The "Treatment and Care for HIV-Positive Injecting Drug Users" training curriculum is designed for clinicians who provide treatment and care, including ART, for HIV-positive injecting drug users. The training curriculum consists of a trainer manual, 12 participant manuals, and a CD-ROM with PowerPoint presentations and reference articles. Topics covered in the curriculum include:

Module 1: Drug use and HIV in Asia
Module 2: Comprehensive services for injecting drug users
Module 3: Initial patient assessment
Module 4: Managing opioid dependence
Module 5: Managing non-opioid drug dependence
Module 6: Managing ART in injecting drug users
Module 7: Adherence counselling for injecting drug users
Module 8: Drug interactions
Module 9: Management of coinfections in HIV-positive injecting drug users
Module 10: Managing pain in HIV-infected injecting drug users
Module 11: Psychiatric illness, psychosocial care and sexual health
Module 12: Continuing medical education

Trainer manual

Module 7
Adherence Counselling for Injecting Drug Users

Treatment and Care for HIV-Positive Injecting Drug Users
Module 7

Adherence counselling for injecting drug users

Participant Manual

2007
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For inquiries, contact The Public Affairs Office, The ASEAN Secretariat, 70A Jalan Sisingamangaraja, Jakarta 12110, Indonesia, Phone: (62 21) 724-3372, 726-2991, Fax: (62 21) 739-8234, 724-3504, E-mail: public@aseansec.org. General information on ASEAN appears on-line at the ASEAN Website: www.aseansec.org.

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and
Family Health International, Asia/Pacific Regional Office, 19th Floor, Tower 3, Sindhorn Building, 130–132 Wireless Road, Lumpini, Phatumwan, Bangkok 10330, Thailand, e-mail: sunee@fhibkk.org
and
HIV Unit, Department of Communicable Diseases, World Health Organization, Regional Office for South-East Asia, Indraprastha Estate, Mahatma Gandhi Marg, New Delhi-110 002, India, e-mail: hiv@searo.who.int

Module 1: Drug use and HIV in Asia: participant manual
Module 2: Comprehensive services for injecting drug users – participant manual
Module 3: Initial patient assessment – participant manual
Module 4: Managing opioid dependence – participant manual
Module 5: Managing non-opioid drug dependence – participant manual
Module 6: Managing ART in injecting drug users – participant manual
Module 8: Drug interactions – participant manual
Module 9: Management of coinfections in HIV-positive injecting drug users – participant manual
Module 10: Managing pain in HIV-infected injecting drug users – participant manual
Module 11: Psychiatric illness, psychosocial care and sexual health – participant manual
Module 12: Continuing medical education – participant manual
Trainer manual: Treatment and care for HIV-positive injecting drug users

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### Abbreviations and acronyms

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<tr>
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<tbody>
<tr>
<td>3TC</td>
<td>lamivudine</td>
</tr>
<tr>
<td>AA</td>
<td>Alcoholics Anonymous</td>
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<tr>
<td>ADR</td>
<td>acquired drug resistance</td>
</tr>
<tr>
<td>AIDS</td>
<td>acquired immunodeficiency syndrome</td>
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<tr>
<td>ART</td>
<td>antiretroviral therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>antiretroviral</td>
</tr>
<tr>
<td>ASEAN</td>
<td>Association of Southeast Asian Nations</td>
</tr>
<tr>
<td>AZT</td>
<td>zidovudine (also ZDV)</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention (US Government)</td>
</tr>
<tr>
<td>CHW</td>
<td>community health worker</td>
</tr>
<tr>
<td>CNS</td>
<td>central nervous system</td>
</tr>
<tr>
<td>d4T</td>
<td>stavudine</td>
</tr>
<tr>
<td>DAART</td>
<td>directly administered antiretroviral therapy</td>
</tr>
<tr>
<td>ddl</td>
<td>didanosine</td>
</tr>
<tr>
<td>DOTS</td>
<td>directly observed treatment, short course</td>
</tr>
<tr>
<td>EFV</td>
<td>efavirenz</td>
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<tr>
<td>FBO</td>
<td>faith-based organization</td>
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<tr>
<td>FDC</td>
<td>fixed-dose combination</td>
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<tr>
<td>FHI</td>
<td>Family Health International</td>
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<tr>
<td>FP</td>
<td>family planning</td>
</tr>
<tr>
<td>HBV</td>
<td>hepatitis B virus</td>
</tr>
<tr>
<td>HCV</td>
<td>hepatitis C virus</td>
</tr>
<tr>
<td>HIV</td>
<td>human immunodeficiency virus</td>
</tr>
<tr>
<td>IDUs</td>
<td>injecting drug users</td>
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<tr>
<td>IUD</td>
<td>intrauterine device</td>
</tr>
<tr>
<td>NA</td>
<td>Narcotics Anonymous</td>
</tr>
<tr>
<td>NGO</td>
<td>nongovernmental organization</td>
</tr>
<tr>
<td>OI</td>
<td>opportunistic infection</td>
</tr>
<tr>
<td>OST</td>
<td>opioid substitution therapy</td>
</tr>
<tr>
<td>PLWHA</td>
<td>people living with HIV and AIDS</td>
</tr>
<tr>
<td>PMTCT</td>
<td>prevention of mother-to-child transmission</td>
</tr>
<tr>
<td>TB</td>
<td>tuberculosis</td>
</tr>
<tr>
<td>TDR</td>
<td>transmitted drug resistance</td>
</tr>
<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
</tr>
<tr>
<td>VL</td>
<td>viral load</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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OVERVIEW

Objectives:
By the end of the session participants will be able to:

- To define treatment adherence
- To discuss the challenges to ensuring adherence among IDUs
- To describe different adherence implementation strategies that can be used with IDUs
- To conduct a client interview to explore the barriers experienced by an individual in maintaining treatment adherence
- To calculate and report on a client’s adherence to medication

Time to complete session:
Part 1 – 1 hour 15 minutes
Part 2 – 1 hour 45 minutes

Session content:
- Overview
- Establishing an adherence programme
- Community–clinic–provider collaborations
- Key elements of patient preparation
- Treatment and adherence programme
- Assessing and facilitating the patient’s understanding of HIV
- Managing individual barriers to adherence
- Ongoing counselling and monitoring of adherence

Training materials:
- PowerPoint presentation 7.1a: HIV drug resistance and adherence
- PowerPoint presentation 7.1b: Adherence: counselling overview and skills rehearsal
- Sub-module 7.1: Overview and skills rehearsal
- Exercise 7.1
- Tools 1–8 in Annexes 1–8
OVERVIEW

Antiretroviral therapy (ART) is complex with multiple medications that once started need to be taken long term. It is extremely important to take time to assess and prepare the patient for this chronic long-term treatment. Injecting drug users (IDUs) are not a homogeneous group and you need to consider the diverse needs of injectors and former injectors.

Setting the ground for adherence to treatment begins before ART is started. It may be best to initiate treatment only when the client:

- Has emotional and practical life supports
- Fits his/her treatment regimen into a daily routine
- Understands that non-adherence leads to resistance
- Recognizes that all doses must be taken
- Feels comfortable taking treatment drugs in front of others
- Keeps clinical appointments
- Recognizes alarming signs and when to see a doctor about them
- Understands the interactions and side-effects of antiretrovirals (ARVs) in combination with opioid substitution therapy (OST) and illicit drugs.

Initiation of ART in HIV-infected IDUs should follow the current recommendations for initiation of ART in HIV-infected patients. Initiation of ART is rarely an emergency, and IDUs should be well-informed and motivated, and potential barriers to adherence should be addressed prior to commencement of therapy. In addition to the above-mentioned considerations, preparation of IDUs to receive ART should include drug dependency treatment including OST. Opioid-dependent patients who have consistent participation in a methadone or buprenorphine maintenance treatment programme have been shown to have a higher probability of ART use and better adherence to ART.

Clinical challenges in supporting and monitoring adherence in IDUs include:

- Management of prescribed and non-prescribed drug interactions and adjusting drug doses
- Dispensing medication in small amounts at frequent intervals. This will:
  - Provide opportunities to detect and address adherence problems before they lead to drug resistance
  - Cause limited disruptions in continuity or misuse of treatment
Once-daily options, a low pill burden, and the use of fixed-dose combinations (FDCs) may be of benefit at this early stage of treatment.

**ESTABLISHING AN ADHERENCE PROGRAMME**

It is important to consider the setting and resources when selecting an adherence implementation strategy.

**Directly administered ART at:**
- Methadone and buprenorphine clinics: once- or twice-daily regimens with methadone/buprenorphine are associated with improved virological and immunological outcomes compared with IDUs taking ART on a self-administered basis.
- Community visit programmes: mobile vans or community-based outreach are potential models for IDUs who are not on methadone/buprenorphine programmes.

**Directly observed treatment**
Directly observed treatment (DOT) is an intensive programme in which patients take their medication under the supervision of adherence staff. In directly observed treatment, short-course (DOTS) for tuberculosis (TB) programmes, health workers observe the intake of all medication doses for the entire treatment period of 6–9 months. TB DOTS is more regimented and provides a tighter monitoring of medication intake. In the case of ART, it is not practical to observe all doses as most ART regimens have multiple doses and treatment is lifelong.

**Health service provider counselling**
Clinicians, nurses, counsellors and pharmacists offer one-on-one counselling within the health setting. This service may be most suitable for facilities with small client numbers and adequate human resources, custodial settings or drug treatment facilities, as part of the discharge preparation.

**What is the role of the physician?**
The physician is the leader of the team. S/he is the main person to make clinical decisions regarding:
- Initiation of ART
- Continuation of therapy
- Treatment failure or non-response
- Side-effects or adverse events and appropriate response
- Change of treatment regimen
- Adherence to treatment
- Prophylaxis therapy
- Responsibility for overall health status of patient
- Information on adherence.

**What is the role of the adherence counsellor/nurse counsellor/adherence support coordinator?**
The adherence counsellor for individual patients works in close collaboration with the physician and is responsible for:
- Adherence counselling for patients
- Adherence-related follow up and data collection
- Adherence strategy
- Liaising with different specialties involved in treatment support (e.g. TB services, dermatology, home-based care)
- Informing the physician of problem areas: side-effects, adverse events and psychosocial problems

**What is the role of the pharmacist?**
The pharmacist is a member of the treatment and adherence team and is responsible for:
- Dispensing medications
- Treatment-related counselling
- Adherence counselling at the time of dispensing treatment
- Checking for side-effects and adverse events
- Pill counts at the time of medication refill

This model is also employed in health settings where the use of non-professionals such as lay counsellors or PLWHA is constrained.

**Ideally, three** preparatory adherence counselling visits should occur prior to starting ART, and continual adherence counselling **after** commencement of ART is required but this may not always be feasible. The preparatory visits should be spaced one week apart to allow for short-term reinforcement of teaching points about adherence, treatment information and practice with mock pills/medications. After the final preparatory visit, the treating physician and nurse counsellor should assess the patient’s readiness to initiate treatment.

**COMMUNITY–CLINIC–PROVIDER COLLABORATIONS**
This model utilizes trained PLWHA and other trained volunteers working in partnership with clinical service providers. The programme links health service delivery to community - and faith-based organizations (FBOs) (e.g. monks in Thailand provide treatment support to PLWHAs). The broader government sectors are regularly consulted with regard to provision of welfare, housing and transportation to support treatment initiatives.

**Role of other PLWHA**
PLWHA, particularly those who are former or "stable" substance users, can play a valuable role as peer educators in the multidisciplinary health-care team. PLWHA peer educators have unique individual perspectives in dealing with the challenges of living with HIV/AIDS and in the real challenges of taking ART daily. In programmes that provide PLWHA counselling and support, adherence is much higher than in clinics that do not offer PLWHA support.

As peers, they are also more likely to be trusted and are able to communicate frankly and openly with the patient. Because of their lived experience, PLWHA peer educators often have practical insights on solving the problems of adherence barriers and reducing side-effects. Because of the responsibilities and challenges in caring for an HIV patient, PLWHA peer educators will need special training, education and close supervision in order to become effective members of the multidisciplinary team.

Peer adherence support volunteers:
- Serve as "peer treatment educators" for group education sessions within health facilities or peer support sessions
Adherence counselling for injecting drug users

- Provide home-based treatment supervision
- Serve as individual ‘treatment buddies’ and help clients manage individual barriers such as forgetfulness through phone calls and assist clients in attending follow-up appointments

Peer adherence support volunteers may need the following support:
- Reimbursement for expenses (e.g. transportation for home visits)
- Education and supervision by professionals
- Emotional support – caring for others with HIV often raises issues for the PLWHA volunteer about his/her own HIV disease and social situation.

KEY ELEMENTS OF PATIENT PREPARATION

Patient preparation is an important step in getting patients to take treatment correctly over the long term and is considered in all three models of adherence support discussed in this module.

Substance dependence (in particular on opioids) is a chronic relapsing condition, which is difficult to control due to compulsive drug use and craving, leading to drug-seeking and repetitive use, even in the face of negative health and social consequences. The Health Belief Model of Behaviour Change is based on the theory that persons usually perceive a threat to their health (in terms of severity and susceptibility) and expect certain outcomes before they adopt new behaviours and develop the self-efficacy to make the change. The model acknowledges that substance dependence is a complex condition that has both metabolic and psychosocial components and is associated with severe morbidity and a high risk of death. In this model, the process of behaviour change is thought to have five stages:

1. **Pre-contemplation:** when the person is unaware or not interested in changing the behaviour
2. **Contemplation:** when the client thinks about behaviour change
3. **Preparation:** when a person actively decides to change
4. **Action:** the person works at changing their behaviour
5. **Maintenance:** when a person is able to sustain behaviour change for more than six months

These stages should be considered when examining the major barriers to adherence.

Successful adherence preparation relies on these principles of behavioural change. It increases information and understanding in patients, helps motivate them, and gives them the skills needed to adhere to their ART regimen. It assists patients who are using substances to reassess their continued drug use and reinforces their recovery from substance dependency. Pre-treatment adherence counselling gives patients time to understand their illicit drug use and its impact on their health, the severity of their HIV disease and coinfections (HBV, HCV, etc.) as well as understand the need to take medications correctly in order to achieve health benefits. It helps the patient make a commitment to take treatment regularly and correctly to achieve the desired health outcomes. The preparation process helps to empower patients prior to starting treatment.

Preparation includes the initial assessment of the patient and can be done over a couple of visits before initiating ART. The preparation process is important both for patients starting treatment for the first time (treatment-naive), as well as those who may have used ART in the past (treatment-experienced).

For treatment-naive patients, the preparation process helps patients (1) to understand the challenges of taking ART; (2) to think through the impact that treatment will have on their lives; and (3) to make a commitment to long-term treatment.

Sub-module 7.1
For treatment-experienced patients, the preparation process helps patients (1) to re-evaluate their commitment to taking treatment; (2) to identify potential and actual barriers; and (3) to address these barriers and adhere to treatment.

Key steps in the pre-treatment process

Establishing trust between the patient and provider
The first step in preparing the patient is to establish trust. This is an ongoing process that is strengthened over time. An assurance of confidentiality, a non-judgemental attitude, mutual respect and clear communication of information contributes greatly to developing a trusting relationship between the provider and patient.

Providing patients with information about their health
Patients who have knowledge about their disease tend to exhibit higher levels of adherence to treatment.

Learn about the patient’s health through a detailed medical history. This includes an assessment of the general health status, past illnesses and hospitalizations, and mental health. Patients who have experienced serious infections or hospitalizations may perceive their illness as serious and adhere better to treatment. Patients with severe mental illness or cognitive impairment may need help with taking medications regularly.

It is important to provide feedback to clients on your concerns about any cognitive impairment, and your reasons for providing additional interventions.

Overall health
A discussion on the overall physical and mental health status, ability to be in control of their life, and conduct routine daily activities sets the stage for the discussion on the importance of taking medications regularly. A detailed medical history forms the basis for understanding some of the barriers to adherence.

Disease stage
A discussion on past opportunistic infections (OIs) the patient may have had and what this implies in terms of disease progression helps the patient understand the severity of their illness and the need to take medications correctly. It is important to emphasize that progress of the disease can be delayed if treatment is taken regularly and correctly.

In case of patients with advanced disease, care must be taken not to discourage them with predictions of life expectancy. When started in time, ART delays disease progression and prevents death. When started very late in the disease process, medications may not be able to control disease progression.

CD4 counts where available
It is important to discuss the CD4 cell count with patients. The discussion should cover the following points:

- CD4 cells count is a measure of the patient’s immune status.
- HIV attacks the CD4 lymphocytes.
- Lower CD4 counts signify advanced HIV disease.
- CD4 cell counts increase with treatment.

The patient should be informed that lower CD4 counts are associated with an increase in the number of episodes of OIs and continued disease progression; and higher CD4 counts indicate a lower risk of OIs and improved health status. Patients should know their CD4 cell count and monitor how it changes.
with treatment. ART reduces the viral load and thereby decreases the destruction of CD4 cells. With successful treatment, CD4 cell counts increase, restoring immune function and patients experience fewer or no OIs.

Simple tools, such as low-literacy flipcharts, can assist clients' understanding.

*Viral load (VL)*
If estimation of VL is available, it is desirable to discuss the VL with patients even when it may not yet be available for routine monitoring. The patient should understand that VL measures the amount of HIV in the blood. If the VL is high, it means that the virus is in a period of greater activity, replicating (producing copies of itself) and further infecting new cells. Higher VL levels signify greater damage to the immune system, faster progression of the disease, and increased risk of transmitting infection. Treatment with ART results in VL reduction, and patients start to feel better when the VL decreases. The patient should also understand how VL measurements change in response to effective treatment.

VL tests, when available (they are very expensive and require advanced laboratory facilities), are used to determine the need for therapy, assess prognosis and monitor the response to ART.

*Prior use of antiretrovirals*
A discussion on the prior use of ART and experience with adherence to treatment is important. Patients with prior adherence problems or irregular use of ARVs need additional support and counselling. Information on other medications that the patient may be taking is required to assess drug interactions and side-effects.

*Patient’s health beliefs and attitudes*
Learn about the patient’s beliefs and attitude regarding HIV and treatment. A positive attitude and beliefs support adherence. Patients who believe that treatment is beneficial are able to make a commitment to long-term treatment, and are confident that they will be able to take medications correctly and regularly such patients tend to adhere better to treatment.

**TREATMENT AND ADHERENCE PROGRAMME**

A discussion about the ARV programme, health facility, medication availability, laboratory facilities and support services helps to familiarize the patient with the treatment programme. An introduction to the staff providing services and familiarizing the patient with the clinic layout is an important step in putting the patient at ease. Patients should be given a positive message. Patients who have adhered well to their treatment are in good health many years after they started treatment.

**ASSESSING AND FACILITATING THE PATIENT’S UNDERSTANDING OF HIV**

Understanding the patient’s knowledge, beliefs and attitudes about HIV infection helps the provider to better ascertain the patient’s readiness and commitment to ART. In addition, educating the patient about HIV helps them understand the need to give truthful answers to sensitive questions during the later part of the assessment. It is important to get a sense of the patient’s:

- Perceptions about the seriousness of his/her illness
- Likelihood of continuing preventive behaviour (condom usage, OST, clean needles/syringes)
- Perceptions about the effectiveness of ART
- Commitment to lifelong treatment.
**MANAGING INDIVIDUAL BARRIERS TO ADHERENCE**

Barriers to adherence related to the individual client can be further divided into (1) barriers in understanding; (2) barriers in motivation and remembering; and (3) barriers in support and logistics. Barriers in understanding originate from poor communication, poor understanding of the language, poor literacy levels, lack of knowledge or erroneous beliefs about HIV as a disease, and lack of awareness or mistrust in the effectiveness of ART. On the other hand, barriers in motivation and remembering can stem from forgetfulness, depression, or other pre-morbid or co-morbid HIV psychiatric disorders.

The initial assessment and preparation should include a discussion on the sources of social support for the patient. Does the patient live alone or with his family? Has the HIV status been disclosed to the family? Does the patient have a friend or family member that they trust and expect support from? The discussion should include sources of support from outside the family such as NGOs, PLWHA support groups, religious or faith-based organizations, or workplace programmes.

Learn about the socioeconomic situation of the patient: housing, employment and income, number of dependent family members, migrant status and living conditions. These factors may influence the regular and correct intake of medications.

It is important to discuss the patient’s daily routine (employment, work timings, eating and sleeping pattern), HIV confidentiality issues at place of work and at home, medication storage and travel plans so as to identify areas where patients may have problems and need support. An understanding of the patient’s daily routine and lifestyle helps to better integrate medication intake into the daily schedule.

Treatment reminder cues can be identified based on the patient’s daily routine. These include tying medication intake to mealtimes or specific routine activity such as leaving for work, notes written to oneself and placed at strategic points in the house, medication kept at a strategic location in the house, or setting an alarm on the mobile phone.

A sample interview for assessing an individual’s potential barriers to adherence can be found in Annex 2: Tool 2 at the end of this module. In addition to the interview schedule, Annex 8 contains a summary of commonly reported barriers to adherence and some methods that can be employed to address them.

**ONGOING COUNSELLING AND MONITORING OF ADHERENCE**

After patients commence ART, adherence counselling should be provided on a continual, regular basis. For each individual patient, adherence barriers can change over time due to changes in life circumstances. Adherence levels change with time as patients get accustomed to their treatment, experience side-effects, feel better or worse, or face new challenges. Counselling needs change over time as well. Different patients require different levels of ongoing support at various points in time. Ongoing counselling and continuing interactive communication are the keys to providing effective adherence support to the patient taking ART. After initiating ART, a follow-up adherence counselling visit should be scheduled within one to two weeks. In addition to adherence support, the adherence counsellor should perform adherence monitoring and assessment. Adherence should be assessed at a basic level at all visits by all members of the multidisciplinary team.

**What is adherence assessment and monitoring?**

Measuring adherence is problematic as there is no single method to assess adherence accurately. Therefore, multiple approaches are used to assess adherence. Some of the currently used
Adherence counselling for injecting drug users

measures are client self-reports, electronic monitoring devices, pill counts, provider estimation and measurement of medications in the bloodstream.

Self-report
Patients are asked to report their own adherence in a self-report. Different periods of recall may be used – four-day, one-week, one-month or most-recent recall of missing a dose. Although patients often tend to overestimate their adherence, several studies have found that the self-report correlates fairly well with actual medication intake when a trusting patient–provider relationship has been established. Self-report assessment can be obtained at the time of clinic visits through a series of questions. The accuracy of the self-report can be maximized by (1) approaching the patient in a matter-of-fact and non-judgemental manner; (2) asking about the most recent days and missed doses; and (3) using prompts to help recall. The self-report is presently the easiest tool to use in a clinical setting.

Pill counts
Health-care workers conduct pill counts during scheduled clinic visits. The main disadvantage of this method is that patients can manipulate pills by dumping them prior to the scheduled visits, leading to an overestimation of adherence. This method also relies on patients to bring their medication at the time of clinic visits. Unannounced pill counts may be more accurate. However, visiting patients’ homes is resource-intensive and there may be issues of confidentiality and stigma in the community. Pill counting may also hinder the development of a trusting relationship between the patient and provider.

Pharmacy refill tracking
Pharmacists play a key role in supporting patient adherence to medication. Pharmacists educate the patient about their medication and conduct pill counts. They also inform providers about lapses in refills or problems the patient may be experiencing with taking medication. Pharmacy refill data have been used as an additional indicator of adherence. Patients collecting their medications regularly on the due dates are assumed to be adhering to treatment, or – better – patients not collecting their medication are not adherent. An effective record-keeping system is essential for pharmacy refill data to be used. Some of the disadvantages with pharmacy refill tracking are that: (1) it is not a measure of intake of medication; and (2) it requires patients to use the same pharmacy for all refills.

Optimizing adherence in the early months (4–6 months) of treatment is crucial to ensure long-term immunovirological success. Moderate deviations from high adherence (88–99%) during follow up (maintenance phase after 6 months) have less of a negative impact. Several interventions for enhancing adherence are possible, but priority should be given to interventions aimed at improving adherence in the early months of ART.

The general process of supporting ongoing adherence counselling and monitoring should include:

1. Review the treatment regimen
   - Monitoring adherence (e.g. pill counts, self-reports)
   - Review medication names and any change in treatment regimen
   - Dosing instructions – during the early follow-up period or if new medication has been added
   - Instructions regarding food and fluid intake – during the early follow-up period or if new medication has been added
   - Storage of medications – during the early follow-up period or if new medication has been added.

2. Discuss adherence
   - Discuss medications taken.
   - Determine the reasons for missed doses. Discuss ways to address problems.
3. **Discuss side-effects experienced and actions taken**
   - Discuss the side-effects experienced since the last visit and how patient addressed them. Advise the patient on how to manage short-term and mild side-effects. For serious side-effects refer to the physician. In collaboration with the physician, set up ways to address side-effects. Identify problem areas. Refer to **Annex 7: Counselling Tool 7: Sample side-effects and actions to be taken by the counsellor.**
   - Review when to seek care and how to contact providers. Use patient symptom cue cards, and photo cue cards of, for example, a serious rash that would warrant immediate medical consultation.

4. **Review the experience with the follow-up plan**
   - Identify problems faced with the follow-up plan. For example, the patient is unable to attend the clinic and collect medications, etc. on scheduled days because of travel upcountry, working overtime.
   - Develop new strategies to address problem areas and barriers.

5. **Review barriers to adherence**
   - Review the barriers to adherence identified earlier as well as new barriers that may have come up and any success in addressing them. These may change during the course of treatment – the patient may start drinking, may be thrown out of the home, may face economic loss and loss of employment, may travel or move, etc.

6. **Review commitment to HIV prevention**
   - The key message is that PLWHA must use condoms and other protective measures in order to reduce the risk of transmission of HIV. Therefore, patient follow-up visits should incorporate an assessment of barriers to sustained behaviour change, with the goal of preventing HIV transmission and acquisition of different (and possibly resistant) strains of HIV.

7. **Discuss the plan for routine follow up**
   - Many IDUs experience significant discrimination from health workers and are cautious about sharing information with them. It is therefore important to prepare the client for issues that you will regularly follow up on, and explain why it is important for you to monitor these.
   - Enquire about any proposed travel – the patient should inform the clinic in advance and collect an extra supply of medications prior to travel.
   - Enquire about any change in life conditions: relapse into drug use, or change in drug or alcohol use, change in address, financial problems, separation or divorce, pregnancy, birth of a child, death of a loved one, etc.

8. **Review the patient’s individual goals and their success with achieving them**
   - Was the patient able to achieve their goals?
   - What can be done to achieve them the next time?
   - Set new goals. For example, over the next two weeks the patient will try to get up early and take all the medications within two hours of the due time; will use an alarm clock.
   - Integrate treatment into the patient’s daily routine of activities.
   - Complete the required data collection forms.

9. **Set up an appointment for the next visit**

10. **Review contact information**
REFERENCES AND RECOMMENDED READING


Additional recommended reading


Acknowledgements

We would like to acknowledge that some of the materials presented in this module were adapted from: *Adherence to antiretroviral therapy in adults: a guide for trainers*. India, Horizons/ Population Council, International Centre for Reproductive Health, 2004; and the *Adherence counselling training package*, FHI/China – UK, 2006
EXERCISE 7.1.1

ADHERENCE COUNSELLING FOR IDU

Activity 1:
All participants are requested to stand. You can only sit down if you have always maintained 100% adherence to the prescribed medication. This means:

- Correct dosage
- Correct manner
- Every time

Think of one time when you were taking a course of medication and were not 100% adherent. The facilitator will ask you to provide a reason why (e.g. I didn’t like the side-effects, or I prefer a “natural” approach to the care of illness). You may sit down once you have provided your answer.

Activity 2:
Discuss the following in the large group:

- What are the limitations of directly administered ART in methadone/buprenorphine clinics?
- What are the limitations or issues related to community directly administered ART?

Activity 3:
Discuss the following in the large group:

How you ask questions will determine the answers you receive.

What types of questions are these?

What are the problems with asking these questions in this way?

1. “Do you take your medication as the doctor told you?”
2. “Do you know what to do if you have diarrhoea or vomit when taking medication?”
3. “You do always take your medication, don’t you?”

Activities 4 and 5:
See the PowerPoint presentation.
Activity 6: Instructions for case study

Read the case study below. Your task is to develop an adherence support plan by identifying key barriers and developing specific strategies for each barrier.

### Activity 6: Case study

- A 22-year-old female bar worker has been told by the doctor that she needs to start ART for HIV. Nobody at home or at work knows that she has HIV. She lives with her family.
- She leads a busy life. She looks after her widowed mother and younger sister during the day and works in a karaoke bar in the evenings. At the bar, she sometimes has to drink with clients. She usually eats with the other girls in the bar at night.
- She injects amphetamine to help her keep awake (crushed pills). She injects when she has a lot of work on the weekend.
- She has lost considerable weight and reports she does not feel like eating.
- She has taken medication in the past for STI but never completed the course. She stopped taking medication when she felt better. She also tended to avoid getting up in the night to take medication. She has started taking some traditional herbal medicine. She has been told that traditional medicines can extend life and are better than the chemicals that doctors prescribe.
- She has problems remembering things lately and also has hallucinations at times (heard things others say they cannot hear). Sometimes she feels like she has lots and lots of energy to the extent that her friends find it unusual.
- She does not know if she is pregnant. She has missed one menstrual period.

- In the large group, “brainstorm” the barriers to treatment adherence.
- In the large group, discuss how these barriers might affect the patient’s future adherence to ART.
- Review Annex 8: “Barriers and strategies to support”.
- Discuss strategies to help the patient overcome these barriers to adherence.
- What other issues might be of concern in this patient's case? Would you refer her for further work-up by other health and community service providers? Who would you refer her to?

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>
Exercise 7.1.2

Role-Plays

Activity 7: Instructions for role-playing

- Find a partner.
- Assign one person to be A, and one to be B.
  - There are two case studies (two rounds of role-play): case 1 and case 2.
    - A is the counsellor in case study 1; B is the patient.
    - B is the counsellor in case study 2; A is the patient.

<table>
<thead>
<tr>
<th>Case study 1</th>
<th>Counsellor</th>
<th>Patient</th>
<th>Who reads the case study sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
<td>B</td>
<td>B</td>
</tr>
<tr>
<td>Case study 2</td>
<td>B</td>
<td>A</td>
<td>A</td>
</tr>
</tbody>
</table>

- Every trainee should get at least one chance to be the counsellor and one chance to be the patient.
- Only the trainee playing the patient gets to read the case study for that particular round.
- The counsellor should NOT read the case study before the role-play round. The counsellor’s job is to practise using their interview skills to elicit information from the patient.
- While you are playing the counsellor’s role, think about the barriers to adherence in this patient and how can you support the patient.
- Timing for each role-play:
  - 10 minutes for each role-play
  - 5 minutes for debriefing of role-play team with patient and counsellor
  - 15 minutes for large group debriefing on each case scenario
- The goal of the activity is to identify the possible barriers to adherence in each specific case scenario.

Counsellor instructions: Assume your patient is HIV-positive. Introduce yourself to the patient explaining that your role is to explain a little about HIV treatment and adherence. Practise eliciting information about the patient and finding out more about possible barriers to adherence in the patient.

Patient instructions: Introduce yourself to the counsellor; indicate the gender and the age of the patient you are playing. It is up to the counsellor to retrieve the information from you. Try to make the role-playing as realistic as possible.
Case study 1
(To be distributed to the patient and observer ONLY; the counsellor should NOT read this prior to the role-playing exercise.)

You are a 26-year-old restaurant manager. Nobody at your restaurant knows you have HIV. You work long hours and are at the restaurant for around 12 hours a day. When you go home, you eat meals with your family. Only your wife knows you have HIV. Your widowed mother lives with you and your two children. Your wife and one of your children have also been diagnosed to be HIV positive. Your wife is well and your child currently has no symptoms.

In the past, you have often forgotten to take your medications because you have so many responsibilities at work. Often, you reduced the dose when you had side-effects such as nausea.

You have been sleeping badly, and you are becoming a bit forgetful. You feel depressed (sleeping but waking early in the morning, and lack motivation) and have to force yourself to get out of bed. You have no appetite.

You believe HIV will kill you. You are not so sure that you can afford to take all your medication. The doctor told you that ART is free but the doctor said you need to take other drugs to prevent something called OIs.

Case study 2
(To be distributed to the patient and observer ONLY; the counsellor should NOT read this prior to the role-playing exercise)

You are a 26-year-old male who was diagnosed with HIV/AIDS four years ago. You have used heroin in the past. You have been on ARVs in the past, but often missed doses because of diarrhoea, and then stopped the medications completely because of a side-effect (burning pain in the hands and feet). Your last CD4 count was 110 cells/mm³.

The doctor now wants to start you on a new ART regimen. You take traditional herbal medicines every day to protect your liver. You work as a peer educator for an organization for PLWHA. You have many different doctors (western and Chinese) telling you different things about your medications. In addition, your friends tell you to enrol in a new trial to study herbal medicines for treating HIV. You travel frequently because of your duties to do outreach work for other PLWHA.

In the course of your work you encounter other IDUs. It would be easy for you to access heroin and when you feel under pressure it is very tempting. Especially lately, you sometimes think of using heroin again as you are starting to feel agitated, restless and have difficulty sleeping. Your friends say you are “too active”; they make jokes about you talking too much and too fast. Your doctor seems to think you are using again but you are not.
Adherence: a drug-user perspective

Objectives:

By the end of the session participants will:

- Have an insight into the issues and problems facing HIV-positive IDUs accessing health-care services and taking ART
- Understand what needs to be in place in order to establish an accessible ART programme for HIV-positive IDUs.

Time to complete session:

1 hour 45 minutes

Session content:

Participants seat themselves in a circle. Four HIV-positive IDUs make short contributions followed by a general discussion, questions and answers. Examples of questions IDUs can be asked to address include:

- Have they had any difficult experiences getting access to treatment and care?
- Have they had any good experiences getting access to treatment and care?
- Was it easy/difficult to be accepted for ARVs?
- What has their experience of taking ARVs been like?
- What are some of the factors that make adherence difficult?
- If they could ask doctors to do one thing differently, what would it be?
Tool 1
Pre-treatment adherence counselling: checklist for counselling visit 1*

Client’s name/code...............................................................................................................................................................

Date of counselling session...............................................................................................................................................................

| Introduction                                                                                                 |
| Introduction                                                                                                 |
| Discussion of confidentiality                                                                                  |
| Discussion of counsellor–patient partnership and interactive communication|
| Introduction to treatment and adherence programme                                                             |

| Assess HIV understanding and beliefs                                                                       |
| Knowledge and beliefs about HIV/AIDS                                                                       |
| Knowledge and beliefs about ART and its effectiveness                                                    |
| Flipchart for HIV education to fill in any gaps in knowledge or understanding |

| Provide prevention counselling                                         |
| Condom usage                                                          |
| Clean needles/syringes (if applicable)                                |

| Conduct patient assessment                                           |
| Medical history                                                       |
| Prior use of ART                                                      |
| Determine social support                                              |
| Disclosure – have they disclosed their HIV-positive status to anyone? |
| Alcohol/drug use (present and past)                                   |
| Mental state                                                          |

| Review the health status                                              |
| Opportunistic infections                                              |
| CD4 count/viral load                                                  |

| Review the living conditions and employment                          |
| Housing                                                               |
| Employment/income                                                    |

| Describe the treatment programme and importance of adherence         |
| Drug regimen – name/frequency/storage/dietary instructions/must not share pills |
| What ART does – suppresses virus/improves immunity/less OIs/not a cure |
| Cost                                                                  |
| Side-effects and what to do                                           |
| Follow up                                                             |
| Importance of adherence and consequences of non-adherence             |

| Discuss adherence promotion strategies                                |
| Buddy reminder – discuss role of support person                      |
| Other reminder cues                                                  |

<p>| Identify barriers to adherence                                       |</p>
<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor communication</td>
<td></td>
</tr>
<tr>
<td>Low literacy</td>
<td></td>
</tr>
<tr>
<td>inadequate understanding about HIV/AIDS</td>
<td></td>
</tr>
<tr>
<td>Lack of social support</td>
<td></td>
</tr>
<tr>
<td>Failure to disclose status</td>
<td></td>
</tr>
<tr>
<td>Alcohol and drug use</td>
<td></td>
</tr>
<tr>
<td>Mental state</td>
<td></td>
</tr>
</tbody>
</table>

| Schedule next counselling session and complete appointment card       |

Counsellor signature:

This checklist may be copied and used as a medical record form

Tool 2
Sample interview form for initial assessment of patient for adherence*

**Client’s name/code**  

**Introduction**
I would like to ask you some questions that will assist me in planning your treatment.
Please consider and answer the questions carefully.
Developing an effective treatment plan is very important.

**General approach**
- Explain to the patient why you are asking these questions.
- Be interactive with the patient on discussion points.
- Be non-judgemental.
- Explain that behavioural change involves providing more information, motivation, and skills in the patient.

**Past experience with medication**
What difficulties have you had with taking medication at the correct dose, at the correct time, for the complete prescribed period in the past?
If you had difficulties, what were some of the reasons you could not take medication as prescribed?

**Notes**
When you have taken medication in the past and had unpleasant side-effects such as nausea or diarrhoea have you done any of the following?

- Reduced the medication dosage without the doctor's advice? Circle answer. **YES/NO**
- Increased the medication dosage without the doctor's advice? Circle answer. **YES/NO**
- Stopped taking the medication? Circle answer. **YES/NO**

**Attitudes and beliefs about medication**
Do you believe HIV medication is harmful to your body? Circle answer. **YES/NO**

**Notes**
Do you believe traditional medicine is more effective than prescribed medication?

Circle answer. **YES/NO**

What does your family believe about medication?

**Notes**

* Source: Adapted by Casey K from Winwood MA et al. The St Mary’s Hospital personality, behaviour and cognitive charges questionnaire (PERBEC). International Conference on AIDS, 1991, 7:281 (abstract no. WB 2396)
What about the attitudes and beliefs of close friends, or other people you know with HIV?

Notes

**Daily routine**

Do you take meals at regular intervals? Circle answer. YES/NO

Do you ever work through a meal break because you are busy? Circle answer. YES/NO

Do you eat meals with other people at work? Circle answer. YES/NO

Do you eat meals with people at home? Circle answer. YES/NO

Are you worried that if other people see you taking medication that they will know you have HIV? Circle answer. YES/NO

Is there anything in your daily routine or work that would make it difficult to take medication at specific times? Circle answer. YES/NO

Notes

**Identifying potential barriers to attending follow-up medical appointments**

Do you travel frequently to other parts of the country? Circle answer. YES/NO

Are you able to attend the clinic/hospital during the service hours? Circle answer. YES/NO

Do you have any problem with travelling to the clinic/hospital? Circle answer. YES/NO

There may be other charges for other treatments or tests. Do you have financial difficulties that would make it hard for you to pay? Circle answer. YES/NO

Notes
**Drug and alcohol use**

Are you currently drinking more than two alcoholic drinks a day on a regular basis?  
Circle answer.  
YES/NO

Do you currently use drugs\(^1\) that have not been prescribed for you by your doctor?  
Circle answer.  
YES/NO

For individuals who use drugs/alcohol:

1. Have you ever felt that you should cut down on your drinking or drug using?  
Circle answer.  
YES/NO

2. Have people annoyed you by criticizing your drinking or drug using?  
Circle answer.  
YES/NO

3. Have you ever felt bad or guilty about drinking or drug using?  
Circle answer.  
YES/NO

4. Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover (eye-opener)? Or do you have to use drugs just to feel normal and be able to function in society?  
Circle answer.  
YES/NO

\(^1\) It is important to enquire about all substances being used, not just injected substances.
Screening for possible cognitive impairment

Memory and concentration

1. How well do you remember what has just been said when somebody is talking to you?

1 2 3 4 5 6 7
Extremely well Not at all

Any change?

Much better No change Much worse
1 2 3 4 5 6 7

2. How well do you remember events from past years?

1 2 3 4 5 6 7
Extremely well Not at all

Any change?

Much better No change Much worse
1 2 3 4 5 6 7

3. How well can you follow the plot of a story on the radio, TV or in plays or films?

1 2 3 4 5 6 7
Extremely well Not at all

Any change?

Much better No change Much worse
1 2 3 4 5 6 7

4. How well can you concentrate on your work, reading and writing?

1 2 3 4 5 6 7
Extremely well Not at all

Any change?

Much better No change Much worse
1 2 3 4 5 6 7
Speech
5. How would you rate your ability to “find words”?

1____ 2____ 3____ 4____ 5____ 6____ 7
Extremely well Not at all

Any change?

Much better No change Much worse
1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7

6. Can you keep track of conversations?

1____ 2____ 3____ 4____ 5____ 6____ 7
Extremely well Not at all

Any change?

Much better No change Much worse
1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7

Coordination
7. Do you have difficulty doing fiddly things with your hands?

1____ 2____ 3____ 4____ 5____ 6____ 7
Extremely well Not at all

Any change?

Much better No change Much worse
1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7

Current mood
8. Are you irritable nowadays?

1____ 2____ 3____ 4____ 5____ 6____ 7
Extremely Not at all

Any change?

Much better No change Much worse
1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7

Annex 2
9. Are you anxious nowadays?

1 2 3 4 5 6 7
Extremely Not at all

Any change?

Much better No change Much worse
1 2 3 4 5 6 7

10. Are you depressed nowadays?

1 2 3 4 5 6 7
Extremely Not at all

Any change?

Much better No change Much worse
1 2 3 4 5 6 7

Pregnancy and infant feeding (for women)

Some medications should not be prescribed to pregnant women.
Are you currently pregnant? Circle answer. YES/NO

If not pregnant, are you using contraception? Circle answer. YES/NO

Type: Circle answer: Intrauterine device (IUD) Oral contraceptive pill
Condoms Other

Are you breastfeeding an infant? Circle answer. YES/NO

Disclosure of HIV status to others

Do you live with other people? Circle answer. YES/NO
Have you told them you have HIV? Circle answer. YES/NO

Do you have one or more regular sex or injecting partners? Circle answer. YES/NO
Ask the client to describe their daily routine from waking through going to bed at night.

**Daily activities and ART schedule worksheet**

*Timetable  Activities  Remarks  
(morning)*

* (afternoon) *

* (evening) *

* (night) *
Tool 3
Pre-treatment adherence counselling: checklist for counselling visit 2*

Client’s name/code ............................................................................................................................................................... 
Date of counselling visit ........................................................................................................................................................... 

<table>
<thead>
<tr>
<th>Review client’s understanding of HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is HIV and AIDS</td>
</tr>
<tr>
<td>Opportunistic infections</td>
</tr>
<tr>
<td>CD4 count/viral load</td>
</tr>
<tr>
<td>Effect of treatment</td>
</tr>
<tr>
<td>Clarify the client’s understanding of their health status</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Review the treatment programme and importance of adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug regimen, how to take ART and other treatment drugs, and implications for meals, etc.</td>
</tr>
<tr>
<td>Storage of treatment drugs</td>
</tr>
<tr>
<td>Dummy pill demonstration, establish a practice run using fake pills</td>
</tr>
<tr>
<td>What ART does – improves immunity/less OIs/ART is not a cure</td>
</tr>
<tr>
<td>Need for continued prevention and explaining about re-infection</td>
</tr>
<tr>
<td>Follow up and what will be required during treatment</td>
</tr>
<tr>
<td>Importance of adherence and consequences of non-adherence</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Review proposed adherence promotion strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review adherence barriers identified in visit 1</td>
</tr>
<tr>
<td>Low literacy</td>
</tr>
<tr>
<td>Inadequate understanding about HIV/AIDS</td>
</tr>
<tr>
<td>Lack of social support</td>
</tr>
<tr>
<td>Failure to disclose status</td>
</tr>
<tr>
<td>Alcohol and drug use</td>
</tr>
<tr>
<td>Mental state</td>
</tr>
<tr>
<td>Use structured problem-solving</td>
</tr>
</tbody>
</table>

| Take client’s address and establish contact system with treatment centre |
| Schedule next counselling visit and complete appointment card |

Counsellor signature: ............................................................................................................................................................... 

### Tool 4
Pre-treatment adherence counselling: checklist for counselling visit 3*

<table>
<thead>
<tr>
<th>Assess client’s understanding of disease and readiness to start</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV disease</td>
</tr>
<tr>
<td>Opportunistic infections</td>
</tr>
<tr>
<td>CD4 count/viral load</td>
</tr>
<tr>
<td>Effect of treatment</td>
</tr>
<tr>
<td>Commitment to adherence</td>
</tr>
<tr>
<td>HIV prevention</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Review the treatment programme and importance of adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug regimen</td>
</tr>
<tr>
<td>Pill demonstration</td>
</tr>
<tr>
<td>What ART does – improves immunity/less OIs/ART is not a cure</td>
</tr>
<tr>
<td>Need for continued prevention – condom use</td>
</tr>
<tr>
<td>Side-effects and what to do</td>
</tr>
<tr>
<td>Follow-up visits</td>
</tr>
<tr>
<td>Link between adherence and successful outcome</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Review proposed adherence promotion strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family, friend or partner reminder – discuss role of support person</td>
</tr>
<tr>
<td>Discuss monitoring system and the patient’s role (e.g. pill diary)</td>
</tr>
<tr>
<td>Other reminder cues</td>
</tr>
</tbody>
</table>

| Complete all national/provincial documentation, schedule next appointment and complete appointment card |

| Refer to pharmacy |

This cue card could also be copied and used as a medical record.

# Annex 5

## Tool 5

### Ongoing adherence counselling: checklist*

<table>
<thead>
<tr>
<th>Client’s name/code</th>
<th>Date of counselling visit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Review the patient’s experience with treatment and adherence over the past month**
- **Drug regimen and adherence – pill counts, self-reports**
- **Discuss side-effects and actions taken**
- **Discuss need for continued prevention**
- **Review experience with follow-up plan**
- **Discuss follow-up plan for next month**
- **Review patient’s goals and success at achieving them**
- **Review barriers to adherence**
  - Buddy reminder – discuss role of support person
  - Review pill diary
  - Poor communication
  - Low level of literacy
  - Inadequate understanding of HIV/AIDS
  - Lack of social support
- **Barriers to HIV transmission reduction**
  - Failure to disclose status
  - Alcohol and drug use
  - Mental state
- **Fill ART register, schedule next appointment and complete appointment card**
- **Refer to pharmacy**

---

## Annex 6

### Tool 6

#### Adherence pill count calculation*

**Adherence from pill counts**

\[
\text{%Adherence} = \frac{\# \text{ of pills patient should have taken} - \# \text{ of pills missed}}{\# \text{ of pills patient should have taken}} \times 100
\]

<table>
<thead>
<tr>
<th>Name of medication</th>
<th>Number of pills dispensed</th>
<th>Number of pills patient expected to have taken (A) (take into account whether patient has come early, on time or after the refill due date)</th>
<th>Number of pills patient actually took (take into account remaining pills and whether patient has come early, on time or after the refill due date)</th>
<th>Number of pills missed (B)</th>
<th>% Adherence ( \frac{A - B}{A} \times 100 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. d4T</td>
<td>60 (for 30 days)</td>
<td>54 (patient came in 3 days early)</td>
<td>50 (10 pills remaining when there should have been only 6)</td>
<td>4</td>
<td>( \frac{54 - 4}{54} \times 100 = 92.5% )</td>
</tr>
</tbody>
</table>

Adherence could be <100% when patients have taken fewer pills than required or >100% when they have taken extra pills by mistake.

### Adherence from self-report

Adherence measured using a self-report will only reflect the adherence over the period of recall (e.g. 3 days in the table below).

Patients should be asked about missed doses: how many doses of d4T did you miss – yesterday, the day before that and the day before that (3 days ago)?

\[
\text{%Adherence} = \frac{\# \text{ of doses patient should have taken} - \# \text{ of doses missed}}{\# \text{ of doses patient should have taken}} \times 100
\]

<table>
<thead>
<tr>
<th>Names of medications</th>
<th>Yesterday (missed dose)</th>
<th>Day before yesterday (missed dose)</th>
<th>The day before that (3 days back) (missed dose)</th>
<th>% Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>e.g. d4T</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>( \frac{6 - 2}{6} \times 100 = 67% )</td>
</tr>
</tbody>
</table>

**Tool 7**

**Sample side-effects and actions to be taken by the counsellor**

<table>
<thead>
<tr>
<th>Name</th>
<th>Side-effects</th>
<th>Action to be taken</th>
</tr>
</thead>
</table>
| **d4T/stavudine**| Common: peripheral neuropathy, headache, rash, insomnia, nausea, vomiting, diarrhoea  
Rare: pancreatitis, lactic acidosis, hepatic steatosis | 1. Inform the physician.  
2. Patient should report if there is severe abdominal pain or vomiting.  
4. Medication will need to be changed if lactic acidosis, pancreatitis or severe neuropathy occur. |
| **3TC/lamivudine**| Common: dizziness, headache, insomnia, fatigue, nausea, rash  
Rare: pancreatitis, peripheral neuropathy, hepatic steatosis | 1. Inform the physician.  
2. Patient should report if there is severe abdominal pain or vomiting  
3. Medication will need to be changed if lactic acidosis occurs. |
| **ddl/didanosine**| Common: anxiety, headache, insomnia, diarrhoea, nausea  
Rare: pancreatitis, peripheral neuropathy, lactic acidosis, hepatic steatosis | 1. Inform the physician.  
2. Patient should report if there is severe abdominal pain or vomiting  
3. Nausea and diarrhoea disappear over 2–4 weeks.  
5. Medication will need to be changed if lactic acidosis and pancreatitis occur. |
| **AZT/zidovudine**| Common: nausea, anorexia, headache, malaise, asthenia  
Rare: bone marrow suppression, anaemia and/or neutropenia, lactic acidosis with hepatic steatosis, myopathy | 1. Inform the physician.  
2. Nausea and diarrhoea disappear over 2–4 weeks.  
3. Patient should report if there is severe abdominal pain or vomiting  
4. Medication will need to be changed if lactic acidosis occurs. |
| **EFV/efavirenz**| Common: rash, central nervous system symptoms, nausea, vomiting, anorexia, diarrhoea  
Rare: severe rash, liver toxicity and hepatitis, severe depression with suicidal ideation | 1. Inform the physician.  
2. Mild-to-moderate rash may disappear over 4 weeks. EFV to be discontinued in case of severe rash.  
3. May consider changing treatment in presence of liver toxicity (enzymes higher than 5 times normal levels) or severe rash.  
4. CNS symptoms generally relieved when EFV is taken at bedtime. In case of severe CNS symptoms, treatment may need to be changed. |

BARRIERS RELATED TO UNDERSTANDING

Communication problems

Communication difficulties may arise from language and cultural differences. Communication difficulties could also arise when the patient’s attitudes and expectations regarding HIV and treatment are different from those of the provider. Some patients may be defensive about their lifestyle and exhibit negative attitudes. Other patients may not feel comfortable giving honest answers to the health-care provider. This may be seen among marginalized or stigmatized groups who may not trust the health-care provider or may be too afraid to ask questions when they do not understand the disease or the regimen.

*How to address the barrier:* Discussion in an open and non-judgemental way, paraphrasing and repeating information. Providing patients with a scientific basis for HIV treatment and related issues helps them develop self-confidence and positive attitudes. Understanding cultural differences and providing counselling in the patient’s dialect and language help to solve communication problems.

Language barriers

In many Asian countries, there is a significant number of people with HIV who use a dialect or a local language other than the official national language as their primary language. Having providers who speak the same dialect/language as the client is very important to ensure good communication, adequate understanding, and establish trust and rapport. In addition, providers should avoid using family members as interpreters if at all possible. The client may not be comfortable with disclosing all information in the presence of a family member. The family member may not provide a truthful translation of what the client states, and may instead insert his/her own opinion or viewpoints (rather than the client’s viewpoint) in the discussion.

*How to address the barrier:* Staff who can speak multiple dialects should be hired, especially in areas serving a large minority population who speak a minority dialect. Provision of written instructions and written materials with pictorial illustrations may help if the patient can read them (depending on literacy and language used).

Low literacy levels

Patients with low literacy levels may not completely understand their disease, its challenges and complications. Patients may not comprehend instructions provided.

*How to address the barrier:* Use verbal repetition of the adherence message, treatment plan and regimen. A practice session with dummy pills may help patients. Use a pictorial representation of the message and review written information with each patient, describing technical terms in simple language and asking patients to repeat instructions. Efforts should be made to avoid uncomfortable situations where the patient’s lack of literacy is revealed. This encourages a sense of trust in the provider and self-assurance in the patient.

Lack of knowledge or erroneous beliefs about HIV

Clients who understand their HIV disease and the relationship between treatment, adherence and successful outcomes do better than patients who do not have such an understanding. It is important to know about the patient’s health beliefs and understanding of HIV. If the patient has misconceptions about the nature of HIV/AIDS or has alternate beliefs about HIV, they may seek alternate providers of care outside of the legitimate health-care system.

How to address the barrier: The most important step is to build a trusting relationship with the patient in order to facilitate an open and frank discussion about HIV and health beliefs. Providers should ensure that they communicate in an open and non-judgemental way, and that their body language is appropriate. Providing clients with explanations of HIV in a manner appropriate to the client’s level of education and his/her cultural background is also important.

Lack of awareness or mistrust in the effectiveness of ART

Clients who believe in the effectiveness of medications also do better with treatment. If the client does not understand the goals of care and treatment, has unrealistic expectations about ART, or has been disappointed with medical care in the past, they may not believe in the effectiveness of ART, which would then increase the probability of non-adherence. In addition, mistrust of the effectiveness of ART may cause the client to seek alternative, non-effective medications such as herbal medicines or other traditional medicines that do not treat or cure HIV, and may lead to more harmful drug–drug interactions.

How to address the barrier: Discussion in an open and non-judgemental way, paraphrasing and repeating information, and providing patients with a scientific basis for HIV treatment and related issues will help patients develop self-confidence. Presenting a case study or experience with other patients may also help patients develop positive attitudes and confidence in the effectiveness of treatment.

BARRIERS RELATED TO MOTIVATION AND REMEMBERING

Forgetfulness

Memory difficulties in an HIV-infected client may indicate an early stage of HIV-associated dementia. In general, the early symptoms of HIV-associated dementia include: apathy, memory loss, slowed thinking, depression and social withdrawal. In addition, the client’s work schedule may be too busy, or their life may be too chaotic for the client to remember to take medications.

How to address the barrier: Personalizing the dosing regimen to specific aspects of the client’s lifestyle may help. For example, if the client works from 8:30 am to 7 pm every day, it may be easier for them to take a twice-daily dosing regimen at 8 am (before work) and then again at 8 pm (after work). A regimen that fixes the doses at 10 am and 10 pm may be more difficult for the client because they would have to remember to take the medicines at work. Giving the client practical tips about how to remember to take medications may also help (daily cues, reminders, using family members or friends). Additionally, the client may find it useful to use daily reminders such as watches, beepers, alarm clocks or mobile phones.

Depression or other psychiatric diseases

Patients with depression and other psychiatric illnesses may have difficulty adhering to treatment. Patients with advanced HIV disease may have HIV disease-related conditions such as
AIDS dementia, which may prevent patients from caring for themselves and taking medications regularly and correctly. Patients may suffer from residual confusion after an episode of meningitis or encephalitis.

How to address the barrier: Active depression can be treated with antidepressants. Physicians can assess the patient and provide relevant medical care. ART helps to resolve some conditions. AIDS dementia may not improve despite ART and these patients require additional support. Enlisting support to help patients take their medications on time – from the family, community health workers and PLWHA support groups would be required.

Active alcohol or active drug use
Patients with heavy alcohol intake or active drug use have problems in adhering to treatment, forgetting to take medications on time or correctly.

How to address the barrier: Counselling is an important tool. Patients should be provided scientific information on the link between alcohol, ARV drug metabolism in the liver and resulting exacerbation of liver damage. It may become necessary to stop or change ARV medications if liver damage occurs. Patients should also be informed about the effect of drinking or using drugs on their adherence to ART.

Discussion in an open and non-judgemental way is essential. Linking patients with PLWHA support groups and peer group interventions may be helpful. Counsellors would need to ask a family member to remind the patient about medication intake (only in cases where the patient has disclosed their HIV status). Referring patients to active de-addiction programmes, where available, is useful.

Inability to set longer-term goals
Sometimes a client may be so emotionally devastated by the diagnosis of HIV that they may not be able to see past day-to-day living to set longer-term goals for their life. In addition, the client may be distracted by other more pressing issues such as heroin addiction, alcohol addiction, or extreme poverty, which make it difficult to see past a day-to-day existence.

How to address the barrier: It is important to assess whether or not the client is ready to make a commitment to lifelong therapy prior to starting ART. The provider must provide hope to the client, reassuring them that it is possible to live well and long with HIV. If the client seems doubtful or too overwhelmed by the diagnosis or too burdened by daily stresses, the provider should help address the acute stressors and at the same time encourage the client to have a longer-term perspective and goals.

BARRIERS IN RELATED TO SUPPORT AND LOGISTICS

Disclosure of HIV status
Disclosure of HIV status is an important factor influencing adherence. Fear of rejection or discrimination may prevent PLWHA from disclosing their status to family members and friends, thereby losing out on social support. In addition, patients may be afraid of making their HIV status known if they take their medications in front of family members, friends or work colleagues. Patients may choose to skip a particular dose of medication in order to avoid having to take their medications in public, in the presence of colleagues at work or family members at home.
Adherence counselling for injecting drug users

How to address the barrier: Counselling can help the patient overcome some of these fears and help with disclosure to family or friends. Once the patient is ready to do so, counselling for family members to facilitate disclosure may be required. It is important that these family members are identified by the patient. In cases where patients are not ready to disclose their status, counsellors can help patients identify a person or two outside the family who could provide psychosocial support (e.g. peers, friends, PLWHA support groups).

Difficult life conditions
Patients who do not have housing, are unemployed, or have very modest or no financial means may perceive lack of income, housing and food, and support for childcare as more urgent needs than taking medications properly.

How to address the barrier: While it may not be possible for the health worker to directly address these problems, linking patients with NGOs and/or FBO programmes, PLWHA support groups and a home-based care programme may offer some help. Some church programmes provide food donation and PLWHA groups have income-generation activities.

Unstable living conditions and lack of social support
Patients may be living alone, in shared accommodation or on the street. Unstable living conditions pose a major barrier to proper medication intake and storage. These patients also tend not to have family or outside support, thereby missing out on a caring atmosphere, proper nutrition and stability in their personal lives.

How to address the barrier: Establishing contact with PLWHA support groups, if the patient is willing, may be helpful in getting some support. Linking the patient with a home-based care programme and community health workers (CHWs) may provide some psychosocial support and nursing care. Support programmes run by FBOs, such as food donation programmes, may provide an additional source of support.

Logistic difficulties
Logistic difficulties include: travel, being away from home, uncertain daily schedules, lack of food, and lack of cool storage (if needed for medication storage).

How to address the barrier: During each visit, enquire about any travel plans and plan for the client to get a supply of medication to take away. Review daily schedules regularly. Try to identify key times when medication can always be taken. Carry medication with you (in a “cool lunch pack”) or wrap medication in a sealed, dry container, wrap a wet cloth around the medication and put it in a plastic bag to keep the cloth moist. If meal times vary, carry extra snacks such as bananas, bread and milk or a soya drink. Consume these and take medication at the regular time.

BARRIERS RELATED TO THE HEALTH-CARE DELIVERY SYSTEM

Negative or judgemental attitudes of providers
Patients who perceive their providers as having antipathy towards them or a negative and discriminating attitude are understandably reluctant to adhere to treatment and maintain a regular schedule of follow-up care.
How to address the barrier: Training of providers will help to overcome this barrier. Regular staff meetings to discuss the follow up of patients may help providers to understand the issues better.

**Structural barriers**

Patient adherence may be negatively influenced by structural barriers. Structural barriers include transportation difficulties (distance, time, cost), inconvenient clinic hours, high clinic fees, high laboratory fees, inadequate drug stock/supply in the pharmacy, overworked, busy health-care staff turning away patients, and lack of proper registration in the province. These barriers need to be addressed by the management. Providers may help by bringing these issues to the administration’s notice.

**BARRIERS RELATED TO MEDICATIONS**

**Regimen complexity**

Clients taking ART are also often on other medicines, such as prophylaxis against OIs. In addition, the client may be taking other medications for non-HIV-related reasons (such as liver protection medications, herbal medicines, vitamin supplements, or other over-the-counter medicines).

*How to address the barrier:* Pill boxes that are pre-filled with ART medications may help the client to better cope with the complex regimen of ART. Additionally, the provider should initiate a discussion with the client regarding whether or not they are taking other medicines as well. In general, non-essential medicines should be reduced to simplify the client’s regimen.

**Frequency of dosing**

Frequent dosing of medications (such as every six hours) can be a barrier to adherence. Clients may find it difficult to have to wake up in the middle of the night to take medications.

*How to address the barrier:* In general, regimens using sustained release formulations of medicines that require less frequent dosing (once or twice a day) are much easier for clients to adhere to. The adherence counsellor should ask the client at what time during the day or night the client takes medications. If the client takes medications more than two or three times a day, the counsellor should ask the prescribing physician if the regimen can be streamlined to fewer doses a day.

**High pill burden**

Evidence has demonstrated that the larger the number of pills a client has to take, the greater the likelihood of non-adherence.

*How to address the barrier:* In general, non-essential medicines should be reduced to decrease the client’s pill burden (as well as reduce the risk of drug–drug interaction). The provider should work with both the client as well as the client’s physician to identify and eliminate non-essential medications (vitamins, herbal medications, etc.). In addition, the provider should advocate for the availability of combination drug pills in their service area.

**Food requirements or restrictions**

*How to address the barrier:* The provider should provide careful verbal and written instructions to the client about how to take the medications before the client begins the ART regimen.
Frequency and severity of side-effects

Most ART medications cause side-effects. Common side-effects include nausea, diarrhoea, headache, peripheral neuropathy and skin rashes. Clients may be reluctant to continue taking ART medications because of the frequency or severity of side-effects, especially if they are mostly asymptomatic or are feeling well.

How to address the barrier: Discussion and education about possible side-effects with a client before they begin ART is important in reducing this barrier. The provider should establish a plan on how to manage potential side-effects with the client before a new drug or a new ART regimen is begun. Initiating a discussion with the client about side-effects is also important because the client may be too embarrassed or hesitant to bring up certain types of side-effects (e.g. diarrhoea). The client may also benefit from a referral to a PLWHA support group to share practical tips on how to manage side-effects. Proper management of side-effects and referral to the prescribing physician is extremely important for long-term adherence.
**How does HIV become resistant?**
- HIV reproduces itself very quickly, making 60 billion copies of new viruses every day.
- Since the virus often makes mistakes when copying itself, each new generation differs slightly from the one before.
- These tiny structural differences are called mutations.
- Mutations change the genetic code of HIV, including the enzymes used in the lifecycle.
- If the enzyme (target of ART drugs) or genetic code is altered, the ARV may no longer work.
- This can result in strains of HIV that have reduced sensitivity to the drugs. These HIV strains are called drug-resistant.

**What is HIV drug resistance?**
- Drug-resistant HIV strains vary. Some may be highly resistant to anti-HIV drugs while others may be less so.
- When an anti-HIV drug is started, HIV that is fully susceptible to that drug disappears rapidly, leaving behind drug-resistant viruses.
- These viruses continue to reproduce themselves despite the drug’s presence.
- Resistance is an important reason for the failure of anti-HIV treatment.

**Two types of HIV drug resistance**
- **Acquired** drug resistance (ADR)
  - Individual develops HIV drug resistance while taking ARVs
  - Poor treatment outcome for the individual
- **Transmitted** drug resistance (TDR)
  - Individual is infected with drug-resistant HIV (i.e. has drug-resistant virus before ARVs are started) – primary drug resistance
  - Individual already under ART is infected with drug-resistant HIV (superinfection)

**Concerns in Asia about IDUs and ART**
We will discuss each of these concerns/attitudes:
- IDUs cannot adhere to ARVs.
- Providing ART to IDUs will generate an epidemic of drug-resistant strains of HIV.
- This will increase the number of people who require expensive second-line ARVs.
- This will increase the cost of ART.
- Countries in Asia will not be able to afford to scale up ART if significant numbers of people need second-line drugs.

**Transmitted drug resistance (TDR)**
- The resistant virus is transmitted from one person to another.
- As a result, some patients are resistant from the time of infection (primary HIV DR)
  - Treatment failure on first-line ARVs
- Overall, 10% of newly HIV-1-infected persons in North America and Western Europe carry viruses with at least 1 drug resistance mutation.

Factors that increase acquired resistance
- No ARVs in the drug cupboard – stock-outs, gaps in supply
- Weak supply chain management
- Poor forecasting
- Setting up ART clinics in sites where supply chain security is not achievable
- Costs of ARVs
  - Transport costs
  - User fees
- Poor prescribing
- Sharing ARVs
- Poor adherence – people miss doses

Can IDUs adhere to treatment?
- The proportion of non-adherent individuals is similar between non-IDU individuals and IDUs who are in OST (Moatti JP et al. AIDS, 2000).
- Rates of ARV resistance are no higher in IDUs than non-IDUs (WHO 2006).
Adherence: overview and skills rehearsal

### Session objectives
- Overview
- Establishing an adherence programme
- Community – clinic – provider collaborations
- Key elements of patient preparation
- Treatment and adherence programme
- Assessing and facilitating the patient’s understanding of HIV
- Managing individual barriers to adherence
- Ongoing counselling and monitoring of adherence

### Treatment adherence includes:
- Taking tablets or liquid medications, applying ointment
- Returning to the clinic for injections, OST and follow-up clinical examinations and tests
- Attending referrals to outside agencies (e.g. TB, family planning, antenatal care)
- Adherence to transmission reduction

### Medication adherence
The extent to which the patient follows medical instructions in taking their medications.
- Correct dosage
- Correct way
- Every time

### The importance of adherence
- Strong correlation between virological response and adherence
- >95% adherence is needed to achieve adequate viral suppression

### In HIV, “treatment adherence” is about more than just taking medication...
## Integrating prevention and care messages

- Encourage and support PLWHA to use condoms and new/clean injecting equipment and other protective measures (e.g. PMTCT) in order to reduce the risk of transmission of HIV.

## Activity 1

- All participants stand.
- Participants to sit down only if they have always adhered 100% to prescribed medication, this means:
  - Correct dosage
  - Correct way
  - Every time
- Discuss reasons for their non-adherence.

## Barriers related to the individual-1

- Barriers to adherence commonly seen among IDUs:
  - Communication difficulties
  - Language barriers – ethnic groups
  - Low literacy level – common among IDUs in resource-poor settings
  - Lack of knowledge or erroneous beliefs about HIV
  - Lack of understanding or belief in effectiveness of ART
  - HIV or substance-related cognitive impairment
  - Pre-morbid psychiatric or intellectual impairment

## Barriers related to the individual-2

- Barriers to motivation and remembering may be accentuated in IDUs:
  - Forgetfulness
  - Depression or other psychiatric illnesses
  - Active alcohol use
  - Active use of other drugs
  - Inability to set longer-term goals

## Barriers related to the individual-3

- IDU lifestyle
  - Discomfort with disclosure of HIV status
    - Cannot take medication in front of those who do not know
  - Lack of social support – nobody to help; often friends are using
  - Difficult life conditions – in and out of treatment or custodial situations
  - Unstable living situation (e.g. living in temporary shelters or on the street)
  - Logistical difficulties (e.g. getting to clinic and other referrals)

## Barriers related to the health-care delivery system

- Negative or judgemental attitude of health-care providers toward IDUs
- Common structural barriers within health facilities
  - Medicines out-of-stock
  - Lack of cold storage
  - Staff shortage
  - Inconvenient clinic hours for client population
  - Transportation difficulties
  - Costs and finances

---

**Activity 1**

- All participants stand.
- Participants to sit down only if they have always adhered 100% to prescribed medication, this means:
  - Correct dosage
  - Correct way
  - Every time
- Discuss reasons for their non-adherence.

---

**Barriers related to the individual-1**

- Barriers to adherence commonly seen among IDUs:
  - Communication difficulties
  - Language barriers – ethnic groups
  - Low literacy level – common among IDUs in resource-poor settings
  - Lack of knowledge or erroneous beliefs about HIV
  - Lack of understanding or belief in effectiveness of ART
  - HIV or substance-related cognitive impairment
  - Pre-morbid psychiatric or intellectual impairment

**Barriers related to the individual-2**

- Barriers to motivation and remembering may be accentuated in IDUs:
  - Forgetfulness
  - Depression or other psychiatric illnesses
  - Active alcohol use
  - Active use of other drugs
  - Inability to set longer-term goals

**Barriers related to the individual-3**

- IDU lifestyle
  - Discomfort with disclosure of HIV status
    - Cannot take medication in front of those who do not know
  - Lack of social support – nobody to help; often friends are using
  - Difficult life conditions – in and out of treatment or custodial situations
  - Unstable living situation (e.g. living in temporary shelters or on the street)
  - Logistical difficulties (e.g. getting to clinic and other referrals)
Adherence counselling for injecting drug users

Medication-related barriers
Regimen complexity – especially when receiving STI and TB drugs, drug rehabilitation, family planning and other HIV medications:
- Frequent dosing
- High pill burden
- Food restrictions or requirements
- Side-effects
- Interaction with OI drugs
- Abstinence – recovery programmes (e.g. NA/AA and injunctions against using substances)

Active drug use is not a valid criterion for denying access to IDUs
- IDUs engaged in stable care with experienced staff and adequate support can adhere to ART and have clinical outcomes equivalent to those of HIV patients who do not use drugs (Wood et al. 2003, 2004).


Strategies to support adherence among IDUs
Assess and consider
- Active IDUs – currently injecting
  - Dependent, regular or infrequent
- IDUs on OST
- Non-using IDUs – risk of relapse

Alcohol
Should not be forgotten
- Substitution of addiction
- Significant patterns of alcohol use among drug users

Facilitating stability – 1
- Addressing “stability issues” – brokering support of non-health sector partners (e.g. housing, welfare, nongovernment sector)
- Brokering support from police and custodial care
  - Address issues related to individuals on treatment moving in and out of custodial care
  - Address legal barriers to current and former users forming associations such as peer support groups (however, illegal in some countries)
  - Address relapse into substance use and ensure that if relapse occurs IDUs have access to clean injecting equipment

Facilitating stability – 2
- Motivational therapies for drug and alcohol use paired with “controlled” use programmes
- Support services for adherence to ART including community outreach
- Psychological support/counselling, group therapy for IDUs and family members
- Peer support groups
- Psychiatric services for psychotic disorders or severe depression
- Social services to deal with discriminatory and other issues (e.g. stable housing)
Adherence counselling for injecting drug users

Strategies used in adherence programmes

- Directly administered ART (DAART)
  - Methadone clinics
  - Community visit programmes
- Clinic-based – provider counselling
- Community – health service provider collaborations

Or even better, a combination of all three!

What works for opioid-dependent IDUs-1

Participation in a methadone maintenance treatment programme has been shown to be associated with a higher probability of ART use, and adherence to ART.


What works-2

- Building health provider–client relationships
  - Patient confidentiality
  - Care setting
  - Good communication skills (verbal and non-verbal)
  - Multidisciplinary team

Motivational adherence counselling

- Therapeutic technique related to decision-making (i.e. aimed at the individual, internal factors)
- Enhanced motivation includes:
  - Reducing inhibitors of change
  - Providing positive alternatives
  - Changing the environment

What works-3

- Clarifying the PLWHA’s understanding of their HIV status, the need for medication, and the need and importance of adherence
- Exploring and managing substance dependency (e.g. OST)
- Exploring and anticipating the specific barriers to adherence that the individual may face
- Engaging in structured problem-solving of the barriers
- Establishing the importance of the patient’s accurate reporting of adherence failures
- Enlisting community and family support for the patient’s adherence (with patient consent)

DAART – limited efficacy studies within resource-poor settings

- Methadone clinics
  - Once- or twice-daily regimens with methadone (1 DOT and 1 take home)
  - Associated with improved virological and immunological outcomes compared with IDUs taking ART on a self-administered basis
- Community-based
  - Mobile vans or community-based outreach
  - Potentially a model for IDUs who are not on methadone programmes
Adherence counselling for injecting drug users

Activity 2
- What are the limitations of DAART in methadone clinics?
- What are the limitations or issues related to community DAART?

Health service provider counselling
Typically provided by clinician or nurse counsellor with support from pharmacy staff
- Three pre-treatment sessions spaced across 3–4 weeks
- The preparation process helps to empower patients prior to starting
- Follow-up regular counselling throughout treatment

Patient preparation
- For treatment-naive patients, helps patients:
  - Understand the challenges of taking ART
  - Think through the impact that treatment will have on their lives
  - Make a commitment to long-term treatment
- For treatment-experienced patients, helps:
  - Re-evaluate their commitment to taking treatment
  - Identify potential and actual barriers
  - Address these barriers and adhere to treatment

Health-provider model: pre-treatment counselling session

<table>
<thead>
<tr>
<th>Session One</th>
<th>Session Two</th>
<th>Session Three</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical assessment</td>
<td>Discussion of clinical exam and test results</td>
<td>Review of previous two sessions</td>
</tr>
<tr>
<td>Exploration of potential barriers</td>
<td>Review of potential barriers to adherence</td>
<td>Detailed treatment plan</td>
</tr>
<tr>
<td>Review basic HIV/AIDS understanding</td>
<td>Problem-solving of potential barriers</td>
<td>Final assessment of patient readiness</td>
</tr>
<tr>
<td>Prevention counselling</td>
<td>Preliminary treatment plan</td>
<td>Family/buddy support meeting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Contact information and follow-up visit</td>
</tr>
</tbody>
</table>

Follow-up ongoing treatment counselling includes: 1
- Review of barriers – actual and anticipated
- Solving barriers problems
  - Management of side-effects – provide medication and strategies
  - Management of social barriers
  - Management of psychiatric–cognitive barriers

Follow-up ongoing treatment counselling includes: 2
- Adherence monitoring
  - Calculate and explore
  - Storage of medication
  - Address any change in medicines or doses (other medications)
  - Change in substance use
  - Diet review and further instructions
Follow-up ongoing adherence counselling-1

**Adherence from pill counts:** % adherence = 
\[
\frac{\text{# of pills should have taken} - \text{# of pills missed}}{\text{# of pills patient should have taken}} \times 100
\]

**Adherence from self-report:** % adherence over last four days = 
\[
\frac{\text{# doses should have taken} - \text{# missed doses}}{\text{# doses should have taken}} \times 100
\]


Follow-up ongoing adherence counselling-2

Should be advised in advance to clients and reinforced at follow-up:

**Strategies for missed appointments (sick, distance):**
- Send tracer or peer educator (must have client pre-agreement)
- Reminders, phone call (client pre-agreement)
- Change to nearest treatment site

**Strategies for missed doses (do not take a double dose):**
- Within 3 hours of scheduled dose take the missed dose
- If > 3 hours of scheduled dose, miss dose and go on to the next dose, carry on the treatment schedule

Volunteer–provider collaboration-1

- In programmes that provide PLWHA counselling and support on adherence, adherence is much higher than clinics that do not offer support.
  - Many examples:
    - Cambodia: 95% of PLWHA 95–100% adherent
    - Zambia: 90–95% of PLWHA 95–100% adherent
    - Canada (IDUs): 90–95% of PLWHA 95–100% adherent
    - Viet Nam (Binh Thanh and District 8): very high 90–95%

Volunteer–provider collaboration-2

- Useful for resource-poor settings
- Utilizes trained PLWHA and other trained volunteers working in partnership with clinical service providers
- Links to external community and FBOs
- Links to broader government sector (e.g. social welfare)
- Links to private sector providers

Volunteer–provider collaboration models

- Relies on trained volunteers and PLWHA
- Serve as “peer treatment educators” for group education sessions within health facilities or peer support sessions
- Provide home-based treatment supervision
- Serve as individual “treatment buddies” helping clients manage individual barriers such as forgetfulness through phone calls, and assist clients in attending follow-up appointments

PLWHA volunteers require support

- Reimbursement for expenses (e.g. home visits)
- Education and supervision by professionals
- Emotional support – often caring for others with HIV
Effective communication

- Effective non-verbal communication
  - You can “close off” the client’s willingness to be honest about adherence by demonstrating frustration, anger and disapproval

- Listening
  - Two-way communication is key to adherence
  - Show empathy and paraphrase to show you have understood the patient
  - Allow silence and reflection time for the client to process information

- Questioning
  - A statement followed by an open question gives the patient “permission” to acknowledge failure and problems.
  - Patients who experience no adherence problems can simply say, “I had no problems, I took all of my pills.”

  "Many people I see have problems taking their pills … what difficulties do you experience in taking medication?"

  "When in your daily life do you find it difficult to take your medication?"

Better questions = more accurate responses!

- A statement followed by an open question gives the patient “permission” to acknowledge failure and problems.
- Patients who experience no adherence problems can simply say, “I had no problems, I took all of my pills.”

Activity 3: Large group discussion

- What type of questions are these? Respond to each question.
- What are the problems with asking these questions?
  - “Do you take your medication as the doctor told you to?”
  - “Do you know what to do if you have diarrhoea or vomiting when taking medication?”
  - “You always take your medication, don’t you?”

Adherence support tools

- Fig. 1.4: Ezy Does Pill Box (1 week, 4 daily doses)


Sample patient pre-treatment education card


Routine follow-up adherence counselling

- Medications
  - Physical assessment and change in medicines or doses
  - Dietary discussion
  - Storage

- Monitoring adherence – patient interview, pill counts, etc.
- Difficulties or side-effects experienced
  - Explore
  - Problem-solving

Annex 10
Activity 7: Role-plays
- Using Exercise 7.1.2, role-play being the counsellor and patient (we will do two rounds, reversing roles at the end of round 1).
- The “counsellor” should not read the case study.
- The goal of the activity is to identify the possible barriers to adherence in each specific case scenario.
- Timing:
  - 10 minutes for each role-play (20 minutes total)
  - 5 minutes for small group debriefing between patient and counsellor
  - 15 minutes for large group debriefing on each case scenario

Other treatment aids
- Treatment buddies
- Cell phone or internet reminders
- Pill charts

Activity 4
- Adherence toolkit review
  - Pre-treatment counselling visit checklists
  - Adherence pre-treatment “practice pills”
  - Adherence self-report form
  - Adherence calculation worksheet

Activity 5
- Large group discussion
- What are the strengths and weaknesses of:
  - Pill counts
  - Self-reports

Activity 6
- Read the case study for Activity 6. Also refer to the adherence strategies support Tool 8. You have interviewed the client and elicited this information.
- We will now make a patient support plan to address adherence barriers.
- Individual class members are invited to brainstorm the key potential barriers to adherence. We will write these in the column marked “Barriers”.
- We will then address each issue one by one, identifying “Strategies”.

Activity 7: Role-plays
- Using Exercise 7.1.2, role-play being the counsellor and patient (we will do two rounds, reversing roles at the end of round 1).
- The “counsellor” should not read the case study.
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  - 10 minutes for each role-play (20 minutes total)
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Module 7

Adherence Counselling for Injecting Drug Users

Treatment and Care for HIV-Positive Injecting Drug Users

The "Treatment and Care for HIV-Positive Injecting Drug Users" training curriculum is designed for clinicians who provide treatment and care, including ART, for HIV-positive injecting drug users. The training curriculum consists of a trainer manual, 12 participant manuals, and a CD-ROM with PowerPoint presentations and reference articles. Topics covered in the curriculum include:

Module 1: Drug use and HIV in Asia
Module 2: Comprehensive services for injecting drug users
Module 3: Initial patient assessment
Module 4: Managing opioid dependence
Module 5: Managing non-opioid drug dependence
Module 6: Managing ART in injecting drug users
Module 7: Adherence counselling for injecting drug users
Module 8: Drug interactions
Module 9: Management of coinfections in HIV-positive injecting drug users
Module 10: Managing pain in HIV-infected injecting drug users
Module 11: Psychiatric illness, psychosocial care and sexual health
Module 12: Continuing medical education

Trainer manual