those on category II) to prevent the TB germ coming back

For hypertension and diabetes, talk about self-monitoring strategies and further clinical check.

Agree on goal(s) with the patient, e.g.

– For HIV: Having first viral load supressed and thereafter viral load below 400 copies/mL
– For TB: complete TB treatment and be cured of TB
– For hypertension: Having a BP<140/90
– For diabetes: To keep my blood glucose within (FPG) 4-7 mmol/L

Encourage the patient to think about their life goals when they experience difficulties

ADAPTATIONS:

This model can be adapted depending on the illness that is being considered. The content of the educational session will vary depending on the condition affecting the patient.

Some **specific additional steps** should be added for certain conditions, e.g. **for hypertension**, it is recommended to add a HEALTHY LIFESTYLE PLAN supporting the patient to (1) adopt healthy eating habits, to (2) get regular exercise, (3) cut down smoking and (4) manage stress.

For PMTCT: Steps should be added to support the woman to make a plan to (1) deliver at the health facility, to (2) choose a feeding option, to (3) give the treatment to the baby and to (4) bring the baby for PCR and rapid test.

REMARKS:

- Each counselling session should start with an introduction and stress confidentiality
- An encouraging message explaining the next steps on treatment should be given at the end of the session
- The helpline number should be given to all patients
- The information about the adherence plan should be recorded in the file. A carbon copy can be provided to the patient to help them take ownership of the adherence plan (see next page).
- Assess Mental Health (Appendix 8). If needed, proceed or refer for SRQ20 and treatment.

health

Department:
Health
REPUBLIC OF SOUTH AFRICA

PATIENT ADHERENCE PLAN

Name and Surname: _____

It is important to note that not all patients will follow the steps sequentially

Session 1 after Chronic disease education session (*date*):
Adherence step 1: Education on HIV ☐ TB ☐ Hypertension ☐ Diabetes ☐ Other: ☐
Adherence step 2: Life goals My motivations to stay healthy are: 1) _____ 2) _____ 3) _____ I will maintain a healthy lifestyle by: adopting healthy eating habits ☐ getting regular exercise ☐ managing stress ☐
Adherence Step 3 – Patient support system Agree for home visit: Yes ☐ No ☐ Who can support me in my treatment: Family ☐ Friends ☐ Work ☐ School ☐ Church ☐ Other: ☐ _____
Adherence Step 4: Getting to appointments I will come to my appointments by : walk ☐ public transport ☐ own transport ☐ If I face a difficulty to come (money, transport, etc.), my alternative plan will be: to ask for assistance from: family ☐ friends ☐ neighbour ☐ other ☐ I will inform facility I am unable to come to set appointment and request for an alternative appointment ☐
Adherence step 5: My readiness to start treatment I feel ready and will start treatment: Yes ☐ No ☐ I do not feel ready and would like to discuss more with: peer ☐ family member ☐ Community Health Worker ☐
Session 2 (*date*):
Adherence Step 6: Medication schedule The best time for me to take my treatment is: Morning ☐ Afternoon ☐ Evening ☐

Adherence step 7: Managing missed doses

If I miss a dose, my plan is to take treatment as soon as I remember ☐

Adherence Step 8: Reminder strategies

To remind me to take medication, I will use: watch ☐ cell phone ☐ alarm ☐
pill box ☐ buddy ☐ other ☐

Adherence Step 9: Storing medication and extra doses

I will store my medication in: Safe place ☐ Far from reach of children ☐
I will carry extra supply and keep it in: bag ☐ pill box ☐
I will keep it in my: handbag ☐ pocket ☐ other: ☐ _____

Adherence Step 10: Dealing with side-effects

If I experience side effects, I will: Refer to treatment adherence pamphlet ☐
Inform facility if side effects do not go away or are too worrying ☐

Session 3 (*date*):

Adherence Step 11: Planning for trips

If I have some trips planned, before going away I will: inform health facility before travelling to receive referral letter and treatment ☐ Get enough supply of treatment for trip ☐

In case I cannot come to the facility before going away:

1) I will go to the nearest health facility in the travel access as soon as I arrive to get access to treatment ☐
2) Carry evidence of my condition and evidence of the treatment I am taking ☐

Adherence Step 12: Dealing with substance use

My plan to make sure I take my medication if I used alcohol or drugs is:

☐ To make sure I take treatment before starting to use drug or alcohol
☐ Arrange for someone to remind me to take treatment in case I am intoxicated

Session 4 (*date*):

Education on follow up: Viral load ☐ Sputum ☐ HbA1c ☐
Other: ☐ _____

Patient's signature: Date:

TREATMENT GOALS:

- ARV goal: My first Viral Load will be suppressed! And thereafter remain below 400 copies/mL.
- TB goal: I have completed 6 months TB treatment and I am cured of TB.
- Hypertension goal: My Blood Pressure is less than 140/90.
- Diabetes goal: I monitor and keep my blood glucose within (FPG) 4-7 mmol/L.

APPENDIX 2: ENHANCED ADHERENCE COUNSELLING

Session 1 (group or individual)

1. Education on test results

Ask the following questions to the patients (leave some time to answer and correct if needed):

- *What does the test measure?*
- *What are the possible results and what do they mean?*

Give the result and explain that it raises some questions:

- *Do you know what the reasons can be for having a high viral load result/ sputum positive/ high BP/high sugar level…?*

Explain: *A common cause for this kind of result is that the person is facing problems in taking the treatment correctly. By taking treatment correctly every day, it is still possible to get a result back to normal.*

In some cases, the patient is adherent but there is another medical problem. It could be that the treatment is not working. In that case, the treatment may have to be changed to 2nd line treatment.

2. 'Rules' of treatment

The rules that we've been taught on the way to take treatment can sometimes make it difficult to adhere to the treatment.

- *How have you been told to take treatment and what are the "rules" you remember?*

3. Flexibility on treatment

Correct general misconceptions around taking treatment and explain there can be some flexibility:

a) flexibility of dosing schedule: *Treatment should be taken around the same time every day (ok if not exactly at the same time, find a time that suits client's daily routine)*
b) Explain what to do with late or missed doses (For ART/TB, take them as soon as you remember)
c) Explain what to do in case of alcohol use while on treatment: *If you drink alcohol, it is important to make a plan to make sure that you don't forget to take your treatment.*

4. Own experiences

Invite patients to discuss their own difficulties around taking treatment:

- Do you have some examples of situations that make it difficult to take treatment correctly?

Let patients share experiences and solutions (if in a group session, let the members support each other in finding solutions / If with an individual, support the patient to find appropriate solutions themselves.)

5. Identify strategies to ensure good adherence

Support patients in making a plan working around the barriers expressed: Make a daily plan for drug intake, introduce reminder tools, prepare for travels, support in disclosure, taking treatment in case of alcohol consumption...

6. Inform about further test to check adherence and effectiveness of the treatment.

Patient with a 2nd results raising suspicion of non-adherence or treatment failure will receive an additional session to prepare them to adhere or for potential switch to the 2nd line treatment as appropriate per condition.

Session 2

1. Assessment of education session and reasons for 2nd Result

- Assess what the patient remembers from the 1st session (meaning of the result and the reason for it) Tell the patient that the 2nd result is still worrying and ask them what the reasons could be.

2. Education on resistance and 2nd line treatment

- Explain to the patient what resistance means and available 2nd line treatment as appropriate for condition.
- Provide explanation on 2nd line treatment and explain that the treatment is very effective if it is taken correctly.

3. Support the patient in making an adherence plan that suits him/her

- Revise the steps of the adherence plan of the Initiation model (or create one if never done) (See each step of Appendix 1).
- Support the patient in identifying a peer support system and link them to a HBC, CHW, support group or access to government support programmes where food security is an issue.
- Support the patient to make a plan in case of substance use and encourage the patient to be linked to a specialised service.

4. Explain the way forward:

- Emphasise importance of adherence and general well-being.
- Explain monitoring, if any laboratory tests shall be taken and when.
- Explain possible side effects of treatment. Reassure that it is important not to stop treatment and to report as soon as possible to the nearest facility to see the health care worker if it happens.
- Encourage the patient to share his concerns with someone he trusts.
- Link the patients with the services available in the community.

5. Assess patient questions and provide an encouraging message to adhere to treatment.

- Give encouraging messages for patients to have a positive outlook on life.
- Remind the patient of the importance and benefits of adherence.
- Assure client you are available to support them and provide them with information of where else they can access support.
- Encourage the patient to share psychosocial issues with someone they trusts.

APPENDIX 3: SPACED AND FAST LANE APPOINTMENT SYSTEM (SFLA)

1. Eligibility criteria

A patient may qualify for Repeat Prescription Collection Strategies (RPCS) if patient meets the following criteria:

- Adult above 18 years
- On the same treatment regimen for at least 12 months
- Most recent 2 laboratory results normal:
  - Most recent VL taken in past 6 months
  - 2 consecutive viral loads undetectable thus a minimum of 12 months on ART
  - 2 consecutive FPG normal for Diabetes and
  - 2 consecutive BP normal for Hypertension
- Clinician confirms the patient's eligibility for RPCS option
- Patient voluntarily opts for the RPCS option
- No current TB and No medical condition requiring regular clinical consultations
- Mothers or responsible caregivers with a child on ART should not be enrolled to the RPCS option especially if the child medication pick up point is different.

2. Guiding principles

- Patients choosing this option should be registered in the facility list of patients in Spaced and Fast lane appointment system.
- Patient files and pre-packaging of medicines , where possible, must be prepared at least a day before to facilitate the fast lane system.
- There must be a dedicated fast lane pick up point at the pharmacy for each facility with the spaced and fast lane system for a specified period decided by each facility.
- Patients shall be traced if they do not return to pick-up medicine within 5 days from the scheduled SFLA appointment.
- Patients shall be de-registered from the spaced and fast lane option if untraceable after 30 days from missed appointment date and followed up closely at the facility regular care.
- All processes must be documented.

3. Procedure

If patient complies with criteria for RPCS option, and chooses Spaced and Fast lane appointment system, the patient shall be informed about Spaced and Fast lane appointment system as follows:

- In the Spaced and Fast lane appointment system option, clinically stable and patients meeting RPCS criteria are requested to attend the clinic once a year for clinical assessment and laboratory testing.
- Patients receive 6 months' prescription for their medication.
- When the patients are coming for the 3rd 2 months refill, another prescription should be prepared in advance and handed over to them for the next refill.
- Each time a stable patient visits the facility, the patient should be allowed to collect at least 2 months treatment.
- Patients should be allowed to go through a fast lane system, meaning direct and quick access to the pharmacy.
- In case of health problems or pregnancy, patients must be advised to return to regular care.

4. Tracing and Retention in Care for Patients in SFLA option

If patients do not arrive at facility to pick-up medicines within 5 to 14 days of set collection appointment date:

- Patients are contacted through reminder calls or sms to return to the facility to collect medicine.
- If unsuccessful, facility initiates patient tracing using Ward-Based Outreach Team, CHWs or Home Based Carers or other suitable means.
- Medicines should be issued to patients as soon as they come back to the health facility and reason for missing the appointment date should be enquired.
- If, after 30 days the patient is not found after tracing, the patient is removed from the RPCS option Spaced and Fast lane appointment system option and followed closely at facility regular care.
- Patients can return to SFLA system if they meet the criteria for RPCS optionin the future.

APPENDIX 4: ADHERENCE CLUBS (AC)

Guidelines for establishing Adherence Clubs

Note: There is no 'one size fits all' strategy for adherence clubs.. There are several models that can be applied according to the context. Clubs have been implemented for HIV, but could be tried for NCDs. Clubs should focus on one main common condition (e.g. HIV or hypertension) but try to provide treatment for different conditions in case some patients are co-infected with other chronic conditions.

This guideline will explore both: facility and community based Adherence Clubs.

1. Broad Overview

- **Membership:** An adherence Club consists of a group of no more than 30 clients who are judged to be adherent to and stable on treatment.
- **Timing:** Club members meet every 2 months as a group. The Club visit lasts approximately 1-1.5 hours. Each Club should consider an appropriate time to meet considering accessibility for working patients (early morning or after work). At facilities, off peak, low patient load periods could be considered with less pressure on space and human resources.
- **Process:** At each club visit, club members are clinically assessed (by weight and basic symptom screening), and sometimes may participate in a group support/education activity and are issued with 2 months pre-dispensed medication in the club venue. Monitoring tests are taken in the Club annually (e.g. for HIV: viral load). At the following visit, all club members have an individual clinician consultation.
- **Facility-based Clubs:** Every 2 months patients meet as a group **at clinic facilities**. Where facility space is limited, community venues close to the facility, that do not require additional logistical support, can be utilised. Clubs at facilities can also make use of extended hours by establishing evening Clubs.
- **Community-based Clubs:** Every 2 months, club sessions are hosted in one of the **patient's homes** or community venues near their homes (e.g. NGO, church). Their pre-packed treatment is brought to them by the club facilitator. They are still patients at the main referral health facility but are only required to attend the facility for annual blood taking and clinical consultation.
- **Team, role and responsibilities:**
  - Each clinic should have a designated **Club Manager** who takes overall responsibility for the activities required to run successful clubs. This manager should be a nurse. Their duties include: ensuring their club's team is in place, the club SOP is being carried out, scheduling annual return dates for club visits, ensuring the 6 monthly prescriptions are being coordinated and completed by the team. The club's manager needs to have a good overview of the club outcomes and is responsible for completing monthly club data's for submission to the facility manager.

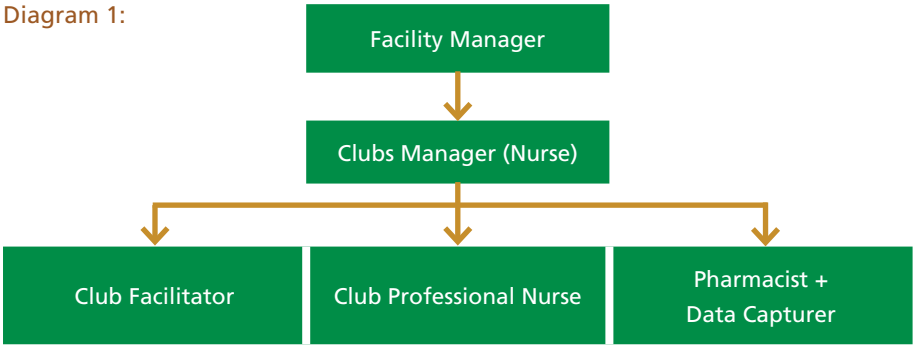
- Each club is assigned a **Club Facilitator** (a home based carer, lay counsellor, peer educator, community health worker or equivalent) and a Club PN (Professional Nurse). Other possible team members could include a data capturer/clerk and pharmacy assistant.
- The **Club Facilitator** (counsellor, peer educator, community health worker or equivalent) is responsible for preparing the clubs and running the club session; their duties include: collecting pre-packed treatment dispensed from the pharmacy, registering members, conducting the support group, conducting basic symptom screening, referring patients to Club PN if necessary, issuing pre-packed treatments, completing club registers and following up patients who miss sessions.
- The **Club PN** is responsible for clinical oversight of a Club on the day of the club visit. His/her duties also include: Seeing symptomatic patients referred by the Club Facilitator, drawing bloods for club patients on the annual blood visit and providing clinical consultation for club patients at their annual clinical review.
- **Pharmacist or Pharmacy Assistant** is responsible for pre-packing Treatment for clubs or medication can be dispensed and distributed via the CCMDD Programme.
- **Data Capturer** is responsible for capturing the club patient's visit from the club register into the facility register after a grace period.

Note: Only the Club Facilitator is always present at each club session. The Club PN is not present at the club session but available during and after the session to see symptomatic patients, take bloods and conduct annual consultation as necessary.

Club organogram

- A club organogram (diagram 1) is useful to clarify each team member's role in managing and supporting facility clubs. Clear roles and responsibilities for each team member improves staff participation in the model. The club's manager requires authority (from the facility manager) to ensure implementation and effective running of the clubs. Daily rotation of the club nurse's function within the facility enables collective responsibility for the club patients' management.

Diagram 1:



Clinical Care and Counselling

- Club members with symptoms/weight loss/other clinical problems are referred by the Club facilitator and receive an individual consultation with the Club PN on the same day.
- Annually, monitoring blood tests are taken in the Club. At the following visit, all club members have an individual consultation with a clinician.
- Club members are re-scripted for ARV drug supply purposes every six months.

Club Records

- Each Club has a club file that contains the scripts of the club members and a Club register which records attendance, weight, results of symptom screening and blood results.
- Patient Folders are only drawn at re-scripting visits, at annual clinical consultation or if a Club member receives a consultation during a routine Club visit.

2. Detailed Outline/Functioning of Clubs

2.1 Eligibility Criteria for Club membership

A patient may qualify for Repeat Prescription Collection Strategies (RPCS) if patient meets the following criteria:

- Adult above 18 years
- On the same treatment regimen for at least 12 months
- Most recent 2 laboratory results normal:
  - Most recent VL taken in past 6 months
  - 2 consecutive viral loads undetectable thus a minimum of 12 months on ART
  - 2 consecutive FPG normal for Diabetes and
  - 2 consecutive BP normal for Hypertension
- Clinician confirms the patient's eligibility for RPCS option
- Patient voluntarily opts for the RPCS option
- No current TB and No medical condition requiring regular clinical consultations
- Mothers or responsible caregiver with a child on ART should not be enrolled to the RPCS option especially if the child medication pick up points is different.

Allocating patients to a Club designated for a specific feeder area makes it easier to move clubs into the community later on (easiest to start with facility-based clubs).

2.2 Club attendance requirements

- Club members may send a buddy to collect medication for them on their Club visit day **except**:
  - on date of first attendance at the club
  - on a Lab test day

  - on a clinical consultation day
  - If s/he did not attend personally on the previous club day i.e. buddy attends twice in succession
- Where the Club member sends a buddy on the Lab test day or the clinical consultation day, the buddy will be asked to inform the Club member that they need to come to the clinic to see the Club's Manager within 5 working days of the club visit date.
- If a Club member sends a buddy to collect medication, 'buddy' is recorded in the register in the place of the weight. The buddy is informed that the Club member must attend the next time.
- Should the Club member be present within 1 week (5 working days), the Club's manager reviews the case and, where appropriate, refers to the pharmacy for issuing the treatment. This will be recorded in the Club register as a visit. If it is a Lab test, clinical or scripting visit, the Club's Manager will ensure that appropriate action is taken for the specific visit.
- However, should a Club member not attend personally or send a buddy to collect meds within 1 week (5 working days) of the club day, the Club member will be regarded as a non-attendee of the Club. He/she will be recorded as a DNA (Did Not Attend) in the Club register.
- In the case of using an electronic register, the patient must be recorded as DNA (not defaulter) as the patient has not defaulted from the clinic.
- Non-attendee members will be recalled through the contact details recorded in the register and the client will be required to return to mainstream care once they attend the clinic again.

2.3 Clinical management of Clubs

At each visit, Club Facilitator is responsible for ensuring that:

- The Club member is weighed, and the weight is recorded in the register.
- The Club member is asked – individually / in group / both – regarding the following, and the results of the screening are entered into register:
  - TB symptoms (cough, weight loss, night sweats, fatigue)
  - Late onset treatment side effects
  - Pregnancy
  - Any other symptoms of concern depending on the condition
- Where the Club member is identified with any of the above symptoms, the Club member is referred to the Club PN for an individual consultation with their folder.
- The Club facilitator should also review the weights in the register to determine whether a client has lost weight. If this is the case, this client should be referred to the Club PN.
- The Club PN consults with these identified Club members.
- The clinician(s) decide whether Club members referred from the Club should remain in the Club or return to mainstream care.

2.4 Pharmacy

The prescription used for the facility must be legally compliant.

- When patient is recruited for RPCS adherence club option, the clinician completes a script for the period until the first club visit and for the following 2 months.
- These scripts are kept in club folder and the pharmacy can either be pre-pack for the 1st club visit from these prescriptions or the patients can go to collect the medication at pharmacy after first club visit.
- At first club visit, M0 a script is completed for 6 months for each patient in the club ensuring supply for M2, M4, and M6.
- The Club's Manager must ensure that Club members are issued with a new repeat prescription 6 monthly at M6 by the clinician at the clinical consultation visit and at M12 and every 6 months thereafter.
- It should be clear on the club schedule when 6 monthly repeat prescriptions should be obtained.
- The Club file will be taken to the pharmacy at least 3 days prior to the club visit for pre-packing, and then be returned by the clinic pharmacy to the Club's Manager.
- Pre-dispensed treatments to be issued at Club visit.
- It is recommended that the Club PN on duty for the club visit be responsible for obtaining new repeat prescriptions.

3. Monitoring and evaluation

- Each club has a Club file, which contains a copy of the Club member's script (standard/CDU script). The file should also contain patient stickers.
- The Club File should be kept with the Club register.
- The Club register to be used every visit. The club tally sheet at the back of the register should also be completed at every visit.
- The Club register should be regularly reviewed by the Club's Manager.
- 5 days after the club visit, relevant information in the Club register must be transferred to the facility ARV register (paper or electronic) by the clinic data capturer/clerk.
- Once a month the Club's Manager is responsible for providing the monthly club attendance data to the ART facility operational manager who will collate data together with other facility indicators and submit it to the sub-structure HAST co-ordinator/MO.
- At Facility level: club enrolment, club attendance, return to mainstream care (i.e. exited club), weight and Viral Load
- At Sub-district level: only enrolment, attendance at clubs and returns to mainstream care.
- These indicators as being captured in eKapa/tier.net only.

APPENDIX 5: CENTRAL CHRONIC MEDICINE DISPENSING AND DISTRIBUTION

1. Eligibility criteria's:

A patient may qualify for Repeat Prescription Collection Strategies (RPCS) if patient meets the following criteria:

- Adult above 18 years
- On the same treatment regimen for at least 12 months
- Most recent 2 laboratory results normal:
  –Most recent VL taken in past 6 months
  – 2 consecutive viral loads undetectable thus a minimum of 12 months on HAART
  – 2 consecutive FPG normal for Diabetes and
- 2 consecutive BP normal for Hypertension
- Clinician confirms the patient's eligibility for RPCS option
- Patient voluntarily opts for the RPCS option
- No current TB and No medical condition requiring regular clinical consultations
- Mothers or responsible caregivers with a child on ART should not be enrolled to the RPCS option especially if the child medication pick up point is different.

2. Guiding principles

- When patients are registering with the CCMDD programme, they must present their valid ID or passport, asylum permit
- Patients can choose a facility or external based PuP
- All patients should complete and sign the registration and consent forms to enrol on the CCMDD programme at the facility
- Patient with side effects or not feeling well can at any time go to the facility for assessment even if they still have repeat prescriptions on the CCMDD database
- Patients that do not pick up their medicine at the selected PuP shall be traced by the facilities within 2-14 days.
- Patient prescription should be cancelled on system if patient is no longer stable, needs active management or requires regimen change.
- All processes must be documented.

3. Procedure

If patient complies with criteria for RPCS, patient shall be informed about CCMDD option as follows:

- Stable patients have to come for clinical assessments every 6 months.
- A 6-month repeat prescription is written up for stable patient during the clinical assessment visit.
- If patients choose CCMDD option they shall be requested to complete the registration and consent form and choose a PuP. A patient can also nominate a person to collect the medicine on their behalf by entering the information on the registration form
- A doctor or nurse assessing the patient shall generate a repeat prescription for 6 months.
- A patient collection card with relevant scheduled collection and return dates to the facility shall be issued to patient.
- The patient shall receive their first supply of prescription from the facility and shall be counselled.
- Remaining repeat prescriptions shall be collected from PuP.
- Should a patient not receive a SMS regarding collection of repeat medicine parcel, the patient should still collect their repeat medicine parcel at the PuP on scheduled collection dates.
- The CCMDD service provider shall inform the patient when their medicine parcel has been delivered to the pick-up point for collection.

All CCMDD patients must be entered into the TIER.Net system as per the SOP at facility level.

All CCMDD patients must be entered into adherence club registers if enrolled in a club.

At the external or facility based PuP chosen by patient, the person issuing the medicine parcel to the patient shall:

- Check the identity document or passport or other unique identifier such as facility number as approved by PDoH.
- A nominated person collecting on behalf of the patient must produce their ID or passport or asylum permit.
- Ask the patient or nominated person to sign the delivery manifest.
- Enquire whether patient is doing well on current treatment and request patient to return to their originating facility if they are not feeling well or perceived unstable.
- Advise patient to log a call with service provider call centre should patient have any questions regarding received medication.
- Advise patient on collection of last repeat medicine parcel to return to facility for assessment and new script.

4. Tracing and Retention in Care for patients on the CCMDD option

- The PuP shall notify CCMDD service provider of all patients who did not collect their medicines within 2 days after the scheduled pick-up date

- Patients who failed to collect repeat medicines after 2 days of collection date, will be contacted by the CCMDD service provider via sms or telephone to remind them to pick up their repeat medicine parcels
- CCMDD service provider shall also notify health facilities of patients who failed to collect prescriptions from external PuPs on scheduled collection date.
- Facilities should activate tracing processes for patients who fail to collect their treatment within 5-14 days.
- PuP shall issue medicine parcels to patients who present within 14 days of their scheduled date of collection
- Patients can be de-activated from the CCMDD programme by facilities if untraceable after 30 days and can continue with CCMDD programme at a later stage if stable and meet RPCS criteria.
- Patient shall be registered out of the system in case of death or if the patient is a persistent defaulter on the programme or relocation to other area where CCMDD is not implemented.
- For further details on tracing refer to Tracing and Retention in Care SOP.

APPENDIX 6: TRACING AND RETENTION IN CARE

1. Criteria for Tracing and Retention in Care

- **Facility:** Patients who have failed to return to facility for scheduled appointments at the facility are identified through facility data base or appointment register as follows:
  - TB patients who have missed scheduled appointment within 3 days.
  - Pre-treatment patient who have missed active referral to linkage to care services (including wellness clinic) for more than 5 days of set appointment date.
- HIV, Diabetes and Hypertension:
  - Early missed appointment refer to patients who did not come back to the facility within 5-14 days from their missed appointment date.
  - Late missed appointment refer to patient who did not come back to the facility within 30 days from their missed appointment date.
  - Loss to follow-up refer to patients who did not come back to the facility within 90 days from their missed appointment date.
- **CCMDD programme:** Patients who have failed to attend CCMDD pick up point within 2 days following the set appointment date.
- **Adherence Club:** Club members who have failed to attend the facility for clinical monitoring, lab tests or medication collection within 5 days following the set Adherence Club appointment date.
  - Adherence club member who sends a buddy on the lab day or clinical consultation day and do not present to Clubs manager within 5 working days.
  - If a Club member sends a buddy twice in a row to collect medication.
- Each time a stable patient visits the facility, the patient should be allowed to collect at least 2 months treatment.
- Patients should be allowed to go through a fast lane system, meaning direct and quick access to the pharmacy.
- In case of health problems or pregnancy, patients must be advised to return to regular care.

2. Guiding principles

- Patients are traced throughout the care cascade at different times depending on the adherence minimum package intervention.
- Patients are traced through contact by phones, sms, home visits depending on what tracing method they have consented for.
- The following activities should be integrated into adherence strategies in all facilities to trace and retain patients in care throughout the care cascade:

- Informing patients about Tracing and Retention in care system.
- Asking patient's consent to be traced.
- Making an active referral for a specific time and date. An active referral is one in which the official referring patient makes an appointment for the patient or accompanies the patient to an appointment, including an appointment for co-located services, and enrolment into linkage into care services.
- Scheduling a follow up visit, including confirming time and date to ensure that the patient is available.
- Providing the list of name of patients and the date they are supposed to come for appointment to the referral service at the facility.
- Identifying patients who miss their appointments.
- Tracing of patients who have missed appointments.
- Reintegrating patients into care.
- Providing additional psychosocial support and active referral to integrated care services for patients who return to facility after tracing.

All tracing and retention in care processes must be documented.

3. Requirements for a successful Tracing and Retention in Care

A. Patient registration at enrolment and follow-up appointments

- The facility staff, data capturer or counsellors should enrol all patients into specific appointment registers during the patient's first visit to the facility.
- If patients test HIV positive, counsellors testing patients should enrol patients into HCT appointment register:
  - Counsellors or official referring patient to wellness clinic should actively refer patients by contacting the referral site and provide the list of patients who are supposed to link to care to ensure they are linked to the facility.
  - Patient should be actively referred from Pre-ART to wellness clinic to ensure the patient knows where the facility is and what date and time the appointment is.
- If patient comes for follow-up visit: Check facility appointment register to confirm that patient is expected on that day:
  - If patient comes **on the day**, they were expected, congratulate patient for coming. Find date in appointment register and document that they came on time, then proceed with item 4 as below.
  - If patient comes **earlier** than expected, congratulate patient for coming. Determine why patient came earlier than expected. Find date in appointment register on which they were expected and indicate that patient came early, then proceed with 4.
- If patient comes **later** than expected, congratulate patient for coming. Find date in appointment register on which they are expected and indicate that they came late. Determine why patient

came later than expected and explore solutions with the patient to minimise recurrence then proceed with 4.

- Updating of patient's contact details:
  - Update patient's and treatment supporter's contacts at every visit in the patient's file and relevant registers as follows:
    - Full name of the patient and the name of his or her treatment supporter or buddy
    - Telephone number of the patient: call the patient at this point to ensure that the number is functional.
    - Alternative phone number such as the number of a relative or a treatment supporter: Call the relative or treatment supporter at this point to ensure that the number is functional.
    - Detailed address: house number and street name should be obtained where possible. Alternatively, detailed descriptions with well-known landmarks should be obtained for patients who do not have street address or those living in rural areas.
    - For school going children, ensure that the patient details include the name of the school the child is attending. (**Refer clinical Paeds Stationary**)
  - All healthcare workers or lay counsellors consulting with patients should ask for the address and contact number of the patient and reassess at each consultation if there are any changes regarding these.
- Provide patient and treatment supporter with the facility's contact number to be used should they have need to contact the facility for information or assistance.

B. Introducing patient to Tracing and retention in Care system

- The patient's consent should be sought by all HCWs or counsellors attending to the patient to allow tracing and agree on the best way to trace them such as through home visits, by phone or SMS if necessary:
  - If patient agrees to be traced through home visits, a patient should be informed that someone, other than a facility staff will come to visit them if they disengage from care.
  - The person conducting home visits may be from a WBOTs, HBC or adherence club or CBO.
  - Caregivers should be made aware that contact with the child's school are made in order to effectively trace the child. Caregivers should also be informed that this process is supported by School health teams.

C. Scheduling appointment for the next visit

If the patient is not yet enrolled into care, agree with him/her on the most appropriate facility and date to link into care. The appointment information related to patients not yet in care should be shared with the receiving facility identified with the patient.

For the patients already enrolled into care, after counselling the patient and dispensing the medication, the dispensing health worker or lay counsellor must schedule the patient for their

next appointment in agreement with the patient and fill out the next appointment date on the patient file, patient appointment card and on the corresponding relevant facility register.

It is recommended that caregivers on ART who also have children on ART should have their facility clinic visits scheduled on the same day and in the same service as their children.

The purpose of providing an appointment date to patients is to ensure that:

- Patients agree on the appointment date and are available or provide alternative return date.
- Patients not yet linked to care are supported to identify a convenient place to link to care.
- Patients in care know when they have to come back to the facility.

D. Documenting patient's appointment in facility appointment register

The healthcare worker or lay counsellor or designated official will fill out the patient's name and ID or passport or asylum permit and enter the date reported for appointment on the correct appointment date page of the facility appointment register.

E. Keeping facility appointment register up to date

- The data capturer or designated official will ensure that the facility appointment register is up to date by liaising with the health care worker or lay counsellor in completing the 'over by one 5 days' column on the page of the facility appointment register corresponding to the facility day 5 days earlier.
- The data capturer or designated official will also liaise with the club facilitator and CCMDD service provider to capture patients who did not attend the club or CCMDD service point.

4. Procedure

A. Identification of patients to be traced

Specifically, patients to be traced are identified as follows:

- **Facility:** The designated official such as a health care worker, lay counsellors, WBOT team leader, HCT mentor or other designated official reviews the facility register during the week to check patients who did not attend their appointment on the set appointment date.
- If a patient has not attended the facility within 5 working days to follow-up on pre-treatment scheduled appointment, collection of medications, clinical review or labs, the patient is classified as a defaulter and registered as such in the facility register to be traced.
- **CCMDD:** Pick-up-point notifies the CCMDD service provider if patients fail to collect the package 2 days after the scheduled pick-up date, which will trigger a patient tracing process.
- **Adherence Club:** At the end of each Club session the Club Facilitator checks register for names of those who:

- did not either attend personally or send a buddy to collect medication, or
- have sent a buddy on a lab day, or on a clinical consultation day, or
- have sent a buddy twice in succession.

If club members identified in the club register as above, do not arrive within 5 working days, the club facilitator includes the patient in the tracing list and informs the club manager.

- If patients present
  - within 5 working days from the Club appointment date,
  - at a facility within 14 working days since the appointment date,
  - at CCMDD pick-up point within 5 working days since pick up day.

Depending on where the patient presents as above, clubs manager, health care worker, pharmacist or official dispensing medication respectively, the respect official will review the case to enquire:

- the reason for missing the CLUB/ facility/CCMDD PuP appointment
- if patient is doing well on current treatment,
- if there are any medication side effects, or
- if there are any adherence barriers, and
- where appropriate refer patient for addressing issues identified before issuing medications or refer to facility as appropriate.

This is registered in the facility register, Club register or CCMDD register as a visit and patients should still be considered as being registered in the specific programme.

If patient in the RPCS option was scheduled for a lab, clinical or scripting visit the health care worker or clubs manager will ensure that appropriate action is taken for the specific visit and refer patient back to RPCS option such as spaced and fast lane, adherence club or CCMDD.

B. Generating defaulters' list

The facility manager should ensure that there is a functional appointment system in place whereby all folders for patients who are coming the following day are pulled out the day before. Folders of patients who did not attend should be kept aside for further action. A list of all patients who missed their appointments at facility, CCMDD service point, or adherence club should be generated every week and the list should be handed over to the facility manager for sign off.

- **Paper based sites:** Every Friday, the designated official or data capturer will refer to the facility appointment register page corresponding to the facility visits to generate a defaulter list.
- **Electronic based sites:** Data capturer or admin clerk can also generate defaulters list through facility database e.g.Tier.Net. (Refer to the Tier.net SOP).

- The data capturer will include list of patients from the clubs or CCMDD service into the list, if not yet captured on database.
- The data capturer will also use TB files and PHC files to compile defaulter list.

C. Initiating tracing

The list of patients who missed their appointments referred to as defaulters list is signed off by the facility manager and transferred to the person responsible for tracing patient such as WBOT lead, CHW or HBC linked to the facility as appropriate.

- If available, a tracing and retention in care meeting is conducted to present the defaulter's list.
- The meeting is attended by data capturer, relevant facility personnel, WBOT lead, HBCarers, tracers team such as in TB and or referral committee where available.
- Minutes of these meetings should be kept for management purposes.
- Patients are traced as soon as the defaulter list is signed off by facility manager.
- The facility manager or delegated official will delegate an individual to contact patients by phone.

D. Tracing of patients by phone or SMS

- The delegated nominee will then extract the contact information most particularly addresses and telephone numbers of the defaulter and their treatment supporter/buddy (in case they have one)from the patient's file or club register.
- The defaulter and treatment supporter/buddy contact information is transferred into the facility tracing register adapted to facility clinical stationary.
- The facility telephone is used to contact patients.
- The delegated official will make telephone calls to all defaulters added to the facility tracing register that week.
- For each tracing effort, the facility tracing register should be marked, indicating the date the tracing was done and the tracing outcome, whether successful or unsuccessful and when the patient will return to the facility.
- First attempt is when the patient is first contacted. The names of patients whose telephone numbers cannot be reached after 3 attempts within 14 days since scheduled appointment date should be transferred to the list of those to be traced through outreach and home visit. Patient consent for home visits should be verified in patient's file.

E. Tracing of patients through outreach in communities and homes

- After 3 unsuccessful attempts to contact patients by phone or sms, WBOT, CHWs, HBCarers linked to facilities are involved to trace patients when they cannot be reached by phone or do not come back to the facility within 2 weeks.
- Patients who have telephone numbers, but the numbers could not be reached should also be included in the list of defaulters to be traced by the WBOT, CHW or HBCarers, if available in the facility.

- If a home visit is conducted, details from the home visits, including outcomes of the visit should be reported back to the Facility Manager.
- For each outreach tracing effort, the facility tracing register should be marked, indicating the date the tracing was done and the tracing outcome, whether successful or unsuccessful and when the patient will return to the facility.
- The following outreach services can be used to trace patients in the communities and homes:
  - **Contact tracing through WBOTs and CHWs:** The consent form should be reviewed to ensure patient consented for home visit through WBOTs and CHWs if patient disengages from care.
  - **Contact tracing through HBCarers:** Where facilities are linked to Home Based Care or Community based organisations, HBCarers will be engaged to trace patients.
  - **Contact tracing through adherence club facilitator:** Patients who miss appointments in adherence clubs, are traced by the club facilitator though telephone, sms or home visits as appropriate. (Refer RPCS Adherence Club SOP).
  - **Contact tracing through TB tracing teams:** If available, TB tracing teams can also be engaged to trace TB patients in the communities.
  - **Contact tracing of children through School health teams:** In order to effectively trace the children, children who miss scheduled appointments are traced through the support of School health teams. WBOTs or CHWs may collaborate with the school health workers to trace children during school health visits.

F. Tracing for patients not seen for 3 months and with no status updated on treatment register

- Registered treatment patients who have not reported to the treatment service point or treatment delivery service point for 90 days since their last visit and not known whether the patient has died, was transferred out or stopped treatment for documented medical or social reasons after 90 days of intensive contact tracing should be registered as: Loss to follow-up. (Ref SOP for capturing data on Tier.net).
- Before this entry is made, one more attempt at phoning and or visiting patient should be made by the WBOTs, CHWs, HBCarers and outreach services.

G. Re-integrating patients into care

- For each successful contact tracing attempt, where the patient agrees to continue treatment, the WBOT, CHW, HBC will inform the patient to report back to the facility. On return to the facility, the patient will be referred immediately to the counsellor for additional support, exploring solutions to patient adherence barriers and actively referred to appropriate support services, as required.

- For patients who return after tracing, the healthcare worker or lay counsellor or data capturer will enter the day the patient returns in the facility tracing register stating the date for missed refill or appointment and mark R to indicate 'return' in the date of return column.
- A patient who agrees to return to care, should be supported through other additional psychosocial support and adherence interventions supporting peer support and education such as Wellness clinic, I ACT, support groups, youth clubs, buddy systems, mhealth, child disclosure and ANC.
- All patients' clinical management should follow integrated care of patients with chronic conditions including prevention and screening, mental health screening, treatment of opportunistic infections, lifestyle modification, nutrition counselling and intensified psychosocial counselling and active referral to supportive services as appropriate.

H. Reports to inform district and provincial teams

Some of the reports to be generated at facility level to inform province and district management on Tracing and retention in care programme implementation could include:

- Reports tracking defaulters:
  - Report on patient supposed to link into care (appointment book/list)
  - Early Missed Appointment List
  - Late Missed Appointment List
  - Report on tracing activities (number of patient traced and outcomes).

APPENDIX 7: CHILD DISCLOSURE MODEL (FOR HIV)

Caregivers and all children from 3 years old should be sent to start progressive disclosure. Use flip file, images or drawings to help children understand the explanations.

Session 1: Partial disclosure

Content to be covered with the caregiver after introduction/presentation:

1. Ask what the caregivers have told the children so far about the reason for coming to the clinic and/or taking treatment.

2. Explain partial disclosure:

The disclosure process is like a journey with many stops. At each stop, we will explain a little more to the child. At the end of the journey, when it is the right time for the child, the child will understand HIV and the treatment s/he is taking.

From 3 years old, partial disclosure is recommended for the child to learn about health, immunity, having a special germ and treatment. HIV will not be named at this stage.

Later, when the child is ready, HIV status will be disclosed to the child (full disclosure).

3. Explain the advantages of disclosure:

Usually, children who know their status take their treatment better because they understand why they have to go to the clinic and take treatment.

Children often know that something is wrong. They may have fears that are worse than the real thing. Hearing about HIV from you rather than anyone else will help the child to accept the situation.

4. Explain the timing for disclosure:

Talking with your child about HIV isn't going to happen on just one occasion. You can take opportunities to tell them part of the story, for example when they have to go to the clinic or have blood tests. The counsellor can help you with that.

It is good to follow the lead of the child. When children ask questions, find ways to respond with adapted explanations for their age (without lying). It is recommended to do it progressively from 3 years old and to tell them about their HIV status when they are ready. All children should know their status by 10 years old latest.

5. Assess barriers to disclosure:

- *How do you feel about giving information to the child on their condition today (without naming HIV)?*
- *What are your fears about disclosing the child's status one day?*

6. Reassure about the benefits of disclosure and suggest that they give explanations to the child about their health without naming HIV.

Content to be facilitated with the child and the caregiver:

1. The visit to the clinic or facility

Ask the child:

- *What do you do when you come to the facility?*

Help the child to talk about clinical check-ups, fetching treatment, having blood test done, etc.

2. The body and the blood system

Explain that we all have blood that travels all around inside the body. It circulates through little tubes called the veins. (Draw the outline of a body and veins inside).

3. Soldiers inside the blood – the immune system

Explain that inside the blood we all have small soldiers that protect us from becoming sick.

(Draw little soldiers in the blood all around the body). The soldiers fight against diseases that try to enter the body. Usually soldiers are strong enough to fight diseases. (Image 1: different type of germs and image 2: soldiers inside the body)

4. A sleeping germ

Sometimes a different type of germ enters the body. It is stronger and acts differently: the sleeping germ. (Image 3: sleeping germ)

5. When the sleeping germ multiplies, the soldiers will not be enough to fight disease anymore.

The sleeping germs make more and more sleeping germs inside the body. The child will get sick and will not feel like playing anymore. If this goes on, the body will become very weak and more diseases will come in. (Image 3: sleeping germ)

6. Treatment to fight the special germ

There is very good news. There is a medicine that contains special warriors. When the child takes this medicine, the warriors enter the child's blood and follow the sleeping germs. These warriors are very, very strong and they fight the special germ and keep it asleep.

When the warriors fight and beat the sleeping germ, it makes the soldiers in the blood happy. They can then multiply and protect our body against other germs that cause diseases. (Image 4: Treatment to fight the sleeping germ).

7. The importance of taking treatment every day to keep the sleeping germs asleep

To make sure that the sleeping germs stay asleep and keeps us well, the child must take their medicines called "Goodnight medicine" every day around the same time. They are called "good night medicine because they keep the 'sleeping' germ asleep... It is very important to take the medication every day to prevent the sleeping germs from waking up again because they could beat the body soldiers and make the child sick.

Remind the child that in case they forget to take medication, they should take it as soon as they remember.

8. Explain to the child that they have the sleeping germ and reassure them that they don't need to be afraid because the pills are very good at keeping the sleeping germ asleep.

Session 2: Full disclosure

By the age of 10, all children living with HIV should be fully disclosed.

Content to be facilitated with the caregiver after introduction/ presentation:

1. Introduction and assessment if disclosure has been done:

- *How is the child doing since the last session?*
- *Did the child asked questions?*
- *Did you disclose the child's HIV status to her/him?*

Explain that, if the caregiver has not disclosed and is willing to do so, we can help her/him talk about HIV status to the child today.

If the caregivers express reluctance to disclose, let them express their fears. Support them in finding solutions and remind them about the advantages of disclosure.

2. Propose specific help to the parents for disclosure:

- Propose role plays to practice disclosure and how to answer difficult questions.

- Prepare the caregiver for the emotional response of the child (crying, shouting, etc). It is important that they accept the reaction, whatever it is. It is normal for the child to be sad or angry.
- Recommend that the caregiver be supportive to the child and respect their emotions.
- Speak with the parents about the distinction between telling all and telling what is necessary for the child's understanding.

3. Discuss about the secrecy

- Ask with whom the child could speak about HIV
- Explain that disclosure inside the family can increase support for the child. It is important that the child feel supported in taking treatment. It is up to the caregiver and the child to decide whom it is good to tell.

4. Assess barriers to disclosure:

- *What are your fears about disclosing the status to the child?*

5. Reassure about the benefits of disclosure and propose to support the caregivers in disclosing the status to the child.

Content to be facilitated with the child and the caregiver:

1. Assess what the child remembers from the previous session.

Ask the child:

- *How can the body fight against diseases? [soldiers inside the body: Image 2]*
- *What does the special germ do to the soldiers of the body? [It makes them weak: Image 3]*
- *What can we do the fight the sleeping germ? [take medicine: Image 4]*
- *Can the medication kill the special germ? [no, it makes them sleep: Image 4]*

Complete the child's answers explaining the importance of taking treatment every day to keep the sleeping germ asleep and to make the body soldiers stronger.

2. If the caregiver is ready for it, support disclosure:

Ask to the child:

- *Do you know the name of the sleeping germ that you have in your body?*

Propose the caregiver to tell the child. If it is difficult, support and tell the child that the sleeping germ is called HIV.

Ask:

- *What do you know about HIV? (Correct misconceptions and reassure)*

NB: It is important that the disclosure be done by the caregiver, the role of the health-care worker or counsellor is to support this process. If the caregiver really cannot do it, then the counsellor can help to do it in the presence of a caregiver.

A child 10 years and older should at least be fully disclosed to at that age through disclosure stepwise process. Let the child talk and ask questions and give the child time to absorb the new information.

3. Assess feelings and support:

Some children may feel sad or angry; others will be in shock when they hear they have HIV.

- *How do you feel about that news?*

It is normal to experience such feelings and you can express whatever you feel.

4. Ways of transmission:

HIV can be transmitted when a mother who has HIV is pregnant and transmits the virus to her baby (during pregnancy, giving birth or during breastfeeding). HIV can also be transmitted when people have sex without using a condom or by sharing sharp materials that were in contact with HIV infected blood.

- *Do you understand how HIV can be transmitted?*
- *Do you know how you got HIV?*

There was not a lot of help for people who had HIV when your mom was pregnant. She certainly could not get the information and/or medication needed to prevent the virus from passing on to you. It was not her fault.

Some people have wrong ideas about the way the HIV is transmitted. It cannot be transmitted by playing, hugging, sharing forks, glasses or a bath with someone who has HIV.

5. Who to tell:

Ask the child and the caregiver if there is anyone else that they can share their experiences with who will support them (close family member, teacher, the nurse, etc).

Do the Hand of Safety activity with the child if they have not yet done one. (Refer to Disclosure talk tool kit).

6. Encourage adherence to keep HIV asleep in the body.

Image 1
Different types of germs

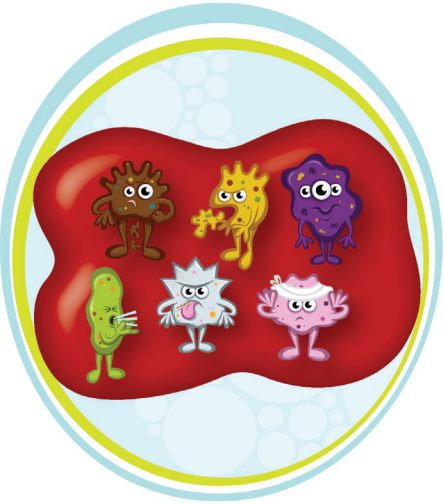


Image 2
Soldiers inside the blood
The immune system

Image 3
The sleeping germ

Image 4
Treatment to fight
the sleeping germ

APPENDIX 8: MENTAL HEALTH ASSESSMENT

As mental health disorders can impact adherence negatively, it is recommended that screening is provided for mental health disorders while treating HIV, TB and NCDs.

Basic screening should assess:

1) What is the patient's appearance?

- Is he/she clean and looking after him/herself
- Does the person look worried or sad?
- Does the person seem agitated?
- Does he/she seem suspicious, nervous or hostile?

2) Assess the patient's mood, asking:

- How have you been feeling over the last week?
- Have you been feeling mostly normal, or sad or happy, or worried?
- How do you feel today?
- What are your feelings about the future?

3) Assess the patient's thoughts:

- Are you having negative thoughts?
- Are you having strange thoughts?
- Any unusual fears (e.g. being followed, spied on)?
- Have you had any strange experiences (e.g. hearing voices/seeing visions other people cannot hear or see) or special abilities?

Negative thoughts can suggest depression, other strange thoughts or experiences could raise suspicion of psychosis.

4) Assess patient's cognition:

- Does thinking seem slow?
- Is the person able to concentrate?
- Does the memory seem impaired?

If you suspect a mental health disorder while asking the previous questions, try to answer the following questions:

- What is the main problem?

- How long has it been present?
- Does it affect the patient's daily functioning?
- Can this be managed at this clinic?

If further assessment and treatment cannot be provided at the clinic, refer to a psychiatric nurse or service. Tools such as SRQ 20 recommended by the WHO can help to identify mental health disorder.

Provide the patient with education on mental health and provide them with advice that can help them overcome symptoms.

Explain to the patient that the following signs could mean that they may need support to improve their mental health condition:

If they feel:
- Constantly angry or very worried.
- Very sad for a very long time.
- They are losing interest in things they use to enjoy doing.
- They can not cope with work or daily activities.
- Their mind is controlled (e.g. by voices) or out of control.
- They need to use alcohol or drugs.
- Obsessively do things such as repeat washing hands, non-stop sport activity, eating too much, obsessive diet or other obsessive behaviours.
- Hurt themselves or other people or destroy things.
- Do irresponsible things that could harm them or others.
- Having problems sleeping or feeling tired and not having energy.
- Feeling anxious, looking or feeling 'jumpy' or upset, having panic attacks.
- Not wanting to spend time with people; spending too much time in bed.
- Hearing and seeing things that others do not see.
- Other differences in the way the person sees what is happening around them, for example believing that someone is trying to harm you, or laughing at you.

If the patients show signs of intense sadness, risk to harm themselves or others or hear or see things that other do not see they should directly be referred for psychiatric support.

If the patients experience some of the other symptoms, explain to them that they can identify some ways to help them cope with their situation by telling them that it might help to:
- Share your feelings and spend time with other people you trust.
- Get back to daily routine as much as possible (e.g., work, school, housework).

- Participate in religious or spiritual activities.
- Play sports or get regular exercise.
- Eat regular meals.
- Get adequate rest.
- Take a break and relax.
- Participate in enjoyable activities (singing, dancing, reading), even if at the moment it may be hard for you to enjoy them.
- Help other people talk about how they feel, but also respect if they choose not to talk about it.

Recommend that they avoid:

- Using alcohol or drugs to cope with the symptoms.
- Withdrawing from family and friends.
- Withdrawing from daily activities.
- Overworking.
- Blaming yourself or others.
- Neglecting your health/self-care (e.g., sleep, hygiene, diet).

You may need to seek help from a psychiatric nurse or a counsellor if you want to talk with someone outside of your family or circle of friends or if your symptoms do not improve with the coping strategies.

APPENDIX 9: I ACT MODEL

What is Integrated Access to Care and Treatment (I ACT)?

I ACT support groups are established in coordination with local health facilities and community organisations (NGOs). The programme offers a participatory, strongly focused, curriculum-based small group intervention that can be implemented in both the health facility and community environment. The programme is designed to follow well-defined steps in preparation for self-care and advocacy and to encourage retention in care and treatment programmes:

- Understand your illness
- Know what care and treatment is available
- Accept that you have a chronic illness
- Discuss your chronic illness with others
- Learn healthy living principles for the chronic illness
- Stay healthy through on-going testing and retention in care
- Plan for the future and educate others

The I ACT programme is administered through 6 group sessions (at least two hours per session) over a finite period of time. Trained and experienced I ACT support group facilitators, typically PLHIV themselves, conduct these sessions in either an open or closed format giving participants a choice to decide their level of involvement and commitment.

Educational sessions are offered to the public to provide information and build interest in the I ACT groups. Educational sessions are frequently held in locations where people might need help, including the waiting rooms of local clinics, churches, taxi and bus ranks, and community centres. Educational sessions are usually less than thirty minutes and designed to convey I ACT's key learning topics.

Closed Support Groups are exclusive to PLHIV, the majority of whom are still healthy and not taking ARVs yet. "Closed" means that after the first session no new participants are allowed to join. The closed support group is established around mutual trust, disclosure, sharing and a strong sense of confidentiality. Closed support group participants commit to attend all six sessions, not only to cover the complete programme content, but also to foster a personal support network for each individual within the group.

Open Support Groups cover the same six content areas but serve both PLHIV and others who are impacted by HIV. "Open" groups allow people to drop in for the sessions they are most interested in; there is no obligation to attend all sessions. This format helps participants address gaps in knowledge and learn about specific areas within the I ACT curriculum. Open groups do not require disclosure.

Open and closed I ACT support groups, and educational sessions, are implemented in a health facility and community settings. Groups may convene in a school hall, community centre, church, places where participants gather, occasionally, even in a facilitator's or a participant's house. The underlying principle is to take the care and support to where people are. This increases participation, comfort, and trust.

Up to fifteen participants attend I ACT support group meetings (thus far, closed groups have had an average of eight participants). The small group size supports the intention for all group members to participate, interact, and have their questions answered. Small group size also creates opportunities for participants to develop a local network for peer support.

The 6 support group session content includes:

- HIV/AIDS and opportunistic infections (OIs) including tuberculosis (TB)
- Treatment Literacy and Adherence
- Acceptance of Status
- Disclosure
- Nutrition and Healthy Living Principles
- Planning for the future and Prevention with Positives

All I ACT offerings are designed to engage participants using adult learning techniques. All meetings are very interactive; participants actively participate in the learning process. In addition to sharing of information and personal experiences, I ACT also provides participants with referrals for on-going care, treatment and support services and helps to promote a timely initiation of antiretroviral therapy (ART) when required.

I ACT Support Group Facilitators

The support group facilitator training is split into two distinct parts: a five-day content training and a five-day skills training.

Content Training provides facilitators with information, supporting articles, group activities, and other resources to empower them to speak accurately, confidently, and consistently on all I ACT topics.

Skills Training allows facilitators to acquire the knowledge and skills to facilitate, organise, and maintain effective and sustainable I ACT groups. The skills training emphasises the role of the facilitator and includes interactive sessions on setting boundaries, seeking self-care, managing challenging behaviours, and understanding key clinical issues facing PLHIV including stigma, disclosure and acceptance of status.

Throughout the Content and Skills training, facilitators learn to exercise respect for the qualities that make participants diverse including race, ethnicity, gender, sexual orientation, age, physical ability, education, literacy level, spoken language and economic status.

An additional five-day TOT Training provides TOTs with a deeper understanding of I ACT topics and facilitation skills. Participants are experienced support group facilitators who are selected to take on more responsibility to train their peers.

How does I ACT fit into the NDOH plan for comprehensive HIV management?

I ACT support groups serve mainly as a psychosocial support activity for PLHIV, their families and their support structures in the community. In addition, targeting newly diagnosed HIV infected individuals; the programme plays a pivotal role in promoting pre-ART and Wellness Programmes and linkage and retention in care. HIV infected clients not yet eligible for ART are educated on the importance of nutrition and adherence to a healthy and safe lifestyle; all clients are educated on the importance of loyalty towards their clinic visits and re-testing dates.

I ACT support group facilitators also seek to follow up on clients on Anti-Retroviral Therapy (ART) by:

- Linking clients on ART identified in the community to the local clinic and other support mechanisms (e.g. Adherence Clubs)
- Providing extensive treatment literacy education
- Promoting treatment adherence and support through health awareness
- Promoting access to care for patients experiencing adverse drug reactions (ADRs).

In Conclusion

I ACT serves as the entry point for newly diagnosed HIV infected individuals into care and support. The programme:

- Increases knowledge and skills about HIV/AIDS, STIs, and OIs including TB
- Inspires PLHIV to accept their status and live positively
- Helps PLHIV to deal with stigma
- Empowers PLHIV to become advocates for their health
- Ensures linkage and retention in HIV care and support
- Strengthens referral systems and linkages in local communities
- Encourages local access to and responsibility for improved HIV care and support.

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