

Patient Support, Education and Counselling Guideline



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**For adults
living with HIV and/or TB**

Internal document
2018 Edition

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Foreword

This guideline includes practical tools and guidance for staff that provide patient support, education and counselling to adults infected with HIV/TB. It serves as a standard of minimum activities to be put in place when dealing with HIV/TB infected patients, but set-up should be adapted to the context and the human resources available. The guideline gives an overview of the activities to be put in place, while the annexes provide several practical tools from different MSF HIV/TB projects.

This guideline is meant to be used with adults. For children and adolescents, refer to the *MSF Patient Support, Education and Counselling Guideline for Children and Adolescents living with HIV, 2018*.

This is the second version of the guideline and has been validated by the MSF AIDS and TB working groups and the intersectional Patient Support, Education and Counselling contact group.

Please send feedback on the guideline to the respective focal point/referent of your Operational Centre, so we can continue to adapt the guideline to the realities in the field.

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Glossary

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal consultation
ART	Antiretroviral therapy
ARV	Antiretroviral (medication)
BID	Bis in die (twice daily)
CAG	Community ART Group
CD4	Immune system cell
CO	Clinical officer
DOT	Directly observed therapy
DTC	Diagnostic testing and counselling
DR-TB	Drug-resistant tuberculosis
EAC	Enhanced adherence counselling
FU	Follow-up
HAART	Highly active antiretroviral therapy
HC	Health centre
HIV	Human Immunodeficiency Virus
HTC	HIV testing and counselling
HTS	HIV testing services
LTFU	Lost to follow-up
OCA	MSF Operational Centre Amsterdam
OCB	MSF Operational Centre Brussels
OCBA	MSF Operational Centre Barcelona
OCG	MSF Operational Centre Geneva
OCP	MSF Operational Centre Paris
OD	Omne in die (once daily)
OI	Opportunistic infection
PCS	Patient and Community Support
PEP	Post-exposure prophylaxis
PrEP	Pre-exposure prophylaxis
PEC	Patient Education and Counselling
PHC	Primary health care
PITC	Provider-initiated testing and counselling
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
PODI	Community ART distribution points
PSEC	Patient Support, Education and Counselling
SAT	Self-administered therapy
TB	Tuberculosis
VTC	Voluntary testing and counselling
VL	Viral load
WHO	World Health Organisation

Note: The use of “he”, “him” and “his” refers to a person of unknown gender and is used to refer to both men and women.

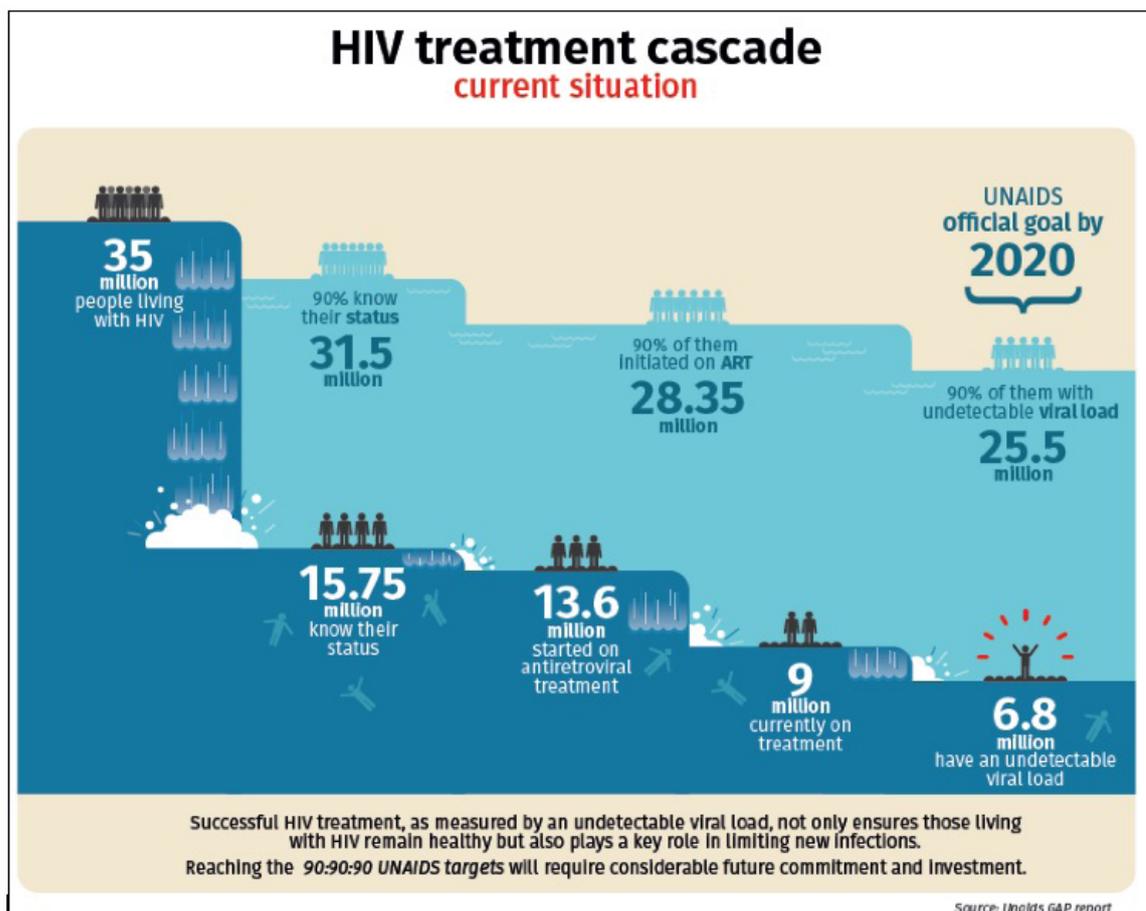
1. The cascade of care for PLHIV/TB

1.1 The concepts of the cascade of care

The cascade of care¹ for people living with HIV (PLHIV), and for other chronic diseases, is marked by different steps. The first step for a patient consists in getting to know their HIV status. After that, a patient has to “link to care”; meaning enrolling in HIV services where eligibility for antiretroviral treatment (ART) will be defined and medication may be started. Once the patient is on ART, he needs to continue on presenting for clinical check-ups and drug refills, also called “retention in care”. A next step for the patient is to ensure his viral load becomes suppressed thru adherence to prescribed treatment.

UNAIDS² set forward ambitious goals to put an end to HIV. By 2020, 90% of people infected with HIV should be aware of their HIV status. Of those, 90% should be on treatment and then 90% of those on ART should reach an undetectable viral load. The present reality is that multiple strategies will be needed to reach the goal of 90-90-90, as big drops exist along the cascade of care.

Figure: HIV cascade of care, 2015³



The following concepts apply both to the HIV and the TB cascade of care:

- Screening & diagnosis.
- Linkage to care: Starting care and treatment in a health structure after being diagnosed.
- Retention in care: Attending clinical consultations, blood drawing and drug pick-ups as planned.
- Loss to follow up: Not having shown up for planned clinical consultations, blood drawing and drug pick-up for more than 2 months.
- Adherence: Treatment adherence refers to the extent to which a person's behaviour - in terms of medication, following diets, or adopting lifestyle changes - coincides with medical or health advice⁴. Treatment adherence is broader than the term "medication adherence", what is the degree or extent of conformity to the recommendations about day-to-day treatment by the provider with respect to the timing, dosage, and frequency⁵. Poor medication adherence limits the effectiveness of treatment and is responsible for the development of drug resistance in HIV & TB. This may in turn lead to virological treatment failure and has been associated with increased morbidity and mortality. A high degree of ART adherence is essential for optimal suppression of the HIV virus^{6,7}. The same is valid for TB treatment: poor adherence to TB medication regimens can lead to the development of resistant strains of tuberculosis and disease relapse. Drug-resistant TB (DR-TB) is difficult to treat and can be fatal.

1.2 Barriers to linkage to care, retention in care and adherence to treatment

Linking to care, staying in care and being adherent to treatment is challenging in the context of a chronic disease. Disengagement from care and fluctuations in medication adherence is common among patients and should be dealt with without judgement.

It is impossible to accurately predict someone's ability to retain in care and adhere to treatment based on their socio-demographic, educational and sexual characteristics, presence of mental health disorders or drug use behaviour. There is no single factor responsible for adapted health-seeking behaviour. However, the factors listed below are recognised as good predictors of poor adherence and retention in care. They can be divided into different categories such as patient-related factors, medication-related factors and health system related factors^{8,9,10,11,12,13}.

1.2.1 Patient factors

- Lack of understanding of the disease and its treatment.
- Patient's perceptions and beliefs about HIV/TB disease and treatment, the health system, the health care providers.
- A lack of motivation to take medications.
- Lack of self-efficacy whereby patient doesn't believe himself able to take his medication as prescribed.
- Mental health concerns, in particular depression, active drug and alcohol use.
- Poor social support and isolation.
- Non-disclosure of HIV/TB status.
- Stigma, rejection and discrimination linked to HIV/TB disease.
- Socio-economic factors such as a lack of income to pay consultations, transport to health facility.
- Behavioural factors such as a lack of structure in daily life and difficulties to remember to take medications.

1.2.2 Medication factors

- Tolerability of medication side effects.
- Dose frequency more than twice a day.
- Pill burden.
- Food requirements (which is the case for only few ARV drugs).
- Bad taste of medications.
- Lack of improvement in health status.

1.2.3 Health system factors

- Poor patient/health care provider relationship.
- Lack or difficulties of access to health care.
- Long waiting times at the health facility.
- Lack of confidentiality of services provided.
- Stock-outs of medication.

Healthcare providers' attitudes

When patients and healthcare providers fail to establish a trusting relationship, patient's health-seeking behaviour will be influenced. If a patient trusts or has confidence in his healthcare provider, he is more likely to follow advice and to collaborate with the healthcare provider. Patients may also be more likely to bring questions and concerns to the healthcare provider's attention.

Some spontaneous attitudes of the health provider will likely provoke resistance to change by the patient¹⁴:

- > **scary, threatening advice.**
- > **direct persuasion.**
- > **providing the solution (telling the patient what he should do).**
- > **ordering, instructing.**
- > **criticising, blaming, disapproving.**
- > **humiliating, mocking.**

1.3 Strategies to improve the gaps in the cascade of care

Several strategies exist to improve linkage to care, retention in care and adherence to treatment. As multiple factors influence the health-seeking behaviour of patients, no single strategy alone will be able to address them. Evidence shows that the following strategies can reduce the gaps in the cascade of care^{15,16,17,18,19} and are recommended by WHO²⁰.

1.3.1 Patient-focused strategies

- Patient support education and counselling interventions,
 - in group or individual/family level.
 - focusing on cognitive-behavioural interventions such as linking life projects to achieving treatment goals like an undetectable viral load.
 - including behavioural skills training such as making a medication schedule that fits into the patients' lifestyle, the anticipation of change in daily routine (e.g. anticipate with patient how to avoid missing doses when he leaves his home).
- Offering peer support through lay health workers, group refill strategies, support groups, etc...
- Involving family, friends or other peers as treatment supporters.

- Use of reminder devices such as daily or weekly pill boxes, alarm clocks, mobile reminder alarm, text messages, calendars, ...
- Screening, management and treatment of mental health issues such as depression.
- Provision of socio-economic support such as providing support for transport, referral to social welfare service, food supplementation/vouchers, etc...
- Support for facilitating HIV disclosure.
- Tracing of patients who fail to link to or stay in care.
- Peer-led outreach and provision of intensified support for key populations.

1.3.2 Medication-focused strategies

- Reduced dose frequency and number of pills, such as once-daily, fixed-dose drug combinations.
- Improved tolerability of medication, and treatment of side-effects when they occur.
- Provision of a security/buffer stock of ARVs and essential medicines.

1.3.3 Health-system focused strategies

- Health services adaptation to reduce time between diagnosis and ART initiation, or during ART follow up, through improved patient flows, referral of stable patients on ART to differentiated ART delivery models.
- Decentralisation of services.
- Longer refill periods.
- Task-shifting or task-sharing of healthcare provider tasks to increase staff efficiency.
- A trusting patient/health care provider relationship.

2. Supporting adults living with HIV/TB

2.1 An approach for HIV/TB comprehensive care

Overall this guideline covers interventions ranging from the broader community to individuals, including patients in care, with a particular focus on patient education and counselling (PEC). All the activities aim at empowering the patient, his family and environment in the face of his illness and treatment, beyond the purely medical aspects of care. This approach is part of a comprehensive package of care for patients living with HIV/TB. It can be applied as well to patients with other, or co-morbid chronic diseases. It aims at achieving the following objectives with patients:

- Understanding and acceptance of his/her health status, illness and treatment.
- Recognition of the consequences of his/her status and illness in his/her daily life (family aspects, emotional and sexual, friendships, occupational, etc.).
- Adaptation of his/her behaviour and acceptance with the reality of one's situation.
- Active involvement and responsibility in the treatment.

The following activities make up the integrated approach and the extent to which all of these activities will be put in place in a given project, and will depend on the characteristics of the target group, patient load and human resources available^a.

Minimum package	Comprehensive package
Patient Education and Counselling <i>Target group: all patients living with HIV/TB</i>	Mental health care <i>Target group: HIV/TB patients with mental health issues</i>
Patient tracing <i>Target group: Patients living with HIV/TB who missed an appointment</i>	Social support <i>Target group: HIV/TB patients who lack social support</i>
	Other health promotion activities targeting the broader community on HIV/TB <i>Target group: Communities where HIV/TB patients originate from</i>

Patient education and counselling entails all educational and emotional support activities offered at the health facility or in the community for HIV/TB infected patients. The PSEC activities along the cascade of care are further described in chapter 3.

Patient tracing includes activities aimed at supporting PLHIV/TB to return to care after disengagement from care. Patient tracing strategies are addressed in chapter 4.

Both patient education and counselling and patient tracing are seen as minimal activities to be put in place in any HIV/TB integrated or vertical project.

^a The naming of this spectrum of activities including the HR and technical referents will depend upon each section. Within OCB this complete spectrum of activities is covered by "Patient and community support (PCS)". Other sections will group Patient Education and counselling, patient tracing and social support under the umbrella of "Patient Support, Education and Counselling (PSEC)" and will refer to health promotion and mental health for the other activities. We chose to title this guideline Patient Support Education and Counselling (PSEC), while mentioning the additional activities for support of patients living with HIV/TB.

The comprehensive package also includes the following activities:

Mental health care aims at screening, diagnosing and treating mental health problems among HIV/TB infected patients, and is described further in chapter 5.

Social support encompasses activities that aim to address the weak socio-economical support system of HIV/TB infected patients in a punctual way. This can include socio-economical support, support groups, home visits and hospital visits, and is further addressed in chapter 6.

Other health promotion activities target the broader community from which HIV/TB infected patients come from, and include awareness raising and promotion of the HIV/TB medical services offered. This is addressed in chapter 7.

2.2 Staff responsible for PSEC activities

The PSEC tasks should be clearly assigned to a specific cadre. According to patient loads, availability of healthcare providers, national legislation and HIV/TB prevalence, a context-adapted decision will need to be made as to who will perform these tasks. Three types of approaches can be distinguished:

- Minimum staffing model: inclusion of PSEC tasks in the job profile of the treating medical doctor or nurse.
- Intermediate staffing model: inclusion of PSEC tasks by the medical doctor or nurse, with referral to specialised PSEC staff for complex cases.
- Full staffing model: dedicated specialised staff for these activities within a multidisciplinary approach.

In many projects where HIV/TB is integrated among other medical activities, the minimum or intermediate staffing model is the most feasible, whereby the above tasks will be included in the job description of doctors, nurses, health promoters and counsellors whom also see patients for other medical issues.

Specific considerations are to be made, when implementing the intermediate/full staffing model.

- Different staff members can be engaged to perform patient support tasks. The majority of MSF vertical HIV/TB projects are in contexts with an excessive workload and a lack of human resources, or contexts with high disease-related stigma. In these settings mostly lay cadres - including PLHIV - have been trained to perform PSEC activities. These are cadres who do not have a professional degree but have been trained on the task. Often there is no national regulatory framework and financing for these positions and an advocacy strategy needs to be defined to ensure continuity of this cadre after project closure²¹. Some settings have higher trained profiles to perform these tasks, such as psychologists, social workers and professional counsellors.
- The paid workforce may be expanded with community volunteers who frequently belong to a patient association. Patient associations are groupings of patients, often registered as official associations, which encourage members to provide mutual support. They can also provide testimony and lobby in civil society on matters such as patients' rights, prevention, awareness of the disease, access to treatment, etc. It is useful to collaborate with them whenever possible.
- A Patient Support Activity Manager should be appointed to coordinate the patient support, education and counselling activities. The activity manager can be assisted by one or more supervisors to support the team.
- The PSEC team is a part of the medical team and falls under the responsibility of the medical team leader / medical focal point.

- Within a multidisciplinary approach, it is important that all health workers (medical doctors, clinical officers, nurses and counsellors) taking care of HIV/TB infected patients, build a supportive relationship with the patient. The health care provider/patient relationship is a crucial determinant of treatment adherence and retention in care. To facilitate a multidisciplinary approach, the following interventions need to be set up to ensure communication amongst the team members:
 - Clearly defined roles of each team member. For example, the doctor plays an important role in the detection of adherence issues.
 - A common patient file, which is shared between the medical doctors, COs (clinical officers), nurses and counsellors.
 - Regular daily contact between medical staff and counsellors to immediately address patient's problems when need arises.
 - Planned team meetings whereby medical staff and counsellors can discuss patients with complex needs (treatment failure cases, non-disclosed adolescents, etc.).

2.3 Training and supervision of PSEC staff

Patient Support activity managers and supervisors are responsible to train and supervise their team. Class-room training is essential to train staff on implementation of new activities, especially with lay workers, who do not have a formal degree but are trained on joining the project. On-job training is extremely important to ensure that new knowledge and competencies are correctly implemented in the field. For any new activity to be implemented, the on-job training phase should be intensive until it is confirmed that the lay worker can independently perform the activity. After that routine supervision should be provided.

Methodologies for on-job training and supportive supervision are:

- Regular observation of PSEC sessions, with a translator if needed. Observation grids as presented in Annex 1 & 2 can be used to structure an observation.
- Review of patient files, to check if these are properly completed and to check for consistency in the follow-up of the patient.
- Case-discussions as proposed by the staff as well as the supervisor.
- Role plays during team meetings.
- Analysis of indicators with the team and identification of gaps and solutions.

For more information on how to organise supportive supervision, refer to Annex 3.

2.4 Monitoring and evaluation of activities

2.4.1 Recording of activities

Recording of activities is time intensive and only useful when the data are also analysed at a later stage. Avoid any unnecessary reporting. Recording in a patient file and a tally sheet should be in place in every project. Always check if the national HIV/TB programme has a recording system in place which can be used.

Patient file

A summary of each session done with a patient is recorded in the patient file. See Annex 4 of an example of a patient file. This documentation allows continuity in the sessions, facilitates communication between counsellors or between the team and other medical staff, and is useful for supervision. Additionally recording of sessions in a patient file makes it easier to

check data retrospectively which is not routinely being recorded such as: disclosure status of children, completion of specific patient support, education and counselling sessions, etc.

Tally sheet

At minimum, cumulative data needs to be recorded by each team member on the number and type of interventions performed. This data can be recorded in a tally sheet (see Annex 5). Recording of these activities will allow the supervisor or activity manager to analyse the workload per counsellor and get an indication of session completion.

Individual Patient Register/database

This type of recording should not be done routinely. In some projects, or for some specific activities, individual patient-level data on session completion and specific session outcomes can be kept in a dedicated register or database. This may be useful for a specific research purpose, or to support the implementation of a new activity whereby new patient flows need to be established and in order to reassure that this is followed up by the counsellor (for example a high viral load register).

2.4.2 Analysing the data

The integrated approach supporting adults living with HIV/TB is meant to have an impact on patients' adherence (viral load suppression), linkage and retention in care, indicators which are routinely followed up in the project.

Based on the reporting by the team, the activity manager should look into additional specific indicators. This will allow the evaluation and adaptation of the strategies. Some of these indicators may be included in the project's log frame / monitoring tools, while other indicators may stay at the level of the team and documented in monthly situation reports ("sitreps").

Process indicators, focussing on the systems put in place may be evaluated by analysing the data recorded by the team and comparing it to other medical project data. Some examples:

- Average number of PSEC sessions performed per counsellor per day.
- % of patients receiving PSEC sessions according to protocol (can be detailed per type of sessions).
- % of patients late for their appointment being traced.

Outcome indicators, focussing on the results, can also be reviewed but may require additional recording/data collection:

- % of patients more than 2 weeks late for their appointment in previous month having returned by the end of the calendar month.
- % of patients having a good understanding of a specific message. An assessment of patient's knowledge among a sample of patients could be done using the assessment tool in annex 8.

See annex 6 for a log frame with examples of activities and their indicators.

3. General principles of patient education and counselling

3.1 Definition and objectives

Patient education and counselling are offered to people who are HIV/TB infected. As HIV/TB is a chronic disease, patients must learn to manage themselves, their treatment and to live with their disease.

Patient education consists of²²:

- Helping the patient to understand his own disease and treatment.
- Enabling him to acquire and maintain abilities that allow him to optimally manage his life with his disease.

According to WHO²³, patient education should be:

- Patient-centered:
 - Have an individualised, tailored message.
 - Start from what the patient knows and needs.
 - Be based on a patient's life plan.
- Based on a partnership between the patient and the health provider.
- Based on a multidisciplinary approach whereby all health providers dealing with the patient have a role to play.
- Integrated in health care whereby patient education/counselling sessions are scheduled on the same date as medical follow-up.
- Structured to be effective:
 - The competencies of the HIV/TB-infected patient, meaning the skills and knowledge the patient needs to achieve, constitute the objectives of the programme (see Annex 7).
 - Incorporate the use of educational tools such as flipcharts and leaflets (see annex 12, 22,24).
 - Include an evaluation of the learning process (see Annex 8).

Counselling aims to help patients find solutions to daily problems that have a negative impact on their adherence to treatment, and to provide emotional support in difficult situations.

Patient education and counselling are complementary. Their aims are to:

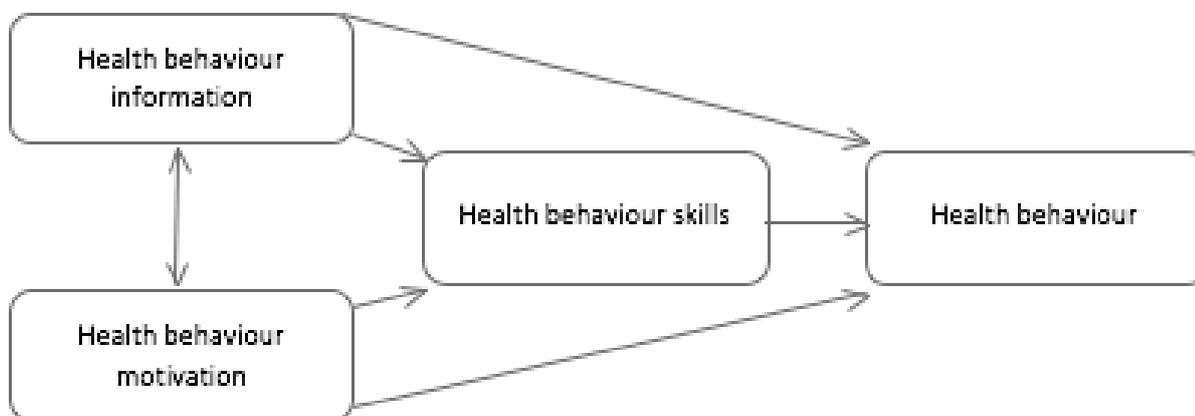
- Empower the patient facing a chronic illness and the ability to follow his treatment.
- Improve his adherence to his treatment plan.
- Ensure healthy preventive habits (condom use, moderating alcohol use, etc.).
- Reduce potential complications due to treatment failure.
- Improve/maintain quality of life.
- Provide emotional support.

Patient education and counselling relies on the quality of the relationship established between the educator/counsellor and the patient. Patient education and counselling should be based on negotiation with the patient and not on judgment, punishment or control.

The information-motivation-behavioural skills model (IMB model)^{24,25}, is a theoretical model for behaviour change that can guide patient education and counselling interventions. The model stipulates that to influence an individual's health behaviour, different factors need to be addressed such as:

- Information that is directly relevant to the promoted health behaviour.
- Motivation to practice/adopt this behaviour.
- Behavioural skills to practice this behaviour effectively.

While all the above factors influence behavioural outcome, behavioural skills are mediators between information, motivation and behaviour. This means that behavioural change cannot be accomplished without working on the practical skills: a patient may know that he needs to be adherent to treatment, but if we do not work with the patient on how to adhere (for example by making a medications schedule and planning for how to get an ART refill when travelling), good adherence will not be achieved.



3.2 Patient-centeredness

Patient education and counselling is based on the principle of providing patient-centered care. Patient-centered care is defined as care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions. *“We cannot make anyone be adherent. We can help a person to reduce the obstacles he/she encounters in the taking of his treatment and also to bring together the conditions likely to support in his/her intention to treat himself.”*²⁶

For didactic purposes, this guide systematically provides defined content for each PSEC session. The topics presented address commonly experienced challenges faced by patients at a specific stage in the cascade of care.

However, it remains important to start from the needs of the patient. Topics should be adapted according to what is most urgent for the patient to address.

3.3 Communication and counselling skills

Staff involved in patient education and counselling need to be competent in using communication skills which will allow the patient to adopt healthy practices. Sometimes healthcare providers have the impression patients are not following their advice, but very often this is because they do not know how to talk to them or because we have talked to them without listening to them. See annex 9 for more on communication and basic counselling skills such as attending, active listening and responding with empathy.

Basic counselling skills may be enough to support most patients. But for high-risk patients, such as patients with mental health problems or patients on drug-resistant TB treatment, more advanced counselling skills, such as skills in motivational interviewing, may be necessary to produce behaviour change. The goal of motivational interviewing is to identify motivation for behavioural change and to improve the patient’s self-confidence and belief in his self-efficacy to produce the desired changes.

Healthcare providers need to be specifically trained to apply these advanced techniques. For more detailed information, see WR Miller and S Rollnick, *Motivational interviewing, Preparing people for change*, 2002.

3.4 Individual and group sessions

Patient education/counselling sessions can be performed individually or in groups. The choice will depend on the content of the session, patient load, and organisation of the clinic day and skills of the staff involved.

	Individual	Group
Advantage	Allows to assist each patient as they arrive in the clinic – little organisation needed. Better adapted to explore patient's issues in-depth.	Less HR and time needed. Allows for sharing of experience and peer support Ideal for educational sessions. Gets patients out of isolation. According to objectives of the session, groups can be small or big.
Disadvantage	Time and HR intensive.	Group facilitator needs strong communication skills to ensure constructive exchange among participants. Needs good organisation to ensure a group of patients can be formed. Patients need to respect starting time and cannot just walk in when they are around. <u>Low attendance when not planned at the same day as consultation.</u> Groups need to be as homogeneous as possible regarding age, challenges faced, ...

Flow of an individual session

Preparation - before seeing the patient

- Prepare the room to ensure confidentiality and a good seating position of the patient.
- Review in the patient file what was previously discussed with the patient.
- Identify the goal of the session according to patient needs.

Introduction phase – with the patient

- Establish a warm rapport with the patient.
- Present yourself and role.
- Present the purpose of the session and the topics to be covered. Check if the patient agrees with this.
- Set the duration of the session, an ideal timing being about 30 minutes.

Body of the session - with the patient

According to the needs of the patient, following topics may be addressed:

- Assess the patient's needs by asking the patient open-ended questions and respond to the patient's preoccupations, even if they do not coincide with the topic prepared.

- Assess social status: social stigma, economic concern, HIV status disclosure, social support.
- Assess emotion: loneliness, self-blame, self-esteem, anxiety, depressed mood, hopes; provide counselling support with regard to emotional reactions.
- Assess behavioural skills: medication schedule, reminder strategies, etc...
- Assess patient's knowledge and then:
 - Validate, acknowledge correct responses.
 - Complete if necessary.
 - Correct misconceptions and explain why.
 - Check understanding.
 - Use visual aids: flipchart, leaflet.
- Discusses the issue consistent with the goals stated at the beginning.
- Then ask patient if there are other areas he would like to discuss.

End of the session

- Summarise with the patient the information, decisions and goals discussed.
- Propose another session to continue if needed and see if the patient agrees.
- Ensure the patient leaves with the necessary material.
- Document relevant information in the patient's file: topics discussed, what patient knows, what needs to be reviewed, barriers to adherence.

Group sessions

Different methodologies can be used to facilitate group sessions. Interactive learning sessions can be used for educational purposes and are more participative than a standard lecture. Roundtables are debates with a group of patients. They can discuss questions and sensitive topics, share experiences, exchange ideas and opinions, and identify values. It is important to plan the topic and the composition of the group in advance.

For more technical information on how to animate a group session (see Annex 10).

4. Patient support, education and counselling sessions along the cascade of care

4.1 Overview of the PSEC sessions

This chart gives an overview of the sessions to be offered along the steps in the cascade of care. Sessions marked in *italics* are optional.

HIV/ART services		
Step in the cascade	Session	Topics
HIV Testing Services	Pre-test information	Benefits of HIV testing Meaning of HIV test result Follow-up services in case of a positive result
	Post-test counselling	Emotional support Meaning of result Linkage to prevention or treatment services
<i>Entry into HIV care</i>	Initial assessment of patient's needs	Assessment of cognitive, emotional, social and behavioural components and barriers
<i>Follow-up of patients not yet eligible for ART</i>	<i>Pre-ART session</i>	<i>HIV/AIDS, importance of regular follow-up, coping with disease</i>
ART initiation and early follow-up	HIV/ART education session	Basic facts on HIV & ART Making an informed decision on starting ART
	<i>ART readiness session</i>	<i>Overcome barriers to start ART</i>
	ART initiation session	How to take medication
	Adherence follow-up at M1 on ART	Evaluate and support adherence Planning for trips Dealing with substance use
	Adherence follow-up at M3 on ART	Evaluate and support adherence Prevent future problems in taking ART Explaining viral load
	Adherence follow-up at M6 on ART	Evaluate and support adherence Explain differentiated ART delivery models

HIV/ART services*(continued)*

HIV/ART services		
Step in the cascade	Session	Topics
Long-term follow-up of patients on ART	PSEC session for patient with an adherence issue or who missed an appointment	Identify the adherence issue and find an appropriate solution
	EAC sessions for patients with a high VL	Educate on VL result Assess previous and current adherence Identify barriers to adherence Evaluate strategies put in place to improve adherence
	PSEC session for patients changing treatment in same regimen line	Explain reason for change and new dose and time management of medication
	PSEC sessions for 2 nd or 3 rd line ART initiation	Prepare the patient to start 2 nd line treatment Support adherence
	Supporting disclosure	Supporting disclosure of HIV results to partner : positive and negative aspect.
Other	Reproductive decisions	Discuss reproductive decisions with everybody in reproductive age or patients who express a wish to have children
	Key populations	Supporting sex workers, men having sex with men, people who inject drugs, people in prisons and transgender people
	Adherence to biomedical prevention methods	Educating on Pre-Exposure Prophylaxis (PreP) and Post-Expose Prophylaxis (PEP).
	Migratory movements	Supporting patients who are highly mobile (look for jobs away from home, because of conflict situations, ...)

PMTCT services		
Step in the cascade	Session	Topics
HIV Testing Services	Pre-test information	Benefits of HIV testing Meaning of HIV test result Follow-up services in case of a positive result
	Post-test counselling	Emotional support Meaning of result Linkage to PMTCT services
ART initiation and early follow-up during antenatal care	ART initiation session at ANC 1	ART/PMTCT education in nutshell How to take medication as prescribed
	PMTCT/ART education session at ANC 2	Basic facts on ART and PMTCT
	Planning for birth session at ANC3	Evaluate and support adherence Plan for delivery, feeding of the baby and medication for the baby
	Review of adherence at ANC 4	Evaluate and support adherence
Follow-up during postnatal care	Feeding and treatment follow-up session	Evaluate and support adherence to medication of mother and baby, feeding Explain need for PCR testing
	PCR session	Evaluate and support adherence Explain family planning Explain switch to Cotrim syrup for the baby
	PCR result session	Give PCR result and support accordingly
	Complementary feeding session	Evaluate and support adherence How to introduce other foods
	Weaning session	Evaluate and support adherence How to stop breastfeeding
	Rapid HIV test session	Explain the result of the rapid HIV test for the baby at 18 months of age
ART initiation for HIV-infected infant	ART initiation sessions	Why and how to take medication

TB care		
Steps in the TB cascade	Session DS-TB	Topics
Drug sensitive TB	PSEC at TB screening	Basic facts on TB TB screening procedures
	PSEC at DS-TB treatment initiation	Basic facts on TB and its treatment How to adhere to TB treatment
	PSEC after DS-TB treatment initiation	Evaluate and support adherence Review TB knowledge Explain monitoring tests for TB
	PSEC at the end of DS-TB intensive phase	Explain reason and change in drug regimen Explain the importance to continue treatment
	Additional PSEC throughout DS-TB treatment	Evaluate and support adherence
Drug resistant TB	PSEC at TB screening	Basic facts on TB TB screening procedures
	PSEC session at DR-TB treatment initiation	Basic facts on DR-TB and its treatment How to adhere to DR-TB treatment Mental health screening
	PSEC session after DR-TB treatment initiation	Evaluate and support adherence Review DR-TB knowledge Explain monitoring tests for DR-TB Discuss side-effects
	Home visit	Basic facts on DR-TB, its treatment and infections control measures Social assessment Contact Tracing
	PSEC sessions during DR-TB follow-up	Support and evaluate adherence
	Other PSEC sessions for DR-TB	Hospitalisation, interrupting treatment, XDR, treatment failure
HIV/TB coinfection	PSEC sessions to start ART while on TB treatment	Integration of counselling sessions for ART and TB
	PSEC session to start TB while on ART	
	Co-infection with DR-TB	

4.2 Patient support, education and counselling for HIV Testing Services

Different type of HIV testing services (HTS) exist. In terms of where services are provided, HTS can be offered at health facility level, as well as in the community. In terms of who requests testing, there is an important difference between client-initiated testing and provider-initiated testing:

- Client-initiated HIV testing, or Voluntary Testing and Counselling (VTC), involves individuals voluntarily seeking HTS (“opting-in”).
- Provider-initiated HIV testing and counselling (PITC) is HIV testing and counselling which is proposed by health care providers to persons attending health care facilities as a component of medical care. Patients do have the possibility to decline (“opting-out”).

More information on HIV testing procedures and ways to implement HIV testing can be found in WHO’s consolidated guidelines for HIV testing, 2015.

All HIV testing services should apply the following principles as defined by WHO, also called the “5Cs”, in all circumstances²⁷:

Consent

People receiving HTS must give informed consent to be tested and counselled. Verbal consent is sufficient according to WHO recommendations, but a few countries may still require written consent. People should always be informed of the process for HIV testing and counselling and of their right to decline testing.

Confidentiality

HTS must be confidential, meaning that what the HTS provider and the client discuss will not be disclosed to anyone else without the expressed consent of the person being tested. Confidentiality should be respected, but it should not reinforce secrecy, stigma or shame. Counsellors should discuss whom the person may wish to inform and how they will proceed with this. Shared confidentiality with a partner, family members or trusted others is often highly beneficial. Shared confidentiality with health care workers is standard practice in MSF programmes in order to better serve the patient.

Counselling

Pre-test information can be provided in a group setting, but all people should have the opportunity to ask questions in a private setting if they request it. All HIV testing must be accompanied by appropriate and high-quality post-test counselling, based on the specific HIV test result and HIV status reported. Quality assurance (QA) mechanisms as well as supportive supervision and mentoring systems should be in place to ensure the provision of high-quality counselling.

Correct

Providers of HIV testing should strive to provide high-quality testing services, and quality assurance (QA) mechanisms should ensure that people receive a correct diagnosis. QA may include both internal and external measures and should receive support from the national reference laboratory. For the testing algorithm in your project, refer to your laboratory referent.

Connection

Linkage to prevention, treatment and care services should include effective and appropriate follow-up, including long-term prevention and treatment support. When access to ART is not ensured in the project, MSF should put all efforts in place to guarantee it. Every effort should be made to connect people with new HIV diagnosis to appropriate care & services.

An HIV testing and counselling session includes three steps: individual or group pre-test education, individual testing and individual post-test counselling.

4.2.1 Pre-test information

Pre-test information can be provided individually or in group. Informed consent should always be given individually, as much as possible in private. Pre-test information should include at the minimum:

- The benefits of testing for HIV.
- What is HIV and its modes of transmission (in contexts where general HIV knowledge is low).
- The reasons why HIV testing is being recommended (in case of PITC).
- The fact that the result and any information shared by the client will remain confidential.
- The fact that the patient has the right to decline the test and the fact that declining an HIV test will not affect the patient's access to services that do not depend upon knowledge of his HIV status.
- The HIV testing process (drawing of blood or finger-prick, testing procedure, timing of results).
- The meaning of an HIV-positive and an HIV-negative result.
- The potential for incorrect results if a person already on ART is given an HIV test.
- Information regarding the follow-up services that are available in the case of an HIV-positive test result.
- A brief description of prevention options and encouragement of partner testing.
- An opportunity to ask the provider questions.

Pre-test information for women who are pregnant is addressed in section 3.8.1.

4.2.2 Post-test counselling

Post-test counselling is provided for all people, whether they test HIV-positive or negative, in an individual session.

Giving NEGATIVE results

WHO (2015) recommends that individuals who test HIV-negative should receive brief health information about their test results. Research to date has not demonstrated that a lengthy counselling session is needed or is beneficial. Further, lengthy post-test counselling for people testing negative may divert counselling resources that are needed by those who test HIV-positive, those whose results are inconclusive and those who are found to be in a sero-discordant relationship.

- Give the result in a simple and clear way.
- Explain the meaning of the result and the window period and assess if there has been 'at risk' behaviour in the preceding 3 months; recommend re-testing in case of a recent exposure.
- Educate on methods to prevent HIV acquisition, and provision of male or female condoms, lubricant and guidance on their use with demonstration.
- Emphasize on the importance of knowing the HIV status of sexual partner(s) and give information about the availability of partner and couples testing services.
- Referral and linkage to relevant HIV prevention services – when available- including medical male circumcision for HIV-negative men, PEP for accidental HIV –exposure and cases of sexual assault, PrEP for people at substantial or ongoing HIV risk.
- Discuss any other immediate concerns the person might raise.

Giving POSITIVE results

It is important to adapt the post-test counselling to the needs of each patient. Some patients receiving a positive HIV result may be unable to understand and absorb a lot of information, due to their emotional state. Therefore, the counsellor should first assist them emotionally and offer further session(s) to explain general facts.

The topics to be addressed for people with an HIV-positive test result are:

- Give the result in a simple and clear way.
- Explain the test results and diagnosis or need for confirmatory test.
- Give the client time to consider the results and help the client cope with emotions arising from the diagnosis of HIV infection.
- Discuss immediate concerns and help the client decide who in her or his social network may be available to provide immediate support.
- Provide clear information on ART and its benefits for maintaining health and reducing the risk of HIV transmission, as well as where and how to obtain ART.
- Make an active referral for a specific time and date within at least 14 days. (An active referral is one in which the tester makes an appointment for the client or accompanies the client to an appointment, including an appointment for co-located services, and enrolment into HIV clinical care.) Discuss barriers to linkage to care, same-day enrolment, ART eligibility assessment and the possibility of same-day ART initiation. Arrange for follow-up of clients who are unable to enrol in HIV care on the day of diagnosis.
- Provide information on how to prevent transmission of HIV, including information of the reduced transmission risk when virally suppressed on ART; provide male or female condoms and lubricants and guidance on their use.
- Discuss possible disclosure of the result and the risks and benefits of disclosure, particularly among couples and partners. Offer couples counselling to support mutual disclosure.
- Encourage and offer HIV testing for sexual partners, children and other family members of the client. This can be done individually, through partner invitation letters, couples testing, index testing or partner notification.
- Assess the risk of intimate partner violence and discuss a safety plan with the client, particularly women, who are diagnosed HIV-positive.
- If staff is trained: Assess the risk of suicide, depression and other mental health consequences of a diagnosis of HIV infection (see annex 13 and 14).
- Provide additional referrals for prevention, counselling, support and other services as appropriate (for example, TB diagnosis and treatment, prophylaxis for opportunistic infections, STI screening and treatment, sexuality counselling, contraception, ANC, opioid substitution therapy (OST), and access to sterile needles and syringes).
- Encourage and provide time for the client to ask additional questions.

4.2.3 Couple HIV testing and counselling

Specific considerations need to be taken into account when testing couples.

HIV pre-test information for couples

Couples should be seen together for the pre-test information. The wish to receive the results as a couple or individually needs to be discussed during the pre-test phase, at which point we may promote that the partners receive their results simultaneously in order to facilitate disclosure and mutual support. The possibility of sero-discordancy needs to be explained.

HIV post-test counselling for sero-discordant results

When sero-discordant results are delivered to a couple, it often raises a lot of questions on the future of the relationship.

- It is important to reduce tension and blame in the couple. The counsellor needs to listen to the couple and encourage them to find a solution together. It is important not to choose sides with any of the partners.
- Sero-discordant couples need to be counselled on risk reduction strategies. It is recommended that the HIV positive partner in a discordant couple is started on treatment regardless of CD4, to reduce the risk of infecting the HIV-negative partner. The couple needs to know that chances of infection are very low when the partner on ART is adherent and maintains an undetectable viral load. Secondly, protective strategies such as condom use need to be discussed.
- Reproductive options and choices need to be discussed (see chapter 3.10.2).

4.2.4 HIV self-testing

HIV self-testing is a process in which a person collects his or her own specimen (oral fluid or blood) and then performs an HIV test and interprets the result, often in a private setting, either alone or with someone he or she trusts²⁸.

Regardless of approach, self-testers must be provided with clear information on how to correctly perform the test, interpret the result, as well as where and how to access stigma-free HIV testing, HIV prevention, treatment, care and support services. This can be provided for example in the form of a leaflet, a hotline, or a group education/counselling session.

4.3 Patient support, education and counselling at entry into care – initial assessment of the patient’s needs

This patient needs assessment is optional and may not be offered in every programme. According to the characteristics of the project’s target group, patient loads, resources available, and ART initiation strategies, one may consider doing an initial assessment of the patient’s needs at the patient’s entry into the HIV/TB programme. Often this is done in projects with groups at high risk of being lost to follow-up, or having problems to adhere like patients on DR-TB treatment, or where there is a time delay between screening, diagnosis and treatment initiation.

Alternatively, this assessment can be done for a restricted group of patients, or for patients facing a specific problem later on in their follow-up (for ex. with patients with a high viral load or hospitalised patients) or completed over different sessions.

When At the first contact with the patient at entry to care.

Mode Individual

Duration 30-45 min

Tools File for initial patient needs assessment (See Annex 11).

Objectives

- Establish a trustful relationship with the patient.
- Assess the patient’s needs on knowledge, emotional, socio-economic and behavioural level.

Topics

Patient’s medical status

- Check the information in the medical file: disease stage, treatment background, etc ...
- Identify problems that might influence the counselling and education process (e.g. fatigue, hearing or visual impairment).

What the patient knows (cognitive component)

- Knowledge and cultural beliefs about the disease and treatment.
- Capacity to memorise information.

What the patient does (socio-economic component)

- Profession/occupation.
- Disclosure of HIV or TB status to relatives.
- Social support and how the patient perceives this support.
- Social stigma and discrimination.
- Economic concerns.
- Drug and alcohol use.
- Possible difficulties in coming to the clinic.
- Intimate relationship and sexual life, relation with partner, desire for children, etc ...

How the patient feels (emotional component)

- The patient's emotional reactions to his disease.
- Level of self-esteem.
- Self-efficacy (belief in his capabilities to achieve a goal).
- Mental health status (See Annex 13 and 14).

Behavioural

- What is the patient's ability to follow a routine/ daily regimen.
- What reminder tools has the patient used before when taking medication ?
- How has the patient managed to take medication before, when taking alcohol/drugs.
- Is the patient mobile and how does he deal with health issues when moving ?

Plan (future)

- Does the patient have a life plan?
- What is this plan? (e.g. having a child, finding a job, taking care of his garden)
- Motivation to accomplish this plan.
- How realistic is the plan?

4.4 Patient support, education and counselling for patients not yet eligible for ART

This chapter covers the interventions between the moment of HIV diagnosis until patients are found to be eligible to start ART. In the majority of projects this phase no longer exists, due to implementation of ART initiation regardless of CD4 count (also called "Test and Start"). In projects where ART initiation for all is not (yet) implemented, patients not yet eligible for ART should come to the clinic 6-monthly appointment for a CD4 count and regularly for follow up of possible opportunistic infections and cotrimoxazole treatment. The same is true for patients eligible for ART but not yet willing to start. For more information on the clinical follow-up of ineligible patients, check the MSF HIV/TB clinical guide (2015).

The percentage of loss to follow-up (LTFU) among patients not yet eligible for ART is quite high and patients often return to the clinic only after becoming/feeling ill. It is in that case important to counsel patients not taking ARV treatment on coping with an HIV diagnosis, facilitating the disclosure process, and the importance of returning for clinic appointments and routine laboratory tests, especially CD4 counts, and ART initiation.

When At day of defining non-eligibility for treatment.

Mode individually or in group

Duration 30-45 minutes

Tools HIV/ART flipchart (see Annex 12)
Patient Knowledge Assessment (see annex 8)

Objectives

- Explain the evolution of HIV infection with and without ART.
- Explain the importance of regular medical follow-up.
- Discuss coping with HIV diagnosis.

Topics

Educational components

Assess knowledge of HIV/AIDS and medication and according to the gap identified explain:

- The ways of transmission and prevention of HIV virus, including a demonstration of condom use.

- The role of the immune system (health and diseases, CD4 and the body's defences) (Flipchart card 1).
- The effect of HIV on the immune system (Flipchart card 1).
- Opportunistic infections and the need to start treatment (Flipchart card 1).
- ARV treatment (the action of ART on HIV, the importance of starting treatment early) (Flipchart card 2).
- Medical and biological (especially CD4) follow-up of patients not yet eligible.
- Consulting at the first signs of TB: cough for more than 2 weeks, fever, weight loss, sweating at night.
- Purpose of cotrimoxazole.
- Importance of coming to the health facility as quickly as possible when the patient becomes sick.

Emotional and social components

- Assess patient's emotional reactions and coping mechanisms when learning his/her HIV status. Provide support if needed.
- Screen for depression and drug use (see annex 13 and 14) and refer to psychologist or physician for diagnosis and care as indicated.
- Encourage testing of family members (partner and children).
- Explore benefits or potential risks of disclosing one's status. Assess to whom the patient has disclosed or is considering disclosing. Provide strategies, invite partner for couple counselling on disclosure, testing, and safer sex practices.
- Assess socio-economic obstacles to coming back to the clinic and staying in care.
- Encourage linkage with community support groups, and/or links to peer educators/support.

4.5 Patient support, education and counselling for ART initiation and early follow-up

This chapter covers the interventions between defining the patient's eligibility to start treatment, until the first viral load (or in absence, CD4 count). WHO now recommends that all patients diagnosed HIV positive regardless of their CD4 count are eligible for ART and could theoretically be started on ART on the day of HIV diagnosis. Its implementation is dependent on country policy. For more medical information on ART initiation and initial follow-up, consult the MSF HIV/TB clinical guide (2015).

Patients eligible to start ART should be supported to adhere to their new ARV treatment and retain in care. Traditionally patients have gone through several education and counselling sessions before starting ART. Recent findings show that rapid ART initiation can be implemented in routine programme settings, reducing delays in ART initiation. Evidence is mixed on the health benefits for patients of same day ART initiation^{29,30,31,32}. This suggests that an approach whereby counselling procedures are adapted to allow for same-day initiation on ART for patients who feel ready to start, while retaining the option to start later if the individual requires more support, need to be considered³³.

This guideline proposes a PSEC intervention for rapid ART initiation, as well as an option for same day ART initiation (meaning initiation at the same day of HIV diagnosis). Projects need to define the best strategy for their target group according to the medical strategy in place, community awareness on HIV and HIV-related stigma, barriers to start ART and country policy. After definition of eligibility by the medical staff, the choice for when to start ART remains however always with the patient.

Routine PSEC sessions are offered within the first 6 months of starting ART, until the first viral load is done, as optimising adherence in the early months of treatment is crucial to ensure long-term immuno-virological success^{34,35}.

Many misunderstandings around adherence exist amongst patients, but also amongst healthcare providers. It is useful to clarify these within your project team, so the correct and same messages are passed by all the staff. See Annex 15- Misunderstanding around adherence

Following tools can be used for all sessions:

- An example of a detailed session guide for ART initiation counselling, integrated for HIV and TB (Annex 16).
- Patient file - Adherence plan (Annex 16).
- HIV/ART flipchart (Annex 12).
- Additional material as a video or leaflet may be used (see health promotion toolkit).
- Sample or pictures of medication.

4.5.1 PSEC for rapid ART initiation

The flow of PSEC sessions for ART initiation and early follow-up consists of one PSEC session before starting ART, one at ART initiation, and one at M1, M3 and M6 on ART.

HIV/ART education session

When	At definition of ART eligibility
Mode	In group or individually for educational component. Individually for other components.
Duration	40 minutes

Objectives

- Explain basic facts on HIV & ART.
- Make an informed decision on starting ART.

Topics

In group/individual

Assess current knowledge and beliefs regarding HIV/AIDS and ARV and according to the gap identified, explain the following topics, using the flip chart:

- The ways of transmission and prevention of HIV virus, including a demonstration of condom use (in case this has not been offered before).
- The role of the immune system (health and diseases, CD4 and the body's defences) (Flipchart card 1).
- The effect of HIV on the immune system (Flipchart card 1).
- Opportunistic infections and the need to start treatment (Flipchart card 1).
- ARV treatment (the action of ART on HIV, the importance of starting treatment early, side-effects) (Flipchart card 2).
- How to adhere to ART (Flipchart card 3).
- Risks of poor adherence to ART (Flipchart card 5).

Individual

- Identify patient's life goals and reasons to start ART.
 - Help the patient think about what is important in his life and write down 2 or 3 goals in the adherence plan.
- Identify a support system and a potential treatment buddy.
 - Explain that it can be a big help to have told somebody about one's HIV status, who can support when needed.
 - Identify who could fulfil this role and what would be the barriers to disclose.
 - Make a plan on to whom and how to disclose.

- Plan how the patient will get to future appointments.
 - Explain the need for regular medical check-up and ART refills.
 - Identify barriers to come to the clinic regularly (like lack of transport money, asking permission at work, etc...).
 - Make a plan on how to remember clinic visits and how to get to the clinic.
- Assess patient's readiness to start ART.
 - Explain the patient that healthcare provider advises the patient to start treatment at their next appointment, but that it is up to the patient to take the final decision.
 - Explore if the patients still has any concerns around starting ART.
 - If the patient feels ready, book an appointment for the ART initiation session(s). In case the patient does not feel ready, book an appointment for the ART readiness session.

ART readiness session

When Within 1 to 2 weeks after the HIV/ART education session for patients not feeling ready to start ART.

Mode In group/individually; preferably with an expert patient / peer supporter.

Duration 20-40 minutes

Objective Overcome barriers to start ART.

Topics

- Explore the reasons why the patient does not feel comfortable to start ART (difficulties to accept status, disclosure, side effects, feeling healthy, etc.).
- Explore what the patient would feel as a right time to start and what needs to be put in place in order to feel ready to start.
- Show understanding and normalise patient's concerns.
- Share the testimony of an expert patient (by expert patient in person, or by a story – see annex 16 -, or by arranging a meeting with an expert patient) and discuss what affected the patient in this testimony.
- According to the patient's concerns, identify a plan to facilitate the patient's coping and their confidence to start ART (for example: making a plan to disclose, normalising certain fears of side-effects, improving social support systems,...).
- Explain the way forward: book for the ART initiation session or re-invite for an ART readiness session.

ART initiation session

When At ART initiation for all eligible patients feeling ready to start ART.

Mode Individually

Duration 25 minutes

Objective Planning around how to take the medication as prescribed.

Topics

- Assess whether information given at the last session has been understood (questions in Annex 8 can be used).
- Creation of a medication schedule
 - Explain how the medication needs to be taken at the same time every day (number of pills, timing).
 - Identify with the patient how a regular day looks like, what may be easy habits to link taking of medication to and what may be difficult times to take pills (e.g. weekends).

- Plan what is the best moment to take ART.
- If pill boxes are available and needed for the patient, educate on how to use those.
- Plan on how to manage missed doses.
 - Explain that it is important to not miss doses to ensure there is always enough medication circulating in the body to fight HIV.
 - Explain how a missed dose should be taken within 12 hours of the scheduled dose time. Explain to not take the missed dose if the next dose is scheduled less than 12 hours later. Advise the patient to return to the regular medication schedule the next day. (This is for once daily regimes - see annex 15 for more info in other regimens).
- Identify reminder strategies:
 - Explain that it can be useful to have reminders to remember when to take treatment and to remind you of the reasons to stay healthy.
 - Identify what difficulties the patient may have had previously to be reminded to take drugs or what tools were used.
 - Plan what tools could be used to reinforce reminders to take the drugs and to be mindful of the reasons to stay healthy.
- Identify where to store medication at home and to keep extra doses when away from home.
 - Explain that it is important to identify a convenient place to store medication and to carry some medication with you in case of travel, or being away from home. In unstable settings explain the patient about the existence of a contingency plan to avoid treatment interruptions.
 - Plan where the medication could be kept at home.
 - Plan where an extra doses could be kept (in pocket of a jacket, in a little envelope in a purse...).
- Plan on how to deal with side effects.
 - Explain the common side-effects of the patient's regimen (see Annex 17) and what to do when they occur.
 - Remind the patient not to stop taking treatment, to come to the health facility and to report any side-effects to their healthcare provider (especially in case of rash or yellow eyes/skin).
- Ask consent for phone calls, SMS and/or home visits.

Adherence follow-up session at month 1 on ART

When At month 1 on ART

Mode Individually

Duration 20 minutes

Objectives Evaluate adherence and verify the patient takes the medication as prescribed.
Plan for trips.
Deal with substance use.

Topics

- Ask how the patient is feeling and how taking the treatment is working.
- Ask the patient to describe the way he takes ARV treatment and evaluate the patient's adherence (see Annex 18 and chapter 3.7.1).
- Ask if the patient has experienced any side effects and how he copes with them (see Annex 17).
- Review how the implementation of the plans made in previous session is working (disclosure, medication schedule, storing drugs...) and adapt the plan as needed.
- Plan for trips:
 - Explain that it important to stay on treatment even when you are travelling (Flipchart card 7).
 - Asses how common it is for the patient to travel and what regular travel destinations are.

- Make a plan on what to do in case of a planned trip (longer drug refill, transfer letter for another health facility...).
- Make a plan on what to do in case of an unplanned trip (taking ART card on trips, keep phone number of regular clinic in phone, asking family member to collect and send medication...).
- Plan for dealing with substance use (alcohol, drugs):
 - Explain how it may be difficult to remember to take ART when using alcohol or drugs (see more details in Annex 15) and how it is important to plan ahead.
 - Assess how often the patient uses alcohol or drugs and how this has affected adherence in the past.
 - Make a plan on how to take medication when going out for drinks.
 - Screen for alcohol substance use (Annex 14) and refer in case needed.
- Address any other topic as identified by patient.

Adherence follow-up session at month 3 on ART

When At month 3 on ART

Mode Individual

Duration 20 minutes

Objectives Evaluate adherence and verify the patient takes treatment as prescribed.
Prevent future problem in taking ART.
Explain the role of the viral load test.

Topics

- Ask how the patient is feeling and how taking the treatment is working.
- Address any topic as identified by patient.
- Evaluate the patient's adherence (see Annex 18).
- Review how the implementation of the plans made in previous session is working (disclosure, medication schedule, storing drugs, planning for trips, dealing with substance use ...) and adapt the plan as needed.
- Preventing future problems in taking treatment.
 - Explain to the patient that learning a new habit like adhering to treatment takes time and practice. Mistakes are normal and it is important to get back to the adherence plan as soon as possible and not give up.
 - Assess how the patient would react if he forgot to take medication and what he could do to pick himself up and start treatment again.
- Educate on viral load monitoring.
 - Explain the facts on viral load: how to know if treatment is working, when to have a viral load test, what a low and high viral load result means (Flipchart card 4) and review the risks of poor adherence (Flipchart card 5).
 - Explain that it is the goal for the patient to reach an undetectable viral load.

Adherence follow-up session at month 6 on ART

When At month 6 on ART.

Mode Individual

Duration 20 minutes

Objectives Evaluate adherence and verify that the patient takes treatment as prescribed.
Explain differentiated ART delivery models.

Topics

- Ask how the patient is feeling and how taking the treatment is working.
- Evaluate the patient's adherence (see Annex 18).
- Review how the implementation of the plans made in previous session is working (disclosure, medication schedule, storing drugs, planning for trips, dealing with substance use ...) and adapt the plan as needed.
- Review that a viral load test will be performed today and its possible results.
- Plan for alternative options for ART refill.
 - Explain the medical follow-up for patient with an undetectable viral load (often yearly clinic visit and blood drawing for viral load).
 - Inform the patient on the differentiated ART delivery models available (individual/grouped, facility or community-based) for patients with an undetectable viral load (Flipchart card 8).
 - Explore what the patients preference would be for ART refill.
 - Explain that the patient can ask the healthcare provider to check if they can join such a model.
- Inform the patient that in the future patient education/counselling is available per the patient's request or as recommended by the health care provider.
- Address any other topic as identified by patient.

4.5.2 PSEC for same-day ART initiation

When a project wants to offer patients the choice to initiate ART at the same day of HIV diagnosis / when ART eligibility is identified, an adapted session flow and content is needed to ensure patients do not get overloaded with information. There is a risk that patients feel forced to start ART initiation the same day³⁶ and coercion to begin same-day initiation should be avoided. The choice to start remains with the patient, who may want to postpone initiation until they are able to have a discussion with their partner, or when they have absorbed the reality of the HIV diagnosis. A follow-up plan needs to be made for patients who do not feel ready to start treatment at the same day of diagnosis.

The first session at the day of ART initiation should focus on:

- Providing brief ART education:
 - Explaining that starting ART improves one's own health and prevents diseases, as it stops HIV from attacking the body's defences.
 - Explain that ART reduces transmission to sexual partners and to an exposed baby, as ART reduces the amount of HIV in the body.
 - Explain that ART needs to be taken daily for life, as ARVs are not a cure but are effective for controlling HIV.
- Assess the patient's readiness to start ART:
 - Explain to the patient that the healthcare provider advises the patient to start today, but that it is up to the patient to take the final decision.
 - Explore if the patients still has any concerns around starting ART.
 - If the patient feels ready, continue with the points below. In case the patient does not feel ready, book an appointment for the ART readiness session.
- Focus on the adherence skills by addressing the individual components of the HIV/ART education and ART initiation session.

The second session should be offered at the next medical visit, normally at week 2 on treatment, addressing the educational components of the ART education session. This can be offered in group at a fixed day for all patients who were initiated on ART over the last 2 weeks.

The adherence follow-up sessions can be offered at month 1, 3 and 6, using the same content as proposed for the rapid ART initiation sessions.

4.6 Patient support, education and counselling for long term follow up of patients on ART

This chapter covers the PSEC interventions after the first viral load is taken, and continues throughout the lifelong treatment journey. Stable patients will begin attending less frequently for clinical consultations, blood drawing and ART refill, while unstable patients will require a more intensive follow-up.

After a first undetectable viral load test result, routine patient support, education and counselling can cease. Patients will be offered PSEC at their own request, or when recommended by the healthcare provider. Ongoing peer support can be offered through support groups and group-models of differentiated ART delivery, whereby health education and peer support are part of the package. More information on such models can be found in the report *Reaching Closer to Home*³⁷ and in the adherence club³⁸, CAG³⁹ or PODI⁴⁰ toolkit on www.samumsf.org.

Adherence patterns can change over time and individual patients will need different levels of support as their life circumstances change. It is therefore expected that all patients will need extra support at certain stages within their life-long treatment paths. Referral criteria to be used by the healthcare provider need to be clearly identified within the project which will trigger additional support to the patients (see chapter 3.7.1). Also during the first six months on treatment, patients may be referred for extra support outside of the routine PSEC sessions as proposed in chapter 3.6, based on the same referral criteria.

4.6.1 Identifying adherence and retention problems

Measuring adherence to medication is difficult, as no completely reliable method exists. Several methods to measure adherence to treatment are currently in use such as patient self-reporting, pill counts and biological markers (VL, or in its absence CD4). All methods have their strengths and weaknesses, which are described in table 1. No one method offers the security of a totally accurate account of the individual's adherence.

Table 1: Methods to measure adherence: advantages and disadvantages^{41,42,43,44}

Method	Advantage	Disadvantage
VL testing	<ul style="list-style-type: none"> - Objective. - Golden standard to monitor adherence and confirming treatment response. - Increasingly routinely available. 	<ul style="list-style-type: none"> - Needs additional methods to explore reasons for non-adherence.
Patient self-reporting <ul style="list-style-type: none"> - by interview - by questionnaire - Morisky scale - with Visual Analogue Scale (VAS) 	<ul style="list-style-type: none"> - Easy to routinely perform in a clinic setting. - Involves the patient. - Can determine the reasons why patients are non-adherent. - Cost-efficient. - Recommended to be done routinely at every clinic visit 	<ul style="list-style-type: none"> - Subjective. - Specific, fairly insensitive. - Overestimation of adherence. Patient has the desire to please health staff. - Reflects short-term adherence (patient cannot remember correctly his adherence for more than 3-4 days). - The way in which questions are asked play a role in the quality of information received.
Pharmacy refill data (being late for ART refill appointment)	<ul style="list-style-type: none"> - Objective. - Feasible in routine clinical practice. - Cost-efficient. - Recommended to be done routinely. 	<ul style="list-style-type: none"> - Fairly specific, fairly sensitive. - No detection of adherence patterns.

Pill count	<ul style="list-style-type: none"> - Objective . - Fairly specific, fairly sensitive ... 	<ul style="list-style-type: none"> - Overestimation of adherence. Accuracy affected by the patient throwing away remaining pills prior to count. - Time-consuming and difficult to perform properly: patient needs to bring back their medication to the clinic; inability to confirm who took the pills, and the timing of doses. - Perceived by the patient as a control and promotes a sense of distrust between patient and provider. - Not recommended to be done routinely.
Electronic pill-container caps (MEMS caps)	<ul style="list-style-type: none"> - Specific, too sensitive. 	<ul style="list-style-type: none"> - High cost. - Accuracy can still be affected by patients.
Drug concentration in biological samples (hair, urine...)	<ul style="list-style-type: none"> - Specific, sensitive. 	<ul style="list-style-type: none"> - Not feasible to be routinely implemented. - High cost. - Typically used for research. - Not possible to verify adherence patterns, only recent consumption.

Based on recommendations from research literature and taking into account the feasibility of patient-centeredness of methods, we recommend using the following methods to evaluate adherence:

- Viral load to be done at month 6 and then yearly (some national ART guidelines may propose an adapted schedule).
- Patient self-report to be done routinely at every clinic visit.
- Identification of patients who missed an appointment to be done routinely.

Additional methods may be chosen according to resources available in different contexts. Performing pill counts may be useful at the start of treatment, but is not recommended to do it routinely.

For a description of methods to measure adherence based on patients' self-reporting, see Annex 18.

As patients are not routinely seen by dedicated PSEC staff at every visit, other healthcare providers will need to be involved to routinely evaluate patient's adherence, like the nurse or doctor consulting the patient or the drug dispenser. It is crucial that everybody approaches the patient in a non-judgmental way.

Patients with adherence issues should be referred to the PSEC staff for additional support. We recommend the use of the following referral criteria:

- A patient with an adherence issue as identified through self reporting and referred by the clinician.
- A patient coming late for appointment (number of days exceeding number of days of buffer stock, generally more than 2 weeks).
- A patient with a high viral load (generally VL>1000 copies/ml).

Patients may also be referred by the healthcare provider for additional support when there is no specific adherence or retention issue, but when there is a change in patient's life requiring support such as:

- Patients planning to move to another area (see chapter 3.10.5).
- Patients with a wish to have children (see chapter 3.10.2).

- Pregnant/lactating women (see chapter 3.8).
- Patients with a new sexual partner.
- Patients with a positive screen for depression, alcohol or drug use (see chapter 5).
- Patients requesting specific education and counselling support.

4.6.2 PSEC for patients with an adherence issue or who missed an appointment

Who Patients with an adherence issue as identified through self-reporting / being late for an appointment.

When At day of consultation when issue is identified.

Mode Individual

Duration 20 minutes

Tools HIV/ART flipchart (annex 12)
Adherence plan (annex 16)

Objective Identify the adherence issue and help patient identify appropriate solutions.

Topics

It is important to remain patient-centered (see chapter 3.1.2). A good understanding of the patients' issues can only be obtained by listening.

- Evaluate patient's adherence and get specific information about missed doses (see annex 18):
 - In what situation(s) were doses missed?
 - Explore the reason for missed doses (forgot, misunderstanding on how to take medication, fell asleep, ran out of pills, difficulty with medication schedule, ...).
- Review the adherence plan (behavioural aspects):
 - How does the current medication schedule fit the daily routines of the patient? In which situations does he find it most difficult to take his medication?
 - What are the reminder strategies put in place? (calendar, reminders, assistance from family members or friends).
 - How does the patient plan for trips? (Asking a longer ART refill, getting medication at nearest ARV treatment clinic at travel destination, need for a transfer to another clinic...).
 - Where are extra doses of medication kept, to take when away from home?
 - How does the patient deal with side effects he may be experiencing?
 - How does the patient manage missed doses?
- Explore other factors that may affect missing doses and try to help identify adapted strategies:
 - Explore cognitive component: motivation to take ARV/TB medication, expectations about benefit of ARV/TB medication, degree of knowledge on HIV and ART.
 - Assess emotion/mental status: level of stress related to medication and related to life events, feelings of loneliness, self-blame, poor self-esteem, depressed mood, hopelessness, substance use, etc. Provide counselling support with regards to emotional concerns. For screening of mental health status, refer to Annex 13 and 14).
 - Assess socio-economic status: transportation problems, social stigma, financial concerns, HIV status disclosure, social support, occupational/educational challenges.
- Assess any need for referral back to the doctor (usually related to side effects).
- Decide with patient if a follow-up session needs to be planned.

4.6.3 PSEC for patients with a high viral load - Enhanced adherence counselling (EAC)

A high viral load test result – generally defined as a viral load of above 1000 copies/ml -is a strong indicator that a patient has problems to adhere to his treatment. While other reasons may explain a high viral load, adherence issues are the most common reason. In the period

between the first and the second viral load test (usually around 3 months), patient's adherence must be reinforced to ensure the viral load suppression. In the absence of viral load monitoring, suspicion of immunologic failure (based on CD4) or clinical failure should be used as a criteria for referral for EAC.

We recommend at least 2 EAC sessions with the patient upon receiving a viral load result above 1000 copies/ml. The first session needs to be offered the same day the viral load result is received. The second session is offered one month later and before the 2nd viral load is taken. Alternatively, the second session can be conducted the same day the second viral load is taken, to avoid delays. More sessions may be offered, according to the patient's needs.

Tools

- Example of a detailed session guide on EAC (Annex 19).
- HIV/ART flipchart (Annex 12).

Enhanced Adherence Counselling 1

When On the same day the high viral load result is given to the patient.

Mode Individually

Duration 40 min

Objectives

- Ensure patient's understanding of the VL testing result (or CD4) and most common reasons for a high viral load result.
- Identify barriers to adherence on behavioural, emotional, socio-economic and cognitive levels.
- Identify strategies to ensure good adherence to treatment.

Topics

- Give and explain the viral load result (Flipchart card 4).
- Explain the EAC procedure.
 - Assess what the patient knows about causes of high VL and explain accordingly that an adherence problem is most often the cause for a high viral load.
 - Explain that by solving the adherence problem, many patients come to an undetectable viral load within three months' time.
 - Explain the flow of EAC sessions.
- Assess previous medication adherence issues and recent adherence (annex 18).
- Explore barriers to adherence.
 - Explore knowledge gaps/cognitive barriers: understanding, beliefs (for example around traditional medicines, feeling sick...).
 - Explore behavioural barriers (medication schedule, managing missed doses,...) by using the adherence plan.
 - Explore socio-economic barriers (disclosure, support, discrimination, income...).
 - Explore emotional barriers.
- Identify ways forward based on the problems identified.

Enhanced Adherence Counselling 2

When One month after the high viral load result is given to the patient.

Mode Individually

Duration 40 min

Objective Evaluate strategies put in place to improve patient's adherence.

Topics

- Assess patient's adherence since the last EAC session.
- Evaluate the implementation of strategies put in place to improve adherence.
- Explain the next step in the EAC process (2nd viral load to be taken) and the next steps depending on the 2nd VL result.

4.6.4 Patients changing treatment within the same treatment line

Sometimes a change of regimen within the same treatment line of 1st line drugs may happen, due to side-effects or a change of medical protocol. One counselling and educational session is recommended to support the patient. Patients get used to their treatment and a change in the ARV regimen might be a factor of poor adherence. On the other hand, if the change is made because of a serious side effect felt by the patient, it could come as a relief.

Usually the clinician explains the reason for changing the treatment. However, the counsellor should:

- Ascertain whether the patient knows the reason for the change in treatment (e.g. side effects, medication intolerance, change in the recommended ARV protocol).
- Explore the patient's feelings regarding this change.
- Explain how to take the new regimen.
- Explain the potential side effect(s) of the new treatment.
- When changing ARV medicines due to side effects, explain the benefit of this change within the ARV treatment regimen.

4.6.5 Counselling and education for second-line or third-line ART initiation

After a patient went through the process of EAC and a second viral load has been taken, the doctor may confirm the patient has treatment failure – meaning the patient became resistant to ARVs and is no longer able to fight HIV with the same treatment. The patient may be switched to second line ART (or 3rd line ART if patient failed on 2nd line ART) after a decision by a multidisciplinary team.

One session at 2nd line ART initiation should be offered, to discuss the following topics:

- Explain the reason of the change.
- Explain the functioning of second-line treatment.
- Explain dose and time management of second-line medication.
- Assess patient's readiness to start treatment.
- Explain the goal of reaching an undetectable viral load.
- Implement strategies for good adherence (medication schedule, storing of drugs, managing missed doses... (see 1st line ART initiation session).

Second line follow-up counselling sessions should be planned until a first viral load at month 6 is taken, at the same intervals as for 1st line ART (month 1, 3 and 6) addressing following topics:

- Identify any barriers to his adherence.
- Identify strategies to ensure good adherence to his treatment.

After month 6 another VL test will help assess whether the patient needs further enhanced adherence counselling.

See Annex 20 for an example of session guide for 3rd line ART initiation.

Additional interventions apart from patient education and counselling should be considered for these patients, such as:

- Supportive home visits by a community volunteer (see chapter 6).

- Standard screening, diagnosis and treatment of mental health or substance use disorders (see chapter 5).
- Socio-economic support like food support or money for transport (see chapter 7).

4.7 Patient support, education and counselling in PMTCT services

This chapter describes the PSEC interventions in services for prevention of mother-to-child transmission of HIV (PMTCT). A few strategies are specific to pregnant and lactating women living with HIV:

- Pregnant or lactating women enter PMTCT services either through the HIV programme, through antenatal consultations (ANCs), at delivery, postnatal care or during community based testing. All pregnant women of unknown HIV status should be offered HIV testing at their first antenatal visit (opt-out strategy). Those women may thus not always be prepared to receive an HIV positive diagnosis. Women who test negative early in pregnancy should be retested at delivery and post-partum, according to the national protocol.
- HIV-positive pregnant women are proposed to start ARVs at the same day of their HIV diagnosis, regardless of their CD4-count, as is recommended for all HIV patients in WHO 2016 guidelines. This is to improve the health of the woman and will reduce risks of passing HIV to her baby.
- Pregnant and lactating women are a group at high risk of loss to follow up^{45,46} and extra interventions to support retention, apart from patient education and counselling, should be considered (see chapter 5, 6, 7) like appointment reminders, tracing and support groups.
- HIV-infected infants with a positive PCR result should be started as soon as possible on ART to increase their survival chances.

For more information on medical and programmatic strategies on PMTCT, consult the MSF PMTCT guidelines⁴⁷.

Depending on the context, patient support, education and counselling sessions are carried out by the ANC nurses/midwives or by dedicated PSEC staff. It is important to clarify within the project what staff will carry out sessions and collaboration may be needed to ensure that this high-risk group gets the support they need.

Women generally attend late in their pregnancy for antenatal care. Below 4 sessions are proposed in case the woman attends all ANC visits. Flexibility is however required and it is recommended to at least do the ART initiation and PMTCT/ART education session with the pregnant woman.

Tools

- Example of a detailed PMTCT session guide and adherence plan (Annex 21).
- PMTCT flipchart (Annex 22).

4.7.1 HIV testing

When	At first ANC visit, during labour & delivery, or at PNC.
Mode	Pre-test information can be done individually or in a group in the waiting room. If given in a group, ensure that everybody can hear. The testing procedure and the post-test counselling should always be done individually.
Duration	The pre-test information session should not last more than 20 minutes. When testing at delivery, women may not be in the state to go through a lengthy session. A shortened version should be offered and informed consent assured. (See annex 21). The duration of the post-test counselling will depend on the result of the patient.

Topics

Pre-test information

- Explain the fact that an HIV test is a routine test, performed as part of a set of baseline tests, recommended for her and her foetus' health, though patients have the option to refuse.
- Explain what is HIV (Flipchart card 1).
- Explain how HIV is treated (Flipchart card 2).
- Explain the risk of HIV transmission to the child if the pregnant woman is HIV-positive (Flipchart card 3).
- Explain possible ways to prevent mother-to-child transmission of HIV, including ART (Flipchart card 4).
- Recommend but do not force partner testing.
- Explain the testing procedure.
- Explain that the result of the test will remain confidential.
- Explain that the woman may refuse to take the test now but will be free to take it at a subsequent consultation.

The individual testing procedure

- Ask for consent for testing.
- Address any fears related to testing.

The individual post-test session for HIV-negative women

- Give the result in a neutral way.
- Explain the meaning of a negative HIV test and the importance of remaining HIV-negative.
- Explain that she will be offered re-testing during pregnancy, at delivery and when lactating.
- Recommend -but do not force- partner testing.
- Discuss methods of HIV prevention, adapted to the known HIV transmission risk factors for the individual or setting.
- Give condoms, as requested.

The individual post-test counselling for HIV-positive women

The post-test session for HIV-positive women is crucial. It is meant to encourage and support a woman with HIV infection to accept her status and the PMTCT intervention that will benefit both her health and that of her future infant.

- Give the result in a neutral way.
- Explain the positive test result and provide emotional support. It is critical to provide a message of hope and to help the woman understand that she is not alone.
- Assess the woman's support system and discuss to whom she could disclose her status.
- Recommend testing of partner and other family members – but do not force.
- Explain briefly that she will be offered ART today for her own health and to prevent risks of transmission to her baby and her sexual partner.

4.7.2 ART initiation session

When At the day of HIV testing and ART initiation.

Mode Individually.

The post-test counselling session for HIV positive women and the ART initiation could be combined and offered by the same healthcare provider.

Women are offered to start ART at the same day of HIV diagnosis. It is important to ensure women can opt-out for same-day initiation and women refusing to start are invited to come as soon as possible for the PMTCT/ART education session to discuss their initiation on ART.

Duration 30 minutes

Objectives Cite the four interventions to prevent HIV transmission to the baby.
Take the treatment as prescribed.

Topics

- Give emotional support.
- Assess understanding of information received during the HIV pre and post-test sessions. Accordingly, give essential but brief ART/PMTCT information (Flipchart card 4) and explain that this will be discussed in detail once treatment starts:
 - It is important for the baby's health and the mother's health to start ART as soon as possible.
 - It is important to deliver in a health facility.
 - It is important to feed the baby correctly.
 - It is important to give treatment to the baby.
- Discuss the motivation to start treatment.
 - Ask what could motivate the mother to stay healthy and start ART.
 - Reinforce the importance to start ART for the baby's health.
- Creation of a medication schedule.
 - Explain how the medication needs to be taken at the same time every day (number of pills, timing).
 - Identify with the patient how a regular day looks like, what may be easy habits to link taking of medication to and what may be difficult times to take pills (for example weekends).
 - Plan what is the best moment to take ART and practice from what container what pills would be taken.
 - If pill boxes are available and needed for the patient, educate on how to use those.
- Plan on how to manage missed doses.
 - Explain that it is important to not miss doses to ensure there is always enough medication in the body to fight HIV.
 - Explain how a missed dose should be taken within 12 hours of the scheduled dose time. Explain to not take the missed dose if the next dose is scheduled less than 12 hours later. Advise the patient to return to the regular medication schedule the next day. (This is for once daily regimes - see annex 15 for more info on other regimens).
- Identify reminder strategies:
 - Explain that it can be useful to have reminders to remember when to take medication. Explain it is useful to have reminders of reasons to stay healthy.
 - Identify what difficulties the patient may have had previously to remember to take medication, or what tools were used.
 - Plan what tools could be used to remember to take the medication and to remember of the reasons to stay healthy.
- Identify where to store medication at home and to keep extra doses when away from home.
 - Explain that is important to identify a convenient place to store medication and to carry some in case when not at home.
 - Plan where the medication could be kept at home.
 - Plan where extra doses could be kept (in pocket of a jacket, in a little envelope in a purse...).
- Plan on how to deal with side effects.
 - Explain the common side-effects of the patient's regimen (see Annex 17) and what to do when they occur.
 - Remind the patient not to stop taking treatment, to come to the health facility and to report any side-effects to their healthcare provider.

- Identify the patient's support system.
 - Explain that it can be useful to tell somebody close to the patient about her HIV status.
 - Identify who could be a trusted person to disclose to and what could be barriers to disclose to her partner.
 - Make a plan on how disclosure to this person could be done or how another person could support disclosure to the partner.
- Plan for coming to future appointments.
 - Explain how it will be important to come for regular clinical consultations and ART refills.
 - Identify what could be a barrier to come for clinic visits.
 - Make a plan on how to get to appointments and how to be reminded to keep appointments.
- Assess patient's readiness to start ART.
 - Explain to the patient that the healthcare provider advises the patient to start treatment today but that it is up to the patient to take the final decision.
 - Explore if the patient still has any concerns around starting ART.
 - In case the patient does not feel ready, book an appointment for the ART readiness session in 1 week. (see chapter 3.6).

4.7.3 PMTCT and ART education session

When 2 to 4 weeks after ART initiation (at ANC 2).

Mode Group or individual

Duration 30 minutes

Objective Explain basic facts on HIV/ART and PMTCT interventions.

Topics

Assess how ART is taken and identify potential difficulties and solutions.

Assess knowledge on following topics and explain- according to needs- the following points in detail.

- Explain what is HIV (Flipchart card 1).
- Explain how HIV is treated (Flipchart card 2).
- Explain how to adhere to ART (Flipchart card 5).
- Explain the risks of not adhering to ART (Flipchart card 6).
- Explain the need for delivery at a health facility and how to prepare for this (Flipchart card 7).
- Explain the need for exclusive breastfeeding in first 6 months and continuation of mixed feeding till 12 months (Flipchart card 8).
- Explain the need to administer ARV syrups for 6-12 weeks and after that Cotrimoxazole syrup to the baby (Flipchart card 9).
- Explain the need and scheduling for testing the HIV status of the baby.

4.7.4 Planning for birth session

When at ANC 3 (in case the woman arrived late, this should be offered at the same day of the previous session).

Mode Individual

Duration 20 minutes

Objective Plan for the delivery, feeding and treatment of the baby.

Topics

- Provide emotional support.
- Evaluate adherence and problem-solve around possible adherence issues.

- Plan for delivery.
 - Review the fact that transmission may happen at delivery and that it is therefore best to deliver in a health facility where they have qualified staff and safe equipment.
 - Identify the woman's barriers to deliver in her regular health facility.
 - Make a plan on how to ensure delivery at her regular health facility or where to deliver in case she would be travelling, or what to do in case the mother does not make it in time to the health facility.
- Plan for feeding of the baby (Flipchart card 9).
 - Review the fact that transmission can occur during breastfeeding and that exclusive breastfeeding in the first 6 months is advised.
 - Assess what could prevent the woman from exclusively breastfeeding (other household members giving other foods, the need to return to work, ...).
 - Plan on how to deal with others' reactions regarding exclusive breastfeeding.
- Demonstrate and make a plan for how the woman will give the ARV syrups to the baby (Flipchart card 9-10).
- Make a plan for how the mother will communicate with the treatment team in case there is a problem.
- Review and reinforce her motivation to be on treatment.

4.7.5 Review of adherence plan session

When At 4th ANC visit (if woman attending).

Mode Individual

Duration 15 minutes

Objective Evaluate adherence and problem-solve to ensure good adherence to ART.

Topics

- Give emotional support.
- Evaluate adherence and revise the adherence plan.
- Review and reinforce motivation for treatment.

4.7.6 Feeding and treatment follow-up session

When Within the week after delivery.

Mode Individual

Duration 20 minutes

Objective Take and give Nevirapine or dual treatment to the baby, and provide exclusive breastfeeding for 6 months.

Topics:

- Give emotional support.
- Evaluate adherence and revise the adherence plan.
- Assess and support how the mother has been breastfeeding the baby. Remind the mother to report any breast health issues, and provide tips for maintaining good breast health and hygiene.
- Assess and support how the mother has been giving treatment to the baby.
- Explain the need for PCR testing of the baby.
- Review and reinforce the motivation for treatment.

4.7.7 PCR session

When Around birth or 4 to 6 weeks after delivery (in case the PCR is done before 6 weeks of age, the part on Cotrimoxazole treatment needs to be explained to the woman at weeks 6).

Mode Individual / group

Duration 20 min

Objective Explain the need for PCR, for Cotrimoxazole treatment for the baby and for family planning.

Topics

- Give emotional support.
- Evaluate and review the adherence plan for the mother and the child.
- Review reproductive options and explain the recommendation to choose a family planning/ contraceptive method (Flipchart card 11).
- Explain that the baby will start Cotrimoxazole syrup and review the current baby prophylaxis administration.
- Explain the need and process of PCR testing and the meaning of possible results (Flipchart card 12).

4.7.8 PRC result session

When When the PCR result has come back.

Mode Individual

Duration 20 min

Objective Sharing of PCR result and review of adherence.

Topics

- Ask how the mother and baby are doing.
- Share the PCR result.
 - If negative: Congratulate the mother and explain that baby is not infected at the moment but that h/she needs still to be followed up until the end of breastfeeding. Motivate her to continue to adhere and exclusively breastfeed to avoid transmission. Explain that other tests will be done over the coming months.
 - If positive: Explain that the baby is found to be HIV-positive and explain that by putting the baby on ART, he has a good chance to grow up to be an adult. Motivate to continue to breastfeed and taking ART for her own health. Proceed with the ART initiation session for infants.
- Review motivation to stay on ART.

4.7.9 Complementary feeding session

When When the baby of an HIV-positive mother is 6 months old.

Mode Individual /group

Duration 15 min

Objective Revise the adherence plan and explain introduction of complementary feeding.

Topics

- Give emotional support.
- Revise the adherence plan and problem-solve in case of adherence issues.
- Plan for complementary feeding.
 - Explain the need to start introducing complementary foods (Flipchart card 8).
 - Identify what type of foods the mother can give to the baby and how to prepare the food.

4.7.10 Weaning session

When When the baby of an HIV+ mother is at least 12 months old (or later as mothers are encouraged to continue breastfeeding even longer).

Mode: Individual /group

Duration 20 min

Objective Make a plan around how to wean the baby from breastfeeding.

Topics

- Give emotional support.
- Explore the relationship between the mother and her infant, above all if the baby has been tested HIV-positive.
- Revise the adherence plan and problem-solve in case of adherence issues.
- Plan for weaning of the baby.
 - Explain the possibility to stop breastfeeding and fully switch to other foods (Flipchart card 13).
 - Explain how stopping of breastfeeding stops the risk of transmission of HIV from mother to child and a final HIV test can be done 6 weeks after stopping breastfeeding.
 - Do not force the mother to stop breastfeeding at 12 months - she can continue longer with breastfeeding.
 - Make a plan on what could be a good time to stop breastfeeding, what other foods she can give the child and when she could come back for a final HIV test for the infant.

4.7.11 Rapid HIV test for the baby at 18 months of age

In addition to the regular HIV testing procedure (see chapter 3.3) following topics should be discussed:

- Explain the result in relation to having stopped breastfeeding or not.
- Reassess and reinforce motivation of the mother to stay on ART.

4.7.12 ART initiation for HIV-infected infants

In addition to the regular ART initiation session (see chapter 3.8.2), administration of drugs to the baby should also be addressed. Assess possible difficulties in administering drugs to the baby and give practical tips on how to work around this (see annex 21).

4.8 Patient support, education and counselling for TB

TB is an infectious disease which is still a major public health concern in low- and middle-income countries. TB requires a long-term treatment, ranging from six months for Drug-Sensitive TB to two years for Drug-Resistant TB. A comprehensive approach, whereby patient support, education and counselling is one of the strategies to be put in place, is thus required.

TB is also the most common co-morbid medical condition and serious opportunistic infection (OI), and the main cause of mortality in PLHIV in all settings where MSF supports HIV care and treatment. It is therefore essential to include systematic screening for active TB, and

reinforce preventive measures early in the patient education and counselling schemes of PLHIV. Integration of HIV and TB activities should be a goal for all projects in settings with a high burden of both infections. This should include:

- HIV testing and counselling being offered to all TB patients who have not been tested recently.
- Systematic screening of all people living with HIV (PLHIV) for TB symptoms.
- Provision of care and treatment for both TB and HIV in one facility on the same day and by the same healthcare provider whenever possible.
- Decentralisation of HIV/TB care and treatment to clinic and community levels.
- A patient-centered approach.
- Patient support, education and counselling to enhance adherence to both the TB and ARV treatments since patients have to combine these two treatment regimens with the risk of intolerance and treatment interruption. Co-infected patients should receive treatment through a “one-stop” service. All health workers should be trained to promote adherence to both treatments.
- Adequate TB infection control measures in waiting areas, consultation rooms and any other areas in health facilities attended by coughing patients, including health education session to promote cough hygiene.

For more information on the medical aspects of TB, consult the latest MSF/PIH TB guideline⁴⁸.

This chapter describes PSEC interventions for patients with drug-sensitive (DS) TB (3.9.1), drug-resistant (DR) TB (3.9.2) and patients co-infected with HIV/TB (3.9.3).

4.8.1 Patient support, education and counselling for patients with drug-sensitive TB (DS-TB)

WHO recommends directly observed therapy (DOT) for the treatment of drug-sensitive TB (using first-line TB medication). However, MSF promotes a more patient-centered approach of Self-Administered Therapy (SAT) with adequate patient education and counselling.

Tools Example of a detailed TB session guide (Annex 23).
DS-TB, DR-TB, DR-TB education flipchart (Annex 24).

PSEC session at screening

When Patients suspected to have active TB disease, including DR-TB, referred for sputum collection.

Mode in group or individually

Duration 15 min

Topics Explain basic facts on TB (what is TB, signs & symptoms, transmission, prevention, relationship with HIV) (Flipchart card 1-2-3).
Explain the procedure of TB diagnosis.
Explain how to produce sputum (Flipchart card 4).

PSEC session at the start of DS-TB treatment

When: Before or at the day of TB treatment initiation.

Mode Individual session

Duration 30-45 min

Topics

- Give emotional support regarding the diagnosis.

- Assess previous knowledge and explain facts on TB disease.
 - What is TB (Flipchart card 1).
 - What are the signs and symptoms of active TB (Flipchart card 2).
 - What are the ways of transmission and prevention of TB (Flipchart card 3).
 - What is the relationship between HIV and TB (Flipchart card 14).
 - What is the difference between drug-sensitive and drug-resistant TB.
- Assess previous knowledge and explain the facts on TB treatment:
 - What does the treatment consist of (Flipchart card 5).
 - How to adhere (Flipchart card 15).
 - Side effects of treatment (Flipchart card 6).
 - Clinic follow-up for DS-TB patients.
- Make a plan on how to adhere to TB treatment (getting ready to start treatment, support system, getting to the clinic, medication schedule, managing missed doses, reminder strategies, storing medication).

PSEC session after DS-TB treatment initiation

When One week after treatment initiation or at the first visit after commencing treatment.

Mode Individual session

Duration 30 minutes

Topics

- Give emotional support.
- Evaluate adherence to TB medication (annex 8) and work around any difficulties taking medication since starting.
- Review knowledge on TB disease and its treatment.
- Explain monitoring tests for TB treatment.
- Explain on use of traditional medication, alcohol and drugs in combination with TB treatment.

PSEC session at end of the DS-TB intensive phase

When At the end of the intensive phase.

Mode Individual or in group

Duration 15 min

Topics

- Evaluate adherence.
- Solve any adherence issues.
- Explain the change in drug regimen for the continuation phase.
- Explain the need to continue to take treatment throughout the maintenance phase, even if the patient might feel better. Assess and reinforce the patient's motivation to continue treatment.

Additional PSEC sessions throughout DS-TB treatment

When adherence issues are detected, patients should be referred for extra patient support, education and counselling sessions, using same referral criteria as for HIV patients (see chapter 3.7.1).

When resources allow, monthly group or individual PSEC sessions can be planned to assess and encourage adherence, when the patient comes for a medical consultation.

4.8.2 Patient support, education and counselling for patients with drug-resistant TB

DR-TB treatment should be patient-centered, comprehensive, ambulatory for all stable patients, integrated with existing HIV/TB/PHC services, decentralised (close to patient home), and as much as possible community-based. MSF recommends treatment under Directly Observed Therapy (DOT) by a trained healthcare provider or by trained, supervised and compensated treatment supporters, adequate patient education and counselling, and close monitoring of adherence. Currently DOT is being questioned^{49,50} and pilots are ongoing in MSF projects to provide treatment under SAT in combination with patient education and counselling and the support of a treatment supporter. Apart from patient education and counselling, additional interventions should be considered for DR-TB patient such as mental health services (see chapter 5) and social support (see chapter 6).

For a detailed session guide for on the content of the sessions, see Annex 23.

The PSEC session at screening is the same as for drug-sensitive TB.

PSEC session at treatment initiation

When Before or at DR-TB treatment initiation.

Mode Individual, with family member or treatment supporter if available.

Duration 30-45 min

Topics

- Give emotional support.
- Assess previous knowledge and explain facts on TB disease:
 - What is TB, signs of active TB, transmission, prevention (Flipchart card 1-4).
 - What is the relationship between HIV and TB (Flipchart card 14).
 - What is drug-resistant TB and when does it occur (Flipchart card 7) (or Flipchart card 10 for XDR-TB).
- Assess previous knowledge and explain facts on DR-TB treatment.
 - What is the treatment for DR-TB (Flipchart card 8) (or Flipchart card 11-12 for XDR-TB).
 - Why is it important to adhere and how to adhere (Flipchart card 15).
 - What are the side effects of treatment (Flipchart card 9, or Flipchart card 13 for XDR-TB).
 - What is the clinic follow-up.
 - What is the rationale for DOT.
- Make a plan to adhere to DR-TB treatment (getting ready to start treatment, support system, getting to the clinic, planning for DOT).
- Address infection control at home and when patient is no longer infectious (Flipchart card 3, 16).
- Perform a mental health screening (annex 13 and 14) with referrals as appropriate.

PSEC session after treatment initiation

When One week after DR-TB treatment initiation or first visit after commencing DR-TB treatment.

Mode Individual with family member or treatment supporter if available.

Duration 30 minutes

Topics

- Give emotional support.
- Assess and review knowledge on TB disease and DR-TB treatment.
- Explain monitoring tests for DR-TB.
- Explain about taking traditional medication, drugs and alcohol when on DR-TB treatment.

- Work around any difficulties taking meds since starting.
- Discuss any side effects to medications. Provide information on management of common side effects and refer to clinician for serious side-effects.
- Ask permission to do a home visit to screen other household members on TB.

Home visit at DR-TB initiation (optional according to patient's needs)

When One week after DR-TB treatment initiation or first visit after commencing DR-TB treatment.

Mode At the house of the patient with his family members – permission from the patient should be asked on forehand.

Duration 30-45 min

Topics

- Explain basic facts on DR-TB and its treatment (Flipchart card 1-4, 8, 9, 15).
- Explain infection control measures to the household members of the patient (Flipchart card 3).
- Make a plan on how to protect the family members and how family members can support the patient (including sleeping in separate quarters while patient is still in active TB phase).
- Screen household members for DR-TB.
- Perform a social assessment (see chapter 3.4, focussing on socio-economic issues).

PSEC sessions during DR-TB follow-up

When At week one, then monthly during intensive phase and 2-monthly during continuation phase.

Patients with poor adherence, depression, or substance use issues should be seen more intensively until the issue is resolved.

Mode Individual or in group, keeping in mind infection control measures.

Duration 15 min or more

Topics

- Evaluate adherence including difficulties to come to ambulatory care point every day.
- Solve any adherence issues.
- At the end of the intensive phase: explain the change in drug regimen for the continuation phase.
- Perform a mental health screening as necessary.

Other PSEC sessions for DR-TB patients

- *Hospitalised patients* should get 1 or 2 sessions before their discharge from the hospital to prepare for the ambulatory phase, and maintain infection control at home. Patients who were too weak during hospitalisation to assist may need to go through the TB initiation PSEC sessions once stable.
- *Patients interrupting treatment* should be offered PSEC sessions to promote adherence to treatment and prevent loss to follow-up.
- *Patients with a pre-XDR or XDR diagnosis* should get one session to educate the patient on pre-XDR and XDR diagnosis, discuss potential future treatment options and limitations, and create awareness of palliative care in the event of ending curative treatment.
- *Patients in whom DR-TB treatment has failed* should be offered palliative care sessions to inform patient and their families about their condition and prognosis, future treatment and psychosocial support options.
- More sessions can be planned according to patients' and families' needs, such as for patients dealing with hearing loss.

4.8.3 Patient support, education and counselling for patients co-infected with HIV and TB

PLHIV who need to start TB treatment while on ART

We recommend the same scheme of patient support, education and counselling sessions as for TB patients not co-infected with HIV, but with integrated follow-up visits wherever possible for ARV treatment and TB medication. The schedule of sessions will depend on how long the patient is already on ART. Counselling sessions for ART and TB should be offered as much as possible at the same place, at the same time and by the same person.

PLHIV who need to start ART while on TB treatment

ARV treatment should be initiated in all PLHIV with active TB disease irrespective of their CD4 count. TB treatment should be initiated first, then ARV medication introduced as soon as possible, preferably within 2 to 8 weeks. Certain patients with advanced disease progression need to be fast-tracked on ART and thus be put on treatment within 2 weeks:

- Patients with CD4 counts below 100 cells/*ul* or in clinical stage 4.
- Children below 2 years of age.
- Pregnant women.
- Patients with DR-TB.

The same scheme of sessions for ART initiation can be used but sessions must be integrated. An example of integrated PSEC sessions for HIV and drug-sensitive TB can be found in annex 16.

PLHIV co-infected with DR-TB

People co-infected with HIV and DR-TB have more difficulty adhering to their treatments because they are confronted with a heavy drug burden: a large number of different medications, the need to take different quantities of medications at different times, an increased risk of side effects, many months of an injectable (and painful) TB medication. It is important to be aware that these patients might require increased support with more frequent sessions.

4.9 Other patient support, education and counselling sessions

4.9.1 Supporting disclosure of HIV results to partner

When couples do not test together, the HIV-positive partner is left with the task to share the status with his/her partner. Since social support is an important factor for adherence to treatment and retention in care, disclosing one's HIV status to partners is important for HIV-infected people. Non-disclosure puts patients at risk for adherence issues and LTFU.

Some people are scared to disclose their HIV-positive status to their partners. The counsellor could help the patient to decide about disclosure by exploring the positive and negative aspects of such a decision. Eventually it should be the patient's decision and the counsellor cannot disclose a patient's status to the partner without the patient's agreement.

Alternatives can be offered to patients who do not feel able to disclose on their own, like doing the disclosure in presence of the counsellor, by giving out an invitation letter for testing addressed to the partner, or by proposing the couple to come for couple HIV testing.

Positive aspects

- It helps the partner to protect him/herself.
- The patient avoids living with a secret and prevents rumours and doubts from arising.

- It can reduce stress.
- It prevents the patient from having to take medication in secret.
- The patient can receive effective emotional support.

Negative aspects

- The patient may face the experience of rejection. Family members may be in shock and react with anger or fear instead of giving emotional support.
- The patient may face discrimination.
- The HIV-negative partner may have fears about sexual intercourse and contracting HIV.

The counsellor could set up a role play in his office to simulate the disclosure process. When the disclosure has been done, the patient's partner is encouraged to undergo an HIV test, to check his or her HIV status.

4.9.2 Reproductive decisions

Reproductive decisions need to be discussed with everybody in reproductive age or patients who express a wish to have children. Many HIV-infected men and women are of reproductive age and are likely to consider becoming parents. In this case there is a risk that HIV is transmitted from the mother to the child and, when in a discordant relationship, between sexual partners.

The wish to have a child represents an important issue for some patients and should be addressed without judgement. While there always remains a risk for transmission, it is important to explain the following:

- Advise on the risks of transmission to the child associated with a pregnancy.
- Advise on the risks of transmission to the partner associated with unprotected sexual intercourse.
- Explain that the risk of transmission can be reduced when the HIV positive person is on ART for at least 6 months and has an undetectable viral load.
- Explain the importance to attend ANC, to regularly test in case the mother is HIV negative or to follow PMTCT interventions in case the mother is HIV-positive.
- Discuss family planning options so pregnancies can be planned.
- Offer disclosure support when the patient would like to disclose to the partner.

4.9.3 Key populations

Key populations are groups of people that in addition to being at higher risk to HIV due to their risk behaviours are also discriminated against the law, which further increases their vulnerability to HIV. The main groups under this definition are sex workers (SW), men having sex with men (MSM), people who inject drugs (PWID), people in prisons and other closed settings and transgender people⁵¹. Additionally, they can experience particular mental health problems like anxiety, a low self-esteem and multiple somatic problems, due to the high stigmatisation they face in many communities. They often have poor access to health care services due to the discrimination they face in health structures, as well as experience socio-economic problems.

Certain considerations should be taken into account when offering patient support, education and counselling interventions to individuals infected with HIV/TB from key populations.

- It is important to work with the all the staff providing services to key populations to sensitise them concerning their prejudices about delivering health care to these often stigmatized and marginalized population. This may have an important impact on their attitude towards individuals from key populations and thus towards the quality of services provided, representing a major barrier to access health care. It is necessary that health workers maintain a non-judgmental attitude in order to promote adherence and retention in care in delivering services to these groups.

- Mental health support should be considered as part of the package of services;
- Specific themes need to be addressed with these groups related to safer sex practices and tailored according to their needs. Themes like the use of lubricant gel, education regarding sexual acts that carry higher risk of transmission, negotiation of condom use with clients/sexual partners, etc. can be addressed in groups or individually.
- The recruitment of peer educators needs to be considered, as they can facilitate promotion of services and anti-stigmatizing messages towards the key population. When trained, they can eventually also take on PSEC tasks.

For more information on key populations, read the WHO's latest guidance on the topic.

4.9.4 Adherence to bio-medical prevention methods

Several bio-medical prevention methods exist which require medication adherence to be effective. Pre-Exposure Prophylaxis (PreP) is increasingly being used for HIV prevention among key populations. A health promotion strategy needs to be put in place, to ensure target groups are aware that PreP exists, how it can be useful for them and that they can request it from their healthcare provider. It is up to the person to decide if they want PreP and their choice needs to be respected. An adapted package for adherence support is needed to ensure clients are supported in taking their treatment.

Post-Exposure Prophylaxis (PEP) is often being offered in the context of accidental exposure to blood or other fluids, and as part of the package for victims of a sexual assault. For these patients the reason for taking PEP and how to do it needs to be well explained. See Annex 25 for an example of a leaflet on PEP.

4.9.5 Populations in movement

Some projects will be faced with patients whom are highly mobile, for example because they look for jobs away from home or because of conflict situations. Besides this highly mobile group, it is to be expected that every patient will travel once in a while and may fail to report back to the clinic for ART refill or their clinic consultation. A number of strategies need to be put in place to address mobility:

- At the project level there is a need to understand the mobility patterns of patients (what is the most common reason for mobility, is there a fixed pattern, is it happening at fixed times) in order to develop the correct strategy.
- All patients need to be educated and counselled on what to do in case they fail to report back to the clinic for their ART refill. This messaging is included within the ART initiation counselling sessions. (See chapter 3.6).
- In case of highly mobile populations, additional education may be needed for some ARV treatments based on AZT/3TC (not for TDF/ 3TC /EFV), on how to quit taking ARVs while reducing the chance of creating resistance. Other programmatic strategies need to be considered such as "run-away packs", collaboration with community health workers to deliver medication to known community points, routine offering of transfer letters to patients, identification of ART sites at places often frequented by patients. These strategies need to be explained well to patients in order for the approaches to be successful.

5. Patient tracing

Loss to follow up, or disengagement from care, is inevitable over a lifelong course of HIV care. This is due to both unintentional reasons for missing an appointment (conflicting demands on the patient's time like going to a funeral, or travelling for work) and intentional reasons (such as dissatisfaction with the care received), along with a reluctance to return to care following an absence. Efforts to prevent missed clinic visits are to be combined with moves to minimize barriers to re-entry into care, like patient tracing, to avoid long term disengagement from care⁵². A systematic review demonstrated that patient cohorts for whom we employed physical tracing had lower estimated loss to follow up (LTFU) and higher retention on ART⁵³.

Efforts to prevent missed clinic visits, apart from other interventions described in this guide, are:

- A clear transfer in/out procedure whereby patients feel at ease to communicate when they move to another clinic.
- Training all clinic staff in patient-centered care and the use of a non-judgmental attitude.
- Sending appointment reminders to patients by SMS⁵⁴.

Tracing of patients that missed their appointment (defined as patients who missed their appointments for more than 2 weeks) is a strategy to avoid that patients become lost to follow up (generally defined as patients who missed their appointment for more than 2 months, but this can vary locally).

Where resources are limited, projects can decide to only trace high risk patients such as patients newly initiated on ART/TB treatment, women in PMTCT care, children or HIV/TB co-infected patients. Tracing of patients lost to follow-up for more than 2 months is not advisable, as these patients will already have been traced in the months before becoming LTFU, and their chance of returning into care is far lower than for those who missed an appointment.

Different steps can be identified in the process of patient tracing, as described below.

5.1 Asking consent for tracing

Patients need to be informed of tracing activities and clear consent to be traced should be obtained from patients on their entry in the programme. A correct and exact phone number or address of the patient and if possible treatment supporter should be asked and updated regularly.

5.2 Identification of patients that missed an appointment

An agenda or appointment register needs to be put in place to track patient's appointments dates. At arrival of patients in the health facility, their attendance needs to be marked in the agenda. On a weekly basis, the agenda needs to be checked for patients who did not show up for their appointment. In sites where facility database monitoring is available, lists can be extracted according to the defined criteria.

Project experience has shown that generally a period of 2 weeks after missing an appointment is used to trigger tracing, based on the observation that patients often come back spontaneously once their ARV buffer stock is finished. This period can be adapted to a project's realities and resources available.

Contact details of patients who missed an appointment need to be passed to the people who do the actual tracing.

5.3 Tracing patients

Patients are preferably traced through an SMS or a phone call when available, as this is the least intrusive and costly intervention. When tracing by SMS and/or phone tracing after 2 to 3 calls have not been successful, a home visit by the staff of the health facility, a community health worker or a peer educator linked to the facility can be done.

The health facility should have standard procedures for sending SMS, calls and/or making home visits, including what to say (text messages should be vague enough to stay confidential, except to the patient), how to log the SMS, call or visit and what to do if the person cannot be reached. The health facility should also have a logbook where tracing actions are recorded and outcomes can be monitored.

For more details on how to trace patients by phone, see Annex 26.

5.4 Support patients coming back to care

Ensure all patients who seek to re-enter care are welcomed. Provide staff training on attitudes and communication skills to promote an easier re-entry into care for patients who have been lost to follow up.

Provide a PSEC session for patients who come back into care, see chapter 3.7.2.

6. Mental health care

People living with HIV and/or TB are for several reasons at a higher risk of mental health disorders.

- Psychiatric disorders can be a consequence of physical and psychological difficulties surrounding these chronic diseases.
- Some treatments can cause psychiatric symptoms as side effects or exacerbate previous psychiatric disorders.
- AIDS-related illness can directly damage the brain and cause mental health disorders.
- Patients with previous mental health issues are frequently more at risk to contract HIV/TB.

Mental health disorders like depression have an impact on adherence, risk behaviour and mortality. Depression is the most common mental health disorder among PLHIV and it is estimated that about 15 up to 40% of PLHIV suffer from major depression^{55,56}. There is growing evidence associating psychiatric illnesses such as depression, anxiety and psychosis with DR-TB and with HIV/DR-TB co-infection⁵⁷.

In order to address the mental health problems of PLHIV/TB, projects can opt to include specialized mental health care, in addition to the basic patient support education and counselling as proposed in this guideline.

Screening for mental health disorders and basic psycho-education can be done by trained lay counsellors, while diagnosis and treatment will require intervention by trained psychologists, professional counsellors, clinical social workers, or medical staff. When not available, lay counsellors can be trained in counselling patients with mental health disorders but should be supervised by a trained psychologist. Alternatively, referral pathways outside of MSF should be identified.

Screening for depression and alcohol/substance use can be integrated in the sessions as defined in this guideline.

It is recommended to at least screen groups at highest risk such as:

- Patients at start of their DR-TB treatment.
- Patients with a high viral load test result, referred for EAC.
- Patients from key populations like sex workers or people living in conflict affected areas.
- Patients whereby the health care worker suspects depression.

Depending on feasibility this could be extended to larger groups of patient and even all patients starting ART or TB treatment.

Tools provided in Annex 13 (PHQ-9 for depression) and Annex 14 (CAGE-AID for alcohol/substance use) can be used for screening purposes. For more information on diagnosis and treatment, refer to MSF Mental Health Guidelines and the MH GAP intervention guide⁵⁸.

7. Social support

Social support encompasses activities aiming to address the weak socio-economic support system of HIV/TB infected patients in a punctual way. This can include socio-economic support, support groups, home visits and visits to the hospital. Social support is a part of the comprehensive package and its implementation will depend on the project's context, target group and objectives.

7.1 Socio-economic support

Certain patients may be living in a difficult socio-economic situation and require punctual support in terms of food, transportation, housing etc. Socio-economic support is an enabler, which means that it is meant to create the conditions to allow a patient to adhere or retain in care. Enablers are different from incentives, which are a means of giving positive reinforcement to the patient for taking the treatment. We do not generally recommend incentives, except for incentives which may go beyond the benefit of one patient, such as for example a "treatment completion party" when a patient finishes treatment, for all DR-TB patients and their staff.

Socio-economic support can be provided by MSF or through partner NGOs whereby MSF ensures the linkage to these organisations.

Following aspects need to be taken into account in terms of implementation:

- Socio-economic support is by preference offered by other organisations in the project's network. A good mapping of organisations offering socio-economic support is needed and should be regularly updated. The project needs to ensure linkage between other partners and the project's patients.
- According to the gaps identified, MSF can decide to provide certain socio-economic support. The project needs to define what type of support will be provided, which can take the form of food vouchers, transport vouchers, food supplements, non-food items such as clothes, cash transfers, hygienic kits, etc.
- The project needs to define who is considered eligible for socio-economic support: what groups of patients (for example only high-risk groups like patients on DR-TB treatment, or patients on 2nd line treatment), or what individual patient criteria need to be met for support. A case-by-case approach may still be needed, but it is useful to have the main criteria defined.
- A good assessment needs to be done of the patient's socio-economic needs before deciding to support the patient. A set of criteria can be established within the project to facilitate the decision.
- Socio-economic support should be punctual and for a defined duration of the patient's treatment course.

7.2 Support groups

A support group is a group of people who come together to talk about a challenge, experience and/or role that they have in common without being judged, blamed, stigmatised or isolated. By joining support groups, people realise that they are not alone in their situation. The group is a forum in which members can share problems and concerns, brainstorm solutions, give each other advice and form friendships. Support groups are effective because members receive first hand advice and the approaches that they learn come from peers who are

copied with very similar circumstances. This means that the guidance is not theoretical, but practical, personal and relevant. In addition, support groups often advocate for members' mutual goals and create awareness about shared challenges. This joint action leads to policies that better serve people living with HIV (PLHIV) and fosters supportive community environments in which group members can thrive⁵⁹.

Networks for PLHIV/TB are active in many project areas, where they have established local support groups. It is important for MSF to collaborate with such groups, for example by referring patients, spreading important health information through these groups, supporting their advocacy etc. In places where support groups do not exist, MSF can support the creation of such support groups, but it is important that the primary drivers and decision-makers should be the PLHIV who belong to the group.

7.3 Home visits

Home visits by a community health worker or community volunteer may be considered, especially for high risk patients. Objectives of such home visits will depend on the need, but can include assessing the patient's support system, providing education and counselling to the patient and his relatives, mediation of family problems, palliative care support...

Following points need to be taken into account for implementation:

- A home visit always needs to be done with the agreement of the patient.
- The home visitor needs to know who at the patient's home is aware of the patient's disease status and prognosis.
- It is important that the patient does not feel obliged to accept the home visit nor perceive it as a control measure.
- A home visit needs to be planned in time and the home visitor needs to have clear objectives, content and educational tools available.

7.4 Hospital visits

Some patients lack a support system and may be hospitalised without a caregiver. A system with community volunteers can be set up, to ensure presence in the hospital and help the patient with food, hygiene, medication and emotional needs. Occasional visits by medical staff providing education and counselling to the patient and his family are valuable as well.

8. Other health promotion activities

HIV/TB projects may set up other health promotion activities which are not directly targeted at people already diagnosed with HIV/TB and their households, but target their broader community.

The aim of these activities is to raise awareness on HIV/TB, fight stigma and promote HIV/TB services among the general population or populations at high risk for HIV/TB, for example promotion of community-based HIV testing strategies and broad-based TB screening, promotion of sex worker friendly services among sex workers, informing community leaders on community-based ART delivery methods adapted to patient needs and lifestyles...

These activities are due to the target group often performed in the community, but may also be performed within health facilities.

Refer to the MSF Health Promotion policy/guidelines in your section. Educational tools and health promotion material can be found in the Health Promotion Toolkit, MSF-OCB, 2015.

Annexes

Most of these annexes can be downloaded from : <https://tukul.msf.org/psec>

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Annex 1. Supervision form for an individual PEC session

Source: Hamel E. mémoire de Master professionnel Education, clinique et santé, laboratoire de Pédagogie de la Santé UPRES EA 3413 Université de Paris 13 "Contribution à l'élaboration d'un outil d'évaluation des activités de counseling et d'éducation thérapeutique mises en œuvre dans les programmes VIH/sida de Médecins Sans Frontières pour favoriser l'observance thérapeutique", année universitaire 2005-2006.

Name of counsellor: Date of session:.....

Name of supervisor: Type of session:.....

Rating scheme: 1 = very good 2 = good 3 = unsatisfactory 4 = absent

1. Pre-session preparation	1	2	3	4
The educator prepares the meeting room (environment, confidentiality) He takes time to review the patient's file				
✎ Comments				
2. Introduction				
The educator establishes a warm rapport (greet the patient, introduces himself, demonstrates respect and interest, attends to the patient's comfort, etc.) He identifies the reasons for the session				
✎ Comments				
3. Consultation process				
The educator: <ul style="list-style-type: none"> - uses appropriate non-verbal behaviour (eye contact, posture, vocal cues, e.g. rate, volume, intonation) - listens attentively and facilitates patient participation (open-ended questions, invites questions and allows patient to express concerns) - explores patient's prior knowledge - explores patient's concerns and how these affect his daily activities - is able to address other issues of importance to the patient that are not related to the session - uses appropriate supports, especially visual - gives clear explanations - regularly checks patient's understanding 				
✎ Comments				

Supervision form for an individual PEC session
(continued)

4. Content				
The issues discussed are consistent with the goals stated at the beginning				
If the consultation format is pre-set, did the educator cover all the main points as defined in the session guide (refer to the locally used documents)?				
If the consultation is a direct result of poor patient compliance, explore the problem of adherence				
 Comments				
5. End of Session				
The educator:				
- summarises the most important points discussed				
- reiterates the decisions and goals set during the session				
- ensures that the patient leaves with the necessary materials				
- records important points in the patient's file to share with other professionals				
 Comments				

Annex 2. Evaluation form for a PEC group session

Source : Hamel E. mémoire de Master professionnel Education, clinique et santé, laboratoire de Pédagogie de la Santé UPRES EA 3413 Université de Paris 13 "Contribution à l'élaboration d'un outil d'évaluation des activités de counseling et d'éducation thérapeutique mises en œuvre dans les programmes VIH/sida de Médecins Sans Frontières pour favoriser l'observance thérapeutique", année universitaire 2005-2006.

Name of counsellor: Date of session:.....

Name of supervisor: Number of patients:

Rating scheme: 1 = very good 2 = good 3 = unsatisfactory 4 = absent

1. Session preparation	1	2	3	4
Appropriate factors are taken into account when forming a group (size of the group, types of patients) The room is set up in keeping with the objectives of the session (the room feels warm and welcoming, provides a learning environment and there is a sense of confidentiality) Educators prepared all the necessary learning materials.				
✎ Comments				
2. Introduction				
Educators establish initial rapport (greet patients, introduce themselves, demonstrate interest/make patients feel comfortable, thank them for coming, etc.) Educators state the goals of the session Participants are made to feel at ease and "ice-breaker" activities are used for introductions				
✎ Comments				
3. Session procedure				
The educator: - uses appropriate non-verbal behaviour (eye contact, posture, vocal cues, e.g. rate, volume, intonation) - explores patients' prior knowledge - encourages patients to participate (open-ended questions, invites to ask questions, express feelings) - gives patients enough time to interact with each other - uses appropriate and varied supports - regularly checks patients' understanding of information - adjusts the length of the session according to patients' needs, physical and/or emotional fatigue				
✎ Comments				

Evaluation form for a PEC group session*(continued)*

4. Content				
Educators provide clear and logical explanations				
Mistakes are corrected in a respectful manner				
In keeping with the objectives of the session, the correct amount and type of information is provided. List these below:				
-				
-				
 Comments				
5. End of session				
The educator:				
- summarises the most important points discussed				
- reminds participants that they are available for further discussion and clarification and that they can discuss things at greater length during their regular one-on-one consultation sessions				
- reviews the materials which patients take home				
- prepares a report to be sent to other professionals.				
 Comments				

Annex 3. Methods for on-job training and supportive supervision of PSEC activities

Source: Adapted from “Supervision and training-on-the-job: Guide for MSF psychosocial programs”, MSF-OCB, 2009.

All supervision methods should be applied in a context of respect and trust, with the aim to help the PSEC team members grow in their role and ensure quality of the PSEC interventions.

1) Direct observation of a session

Observation is very important when learning a new intervention (on-job-training) and should be continued on a regular basis. It can also be requested on demand by the counsellor for complicated cases.

- It should be agreed in advance between the counsellor and the supervisor in which way the supervisor will behave during the session: silent observation, intervening in specific moments with short contributions or playing an active part in the session at the same level as the counsellor in charge, etc.
- If it is not the first session with the patient, a short discussion should be held between the counsellor and the supervisor to present useful antecedents, previous to starting the session with the patient.
- The patient should be informed of the supervisor’s presence and give his consent before starting the actual session.
- The supervisor may take some notes or use an observation checklist to facilitate discussion after the observation.
- When there is a language problem, one needs to work with a translator. Avoid as much as possible disturbance for the counsellor and client staying at a distance from them and not intervening in the session without request from the counsellor. Even when there is no translator, it can be useful to observe and focus on the nonverbal communication skills.
- Feedback should be given to the counsellor after the client left the room. Be constructive and point out both positive and negative points.

2) Individual or group case discussions

Difficult cases can be discussed on a regular basis or on request of the counsellor. This can be done:

- individually between the counsellor and the supervisor
- in group with the other PSEC team members (interview – supervision between colleagues)
- in group with other PSEC team members and guided by the manager or supervisor or an external supervisor (clinical team supervision)

The counsellor who presents the case should prepare in advance a summary of the situation of the patient with key information that will help the discussion, as well as questions and doubts.

3) Revision of project and PSEC indicators

On a regular basis team meetings should be planned to discuss the evolution of project’s indicators and specific PSEC indicators. On this basis problems can be identified and targeted solutions can be put in place.

4) Role-plays

Role-playing is a very useful method to observe and practice communication and counselling skills, and to empathize with both patient and counsellor situations. It is a very valid method especially for beginning counsellors, who are learning and developing their skills.

- One will need to play the patient, while another one takes the role of counsellor. Instruction for the patient and the counsellor should be prepared on forehand.
- Others participants observe the interactions. Some may be asked to focus on the content, while others may focus more on the counselling skills. Observers can use the observation grid to give feedback.
- After the role-play, first debrief with the person playing the counsellor, then with the person playing the patient and then with the observers. This is less threatening for the ones volunteering to do the role play. Insist on both what went well and what was difficult.

5) File reviews

It is important to review clinical files of patients on a regular basis from all counsellors in order to assess the quality of the identification of the patient's problem(s), the support provided, to identify points that need to be reinforced amongst the counsellors and to get a general overview about the cases treated.

Annex 4. General patient file for PSEC

Source: adapted from MSF-OCP Paoua, 2009

Patient's name:

File Number:

Date:	
Medical information:	
Treatment:	
Assessment of adherence/counselling: (behavioural, knowledge, social, emotional)	
Other Patient Support, education and counselling intervention:	
Next appointment date:	With:

Annex 5. Tally sheet for PSEC activities

Source: Adapted from MSF-OCP Malawi, 2010

Health Facility: Month - year:..... Name of staff:.....

Activity	Adults	Children (0-15yrs)	Total
Patient support education and counselling			
HIV testing services			
Pre-test information			
Post-test counselling HIV+			
Post-test counselling HIV-			
PSEC ART initiation & early follow-up			
HIV/ART education session			
ART readiness session			
ART initiation session			
Adherence FU at M1			
Adherence FU at M3			
Adherence FU at M6			
PSEC long term FU			
Adherence issue/missed appointment			
EAC 1			
EAC 2			
changing regimen			
2 nd line initiation			
2 nd line FU			
PMTCT			
ART initiation			
PMTCT/ART education			
Planning for birth session			
Review adherence session			
Feeding and treatment follow-up session			
PCR session			
PCR result session			
Complementary feeding session			
Weaning session			
HIV rapid test session			
ART initiation infants			

Activity	Adults	Children (0-15yrs)	Total
TB			
Screening session			
Start session			
After initiation session			
End of intensive phase session			
Follow-up session			
Number of PSEC sessions / counsellor /day			
Patient tracing			
Number of patients late for appointment			
Number of patients late for appointment traced			
Number of patient late for appointment last month that returned to care after tracing in current month			
Social support			
Number of patient that received socio-economic support			
Number of home visits			
Number of hospital visits			
Number of mental health sessions			
Number of other health promotion activities			

Annex 6. Log frame PSEC activities

Source: Adapted from MSF-OCB; Patient support log frame 2011

Available in full version on: <https://tukul.msf.org/psec>

Annex 7. List of patient's competencies

Source: adapted from *Format Santé, 2002*

This list of patient's competencies is used as a basis for the development of a patient support, education and counselling program. This tool identifies the objectives to be reached by the patient during a patient education and counselling session. It can be used to register at each visit the competencies that were acquired by the patient.

To assess patient's knowledge, use the questionnaire in Annex 8.

	Patient's competencies	Date							
1	Explain the evolution of HIV infection without any ARV treatment								
2	Explain the ways of transmission and modes of prevention of HIV								
3	Explain the evolution of HIV infection with ARV treatment								
4	Explain when to start ART*								
5	Explain the importance of the medical and biological (VL, CD4) follow-up*								
6	Interpret the result of CD4 count*								
7	Use a condom								
8	Describe the purpose of each drug (ARV and Cotrimoxazole)								
9	Cite and identify the medication (ARV and OI prophylaxis medication)								
10	Explain the importance of adherence and consequences of poor adherence								
11	Explain why ARV treatment should be taken for life								
12	Identify a medication schedule (for each of the medication, describe the number of doses per day, the number of medication per dose and identify best timing)								
13	Identify reminder strategies for taking medication								
14	Cope with his medication schedule during special situations (when outside home, during travel, during religious events, etc.)								

*Questions only relevant if not all HIV-diagnosed patients are eligible for ART

List of patient's competencies*(continued)*

	Patient's competencies	Date							
15	Bring forward or move back a dose in case of missing a dose or vomiting								
16	Identify the clinical signs which could indicate side effects								
17	Manage minor side effects (e.g. headache, nausea)								
18	Identify serious side effects that need to be managed by a doctor urgently								
19	Explain the practical organisation of follow-up treatment (appointments at the clinic, etc.)								
20	Manage his drug stock until next appointment to avoid shortage								
21	Store medication in good conditions and keep extra drugs in case away from home								
22	Disclose his status and identify a support system								
23	Getting to appointments								
24	Convince close family member(s) to have an HIV test								
25	Negotiate with the partner to use a condom								
26	Explain and interpret a viral load result								

Legend: D: Done, if the educational session has been done

A: Acquired if the skill/knowledge has been assessed and the skill/knowledge acquired

R: Review, if the skill/knowledge needs to be reviewed

Annex 8. Patient's knowledge assessment

Source: adapted from MSF-OCP Malawi, 2011

This evaluation of patients knowledge can be included in individual counselling and education sessions (for example after the first patient education session when HIV diagnosis is made or after ART initiation) or may be used to assess the patient education and counselling programme's quality by interviewing a sample of patients.

Instructions for the counsellor

In administering this evaluation:

- Explain to the patient that this evaluation is intended to provide the counsellor with more information
- Ask the patient if he agrees to participate in the evaluation

During the evaluation:

- Make the patient feel comfortable and ensure that he does not feel judged if he answers incorrectly
- Do not make suggestions or offer corrections during the evaluation

After the evaluation:

- Discuss the results with the patient and correct any misunderstandings in a positive and supportive manner

OPEN QUESTIONS

- 1) Could you explain why you need to come regularly to the clinic for follow-up?
- 2) What are some of the infections that a person can have when CD4 drops?
- 3) Could you give me the name of the ARV medication you are taking?
- 4) Could you tell me how you take your ARV medication? (Prompts: How many tablets? At what time of day?)
- 5) What was your last viral load result?

TRUE / FALSE QUESTIONS

	Prevention – transmission	Security	True	False
1	An HIV-positive woman who is not on ART can transmit HIV to her baby during delivery		x	
2	An HIV-positive woman who is not on ART can transmit HIV to her baby during breastfeeding		x	
3	Using a condom during sex prevents the transmission of HIV	S	x	
4	HIV can be transmitted by a mosquito			x
5	Patients on ARVs still need to use condoms	S	x	
6	There is a risk of transmission of HIV when sharing food or plates with an HIV positive person			x
7	There is a risk of transmission of HIV when sharing the clothes of an HIV-infected person			x

Prevention – transmission		Security	True	False
8	There is a risk of transmission of HIV when an HIV-infected person takes a child in his arms			x
9	A condom can be used several times	S		x
10	The risk to transmit HIV is very low when the HIV-infected person's viral load is undetectable	S	x	
Understanding the disease and the treatment		Security	True	False
11	The HIV virus destroys the immune system		x	
12	You can be infected with HIV without feeling sick.		x	
13	When an HIV infected person does not start ART, more infections will appear.		x	
Understanding the treatment		Security	True	False
14	Cotrimoxazole (or Bactrim) is an ARV drug			x
15	ARV is started with every person that is HIV-positive		x	
16	ARVs are medication that can kill the HIV virus completely			x
17	If I stop taking ARVs I will become sick	S	x	
18	ARVs are medication which stop HIV replication		x	
19	Starting ART early is important for your own health and to reduce the risk of transmitting HIV to others.		x	
How to take ARV		Security	True	False
20	ART has to be taken for life	S	x	
21	ART should be taken every day	S	x	
22	HIV can become resistant to ART if doses are missed	S	x	
23	A viral load test measure the amount of HIV in the blood.			
24	An undetectable viral load means I no longer have HIV.	S		x
25	An HIV-infected person could stop taking ARV when he feels better	S		x
26	If you vomit within 30 minutes of taking your drug, you should take the drug again	S	x	
27	If you forget to take your daily dose you should take the forgotten dose within 12 hours (if OD regimen) of the scheduled time	S	x	
28	If you forget regularly to take your ARV, your viral load will be high		x	
29	The most common reason for a high viral load is an adherence issue.		x	
30	When travelling, you can stop taking ARVs	S		x
Side effect of ARV		Security	True	False
31	If you have a headache or nausea you should stop taking your ARVs	S		x
32	If you develop a skin rash while taking ARVs you should tell your doctor, as this could be a sign of a serious side effect		x	

Total score:

%:

Patients should be able to answer the true/false questions correctly with a score > 80% and should answer all questions followed by an S (security) correctly.

Annex 9. Communication and basic counselling skills

Source: Summarised from “Training manual mental health in primary health care: A training course for MSF medical staff”. MSF Mental Health International Working Group, 2012.

People involved in PSEC activities need to be trained in communication and basic counselling skills. The following skills are essential:

Attending skills

Attending means signalling physically that you are listening. The use of nonverbal signs of attending sets a comfortable tone, encourages the speaker to keep talking and demonstrates your concern and interest. It also signals the speaker that you are interested in what he or she has to say and are following the conversation.

Attending skills can be described by the acronym SOLER:

- S – Sit squarely
- O – Open posture
- L – Lean forward
- E – Eye contact
- R – Relax

Active listening

In active listening, the listener encourages the patient to speak, tries to understand what the patient is saying, what he is feeling, or what the message means. The listener then responds in his own words. The listener does not evaluate, offer opinions, advise, analyse or interrogate. The listener has to be careful not to misinterpret the client.

By consistently practicing “active listening”, the listener shows understanding and empathy for the patient’s feelings, but at the same time allows the client to retain the responsibility for the problem. The client gets the possibility to reflect and has a “concentrated dialogue with himself”, which will help to sort and understand his problem and become less afraid of his feelings.

- Using open- ended questions

Open-ended questions are useful to explore a problem. Open-ended questions can bring out many different answers and often start with *how, what, when or who*. These questions are sometimes difficult to answer for the patient; he must think before he can answer. They often result, after some hesitation, in long answers but they may also bring about an uncomfortable silence. The patient is encouraged to speak freely narrating whatever s/he wants related to the question posed.

It is important to use open-ended questions in addition to directive, close-ended questions which are mostly answered by yes or no.

- Restating

Restating what you have just heard often helps the person to carry on talking, without distracting a train of thought.

E.g. Patient: “...and I didn’t know what to do.”

Doctor: “You didn’t know what to do?”

Patient: “No, so I just stood there and screamed at them.”

- Invitations to talk

Sometimes it is useful to make an encouraging remark like: *“Would you like to talk about that?”*, *“Could you tell me some more about it?”*

- Acknowledgement responses.

These are encouraging sounds like *“Yes.”*, *“Yes, go on.”*, *“I’m with you”*, *“Uh-huh”*, and *“I see.”*, *“Of course.”* Or *“Mmm-hmm.”*

- Paraphrasing:

Paraphrasing by the counsellor is a brief rephrasing of information provided by the client. It provides a restatement of the essence of the information in your own words. The use of paraphrasing demonstrates you are listening and it helps you make sure your understanding is correct. It lets the speaker explore the issues, but does not suggest that you agree, and encourages the speaker to analyse and discuss the subject matter more fully.

e.g. *“It sounds like.., Let me see if I heard you right... Are you saying that...?”*

- Clarifying

Clarifying means asking questions until you are both confident that you have understood. *“I’m not sure what you mean. Can you explain a bit more?”* *“Do you mean that?”* *“What do you mean by...?”*

You will need to be clear about the problem and the feelings and check your understanding with the patient at various points throughout the conversation. Do not hesitate to ask the client if you did not understand a certain point of the story.

- Talking about feelings

Talking about the feelings and emotions of the patient is very important in all forms of counselling. If the listener understands the feelings of the patient, he may better understand the behaviour of the patient that at first might strike him as disturbing or strange. If the patient behaves in ways that are illogical or contradictory, this may be the result of conflicting feelings of which the patient is hardly aware. The healthcare provider can help the patient by sorting out these contradictory feelings.

- Summarising

Summarising is pulling together, organising and integrating the major aspects of the dialogue, briefly going over it together, agreeing on the problem or the next course of action. Remember to pay attention to various themes and emotional overtones and to put key ideas and feelings into broad statements. DO NOT add new ideas. This gives a sense of movement and accomplishment in the exchange and establishes a basis for further discussion. It pulls together major ideas, facts, and feelings and helps to sort them out.

Showing empathy

Empathy is the experience of understanding another person’s condition from their perspective. It is important to show empathy towards the patient, which is different from showing sympathy.

Empathy	Sympathy
(1) I can understand what you are going through.	(1) Poor you, it is really bad that this happened to you.
(2) I can understand that you are feeling angry at what has happened to you.	(2) It is horrible that this has happened to you
(3) I accept that you are very scared	(3) Don’t be scared, I am here to help you however I can.
(4) Simply sitting in silence while the patient expresses his/ her feelings or weeps.	(4) I am so sorry for you, don’t worry everything will be all right.

Annex 10. Group sessions

Group sessions may help people with emotional, behavioural and educational needs. During group sessions patients can share their experience which is a supportive process. This might reduce feelings of fear, anxiety, guilt and other negative emotions associated with the disease and/or treatment. It also helps them identify positive coping mechanisms and practice skills. Adults and children should be seen in different groups. Duration on medication, age, disclosure status, etc. can be taken into account when forming the patient groups.

There are 2 kinds of group sessions: the interactive learning session and the roundtable discussion.

Interactive learning session

An interactive learning session is a presentation (without slides!) where questions are central to the dynamic. It can be used for educational purposes.

Set-up

- Maximum participants: 10-12
- Duration: 15-30 minutes depending on the topic
- Participants are seated in a circle with the educator
- Tools: flipchart, pens

Objectives

- To make participants actively engage in their learning process
- To explore participants' existing, previous knowledge
- To facilitate the exchange of ideas
- To transmit new knowledge to cover gaps identified by the participants

The role of the educator is to

- Before the session
 - Decide on the learning objective(s) to be achieved
 - Prepare a set of questions to initiate, maintain and re-launch discussion
 - Prepare content
 - Prepare the room and material
- During the session
 - Present session objectives and plan
 - Have people introduce themselves, so participants feel more comfortable with one another
 - Initiate discussion by asking a series of questions
 - Give positive reinforcement, encourage participation
 - Organise the correct knowledge expressed by participants in a structured way
 - Check for missing knowledge
 - Give a synthesis of the main points covered

Encourage participants to speak with you in private afterwards if they have concerns they do not want to share with the group.

Roundtable discussion

A roundtable discussion is a debate to discuss a question with a group of patients.

Set-up

- Maximum participants: 10
- Duration : maximum 90 minutes
- Participants are seated in a circle with the educator

Objectives

- To exchange real-life opinions, share experiences
- To discuss ideas and opinions
- To identify values, perceptions on a sensitive topic

The role of the educator is to

- > Before the session
 - Define the question to be debated *
 - Prepare a list of points, ideas that should be covered during the debate
 - Invite, select participants and invite them to join according to criteria (e.g. age, medication duration)
- > During the session
 - Have people introduce themselves, so participants feel more comfortable with one another
 - Ensure each participant can express his opinions and ideas
 - Keep discussion focused on the topic
 - Re-launch debate by reformulating ideas, involving participants
 - Ask open-ended questions to the group so as to cover all points
 - Remain neutral and non-judgmental during the debate
 - Give a synthesis of the main points covered

Encourage participants to speak with you in private afterwards if they have concerns they do not want to share with the group.

*** Examples of topics that could be discussed in group**

- Medication side effects and ways to cope with them
- Methods to facilitate disclosure of HIV status
- Taking the ARV treatment: How do you remember to take your pills? How do you take your pills when you are not at home? What helps you in taking your medication?
- Healthy sexuality
- Medical issues: treatment resistance, CD4 and viral load (include the support of a medical person)
- Desire for children: When to plan having a baby? What's the PMTCT experience of patients?
- Encouraging your partner for HIV testing: How to encourage your partner to come for testing? How did patients manage to do this?

Annex 11. Initial patient needs assessment

Source: adapted from MSF OCG Bunia, 2010

File number: Health Facility:

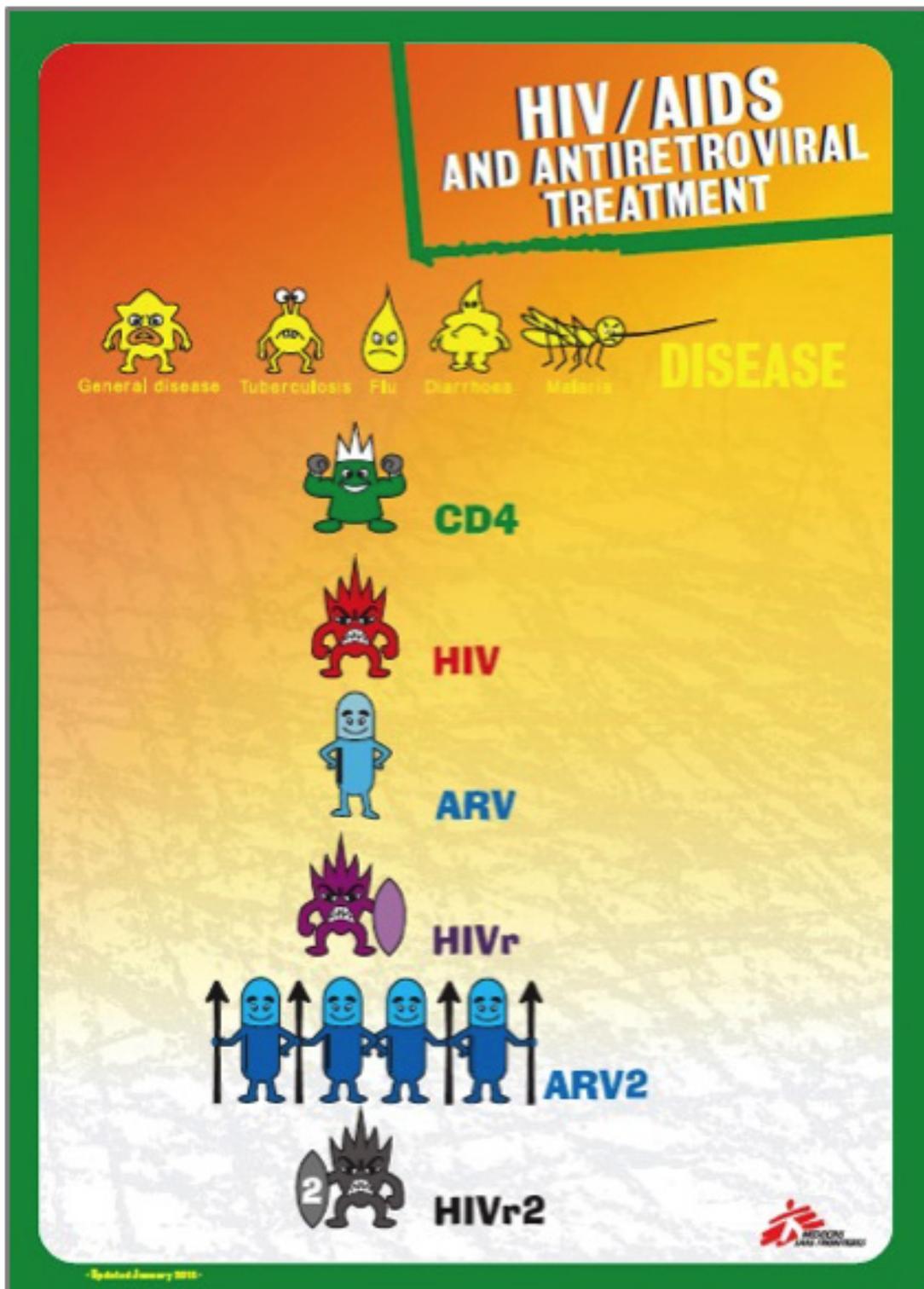
First name: Last name:

<p>Knowledge, beliefs (on HIV, on the treatment)</p>	<p>Education level, literacy</p>
<p>Daily activities (occupation, hobbies)</p>	<p>Social situation (Married, children, social position, how many dependants?)</p>
<p>Social support (family, professional, friends, HIV disclosure, stigmatisation)</p>	<p>Economic situation (financial status, housing, nutrition)</p>
<p>Psychological status (sleep, appetite, capacity to do daily activities, feeling of self-efficacy, self-esteem, feeling concerning his illness, history of psychiatric illness)</p>	<p>Life plan and future goals/motivation</p>
<p>Medical info (CD4 count, medication, other diseases and other medication)</p>	<p>Synthesis: Important points to discuss (strengths, barriers to medication, concerns)</p>

Annex 12. HIV/ART flipchart

Source: MSF SAMU, 2015

Available in full version on: <https://tukul.msf.org/psec>



Annex 13. Patient Health Questionnaire (PHQ 9)

This tool allows the healthcare provider to screen the patient for depression. It is preferable that the patient self-administers the questionnaire. When the patient is illiterate, then the counselor can ask the questions.

The first two questions (also called PHQ-2) can be used as a first-step screening approach for routine inquiry about depression. If the patient scores 2 or more on any of these questions, or if the counsellor has concerns that the patient is experiencing depression, it is recommended to administer the full PHQ-9 to determine whether they meet the criteria for depressive disorder.

Name / File number:..... Date:.....

	Not at all	Several days	More than half the days	Nearly every day
<i>Over the last 2 weeks, how often have you been bothered by any of the following problem?</i>				
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
<i>If that patient scores one or more on any of the above questions, go on with the following questions :</i>				
3. Trouble falling or staying asleep, or sleep so much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating (on things linked with patient's usual activities)	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite- being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
Add columns :				
TOTAL :				

10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all: _____

Somewhat difficult: _____

Very difficult: _____

Extremely difficult: _____

If you faced any difficulty, did it occur for two years or more? _____

A patient is considered as having signs of depression if:

PHQ9 score	Provisional diagnosis	Recommendation
5-9	Minimal symptoms	Support and educate to call if worse
10-14	mild depression <i>or</i> chronic depression (symptoms lasting for two years)	Support and watchful waiting Reassess in one/two weeks Consider starting treatment
15-19	Moderate depression	Refer to clinical officer / psychologist for assessment and treatment
> 20	Severe depression	Major impairment and need for immediate medical treatment and counselling

If question #9 is answered with a score of 1 or more – then the patient requires referral and further assessment by the clinical officer/psychologist or other appropriate available clinician.

For moderate, severe and chronic depression, treatment and follow up consists of:

1) Regular supportive counselling

- Reassure patient about his symptoms, build a trustful and confidential relationship
- Evaluate depression (when did it start, precipitant, support systems, etc.)
- Assess functional impairment: ask question 10 to determine symptoms have been present 2 or more weeks and impact functional status.
- Provide regular counselling sessions as complementary to medical treatment.
- Re-assess symptom severity on a monthly basis with the PHQ 9.

2) Refer to clinical officer/medical doctor if score > 15 for assessment for medical treatment

Annex 14. CAGE-AID Questionnaire

This tool is used to screen for alcohol and drug problems conjointly. One or more responses to the CAGE-AID is a positive screen and requires further assessment to ascertain severity of alcohol and/or drug use and impact on patient's life and adherence to treatment.

Patient Name: Date of visit:.....

When thinking about drug use, include illegal drug use and the use of prescription drug use other than prescribed by a qualified prescriber.

Questions	Yes	No
1. Have you ever felt that you ought to cut down on your drinking or drug use?		
2. Have people annoyed you by criticizing your drinking or drug use?		
3. Have you ever felt bad or guilty about your drinking or drug use?		
4. Have you ever had a drink or used drugs first thing in the morning to steady your nerves or get rid of a hangover?		

Annex 15. Misunderstandings around adherence

Source: Adapted from “Misunderstandings around Adherence, Viral Load Toolkit”, MSF-OCB, 2013.

This tool can be used with HIV-infected patients and with healthcare providers.

Hand out red/green cards to all participants.

Explain how different statements will be shared and it is for them to agree (green card) or disagree (red card).

Alternatively you can ask participants to come and stand in the middle of the room and move to one side if they agree or move to the other side of the room if they disagree.

After each statement & positioning of participants, you can discuss and explain how all these statements are correct. Consider in sensitized settings having participants write their answers on a piece of paper so they can answer anonymously.

“You can drink alcohol when taking ARVs”

In the past, the message was frequently given to patients that they must never mix ARVs with alcohol or recreational drugs. The result is often that often patients decide not to take their ARVs the day that they use alcohol or drugs. Alcohol or drugs do not reduce the medicinal action of ARVs, but they increase the chance that a patient will forget to take their ARVs. If the patient remembers however, there is no reason why they should not take their ARVs even if under the influence of alcohol or some other drug.

We need to ensure that patients adhere to ARVs while using alcohol or drugs, by identifying ways of taking ARVs before they start drinking or how to remember to take ARVs while drunk or high. If there is ongoing abuse of alcohol or drugs, then additional support and/or referral to a substance abuse programme should be offered.

“Taking your medication 10 minutes late will not cause viral resistance”

We always tell patients to choose a time to take their ARVs to help them establish a habit of taking their ARVs at a specific time, so that they do not forget to take them.

ARVs will still work if they are taken at a different time. It is important that patients take ARVs as soon as they remember, no matter how late it is. The next dose must then be taken at the normal/usual time.

Regularly taking ARVs 10- 20 minutes late will not cause resistance to the medication.

“It is okay to take medication on an empty stomach”

We used to say medications need to be taken with food. We see now that some patients do not take medication when they have no food available.

Medication may work a bit better if taken with some food, but ARVs can be taken on an empty stomach.

“Dosing time may be changed during fasting”

Some patients may take their medication earlier/later during fasting, when they are allowed to eat according to their religious beliefs. This is okay: it is better that a patient takes medication at another time than not to take medication at all.

“Unprotected sex is not a common reason for a high viral load”

We always say it is important for patients to use condoms to avoid passing HIV to others or to avoid reinfection. Patients may be re-infected with a resistant HIV virus through unprotected sex and thus have a high viral load. The chance of this happening is however very small. Instead, the most common reason for a high viral load is an adherence issue.

“Patients should not be obliged to disclose their status”

It is a personal choice of a patient to disclose their status to a person they trust or live with. Patients should be encouraged to disclose, but should not be obliged to disclose, nor should they be discouraged to do so. If patients are not ready to disclose their HIV-status to anybody, they should be helped to plan a way to still being adherent to ARVs every day, for example by taking medication before others in the household are awake, or by excusing themselves to go to the bathroom to take medication.

“Medication needs to be taken daily, even when the patient’s viral load is undetectable”

An undetectable viral load just means there is so little HIV in the blood that it can hardly be seen with the tests we have. It does not mean there is no more HIV in the blood. If an HIV test was repeated, the test would still show an HIV-positive result.

The PLHIV on ART needs to continue taking ART to keep the viral load undetectable. From the moment one stops ART, the few viruses in the blood will multiply again, begin attacking CD4 cells, which in turn will make the person fall sick.

“Patients can start ART without having a treatment buddy”

A treatment buddy or treatment supporter is someone who is chosen by a patient about to start ARV treatment to provide ongoing support for adherence to treatment. A treatment buddy is usually a patient’s friend, family member or another PLWHA who is also enrolled in care and is a trusted person to whom a patient can disclose his status. A treatment supporter can be invited to join the PSEC sessions with the patient. Despite the benefits for a patient’s adherence and retention, a lack of treatment buddy should never be part of exclusion criteria to start treatment. Disclosure to a trusted person can be worked upon after treatment initiation.

“When one misses a dose of ARVs, the forgotten dose needs to be taken within 12 hours of the scheduled dose time.”

It is important to never take a double dose of ARVs, meaning 2 doses at a time. The level of ARV medication in the blood should be high enough to fight HIV properly. If the level is too high it could produce toxic effects. If the level is not high enough, the treatment will not be effective.

For medicines taken once per day:

- One should take the missed dose if he remembers within 12 hours of the scheduled dose time.
- He should not take the missed dose if the next dose is scheduled less than 12 hours later.
- Then he should return to the regular schedule.

For example, let’s say that a PLHIV usually takes his medication at 7am, once every day. If he misses this dose, the missed dose should be taken before 7pm. He should not take the missed dose after 7pm. Instead, he needs to wait to take the next dose in the morning.

For medicines taken twice per day:

- One should take the missed dose if the next dose is scheduled more than 6 hours later.
- He should not take the missed dose if the next dose is scheduled less than 6 hours later.
- He should then return to the regular schedule

For example, let’s say that a PLHIV usually take medications at 7am and again at 7pm. If he misses the first dose at 7am, he should take the missed dose if he remembers before 1pm. He should not take the missed dose if he remembers after 1pm. Instead, he should just wait to take the next dose at 7pm.

Annex 16. PSEC session guide for ART initiation and early follow-up

Source: MSF-OCB Khayelitsha, 2015

Available in full version on: <https://tukul.msf.org/psec>

Training material and other tools related to this intervention can be found on: <http://samumsf.org/blog/portfolio-item/patient-education-and-counselling-for-art-initiation/>

ART/TB Rx initiation and adherence counseling model
 Updated January 2015

Structure

The key features of the proposed ART/TB initiation and adherence counseling model, in contrast to current ART preparation models are:

- The limitation of the number of preparation sessions, to allow for faster initiation on ART
- To strengthen the post-initiation support, enabling active learning for patients while they are on ART
- To allow fast tracking without compromising the content of the sessions
- To integrate TB counseling in order to support TB/HIV co-infected patients

Approach

The approach is characterized by:

- Limited time spent on repeated treatment literacy, while focusing on the integration of ART and TB treatment into daily life
- A patient centered approach where patients decide when they are ready to start ARV's
- 14 simple specific adherence support steps to address. The objective of these steps is to support the patients in reflecting on solutions to overcome their barriers to initiation and adherence on treatment

Tools

- Session guide for counselor and counselor supervisor's use
- Adherence plan for patient's use and a copy to keep in patient's file
- HIV/ART, TB flipchart as educational tool for counselor
- HIV/ART and TB brochure as handout for patient
- HIV/ART video as educational tool for counselor (optional)
- Testimonies (live, video or written)

Training

Training of counsellors

- Training of counsellors (3 day training):
 - Theoretical training on initiation and adherence counseling model, guidelines and tools
 - Practical training based on the use of the guideline and tools through exercises, role-plays and case studies
- For each counselor, mentoring on-site by a counselling supervisor

Training of counselling supervisors

- Basic training of counsellors + a half day training on supervision tools and practical exercises
- Mentoring on-site by trainer

Supervision

- Who:
 - NGO counselling supervisors/coordinators supervise the counsellors and report to facility manager.

Annex 17. Side effects - what to do?

Source: Adapted from *Adherence Support Worker Training Facilitator's Guide, Family Health International, 2007*

Side effect	Medication	What a patient can do	When a patient should seek help/ go to the clinic
Fatigue	AZT	<ul style="list-style-type: none"> - Get up and go to bed at the same time each day - Exercise 	<ul style="list-style-type: none"> - The patient is too tired to eat or move - The patient cannot swallow or eat enough to feel strong
Headache	AZT DTG	<ul style="list-style-type: none"> - Rest in a quiet, dark place - Place cold cloths on your eyes - Take Paracetamol 	<ul style="list-style-type: none"> - The patient's vision becomes blurry or unfocused - Paracetamol does not relieve the pain - Headaches are frequent or very painful - The patient's neck is stiff
Insomnia	AZT EFV DTG	<ul style="list-style-type: none"> - Get up and go to bed at the same time each day - Exercise 	<ul style="list-style-type: none"> - The patient is too tired to eat or move
Jaundice (yellow eyes, skin)	ATV/r		<ul style="list-style-type: none"> - If also generally feeling unwell or change in skin or eye colour is bothersome.
Diarrhoea	LPV/r	<ul style="list-style-type: none"> - Eat frequent, small meals - Drink lots of clean water and tea. Take oral rehydration salts (ORS) 	<ul style="list-style-type: none"> - There is blood in the stool - The patient has a fever - The patient has more than four watery or soft bowel movements per day - The patient is thirsty, but cannot eat or drink properly
Nausea, vomiting, and poor appetite	AZT ETV DRV/r DTG RAL	<ul style="list-style-type: none"> - Take ART medication with food^b - Eat frequent, small meals - Eat rice - Take sips of tea or ORS until vomiting stops - Don't eat greasy or spicy foods 	<ul style="list-style-type: none"> - The patient has sharp stomach pains - The patient has a fever - The patient is vomiting blood - Vomiting lasts more than one day - The patient is thirsty, but cannot drink or eat
Dizziness	EFV DTG	<ul style="list-style-type: none"> - Sit down until it goes away - Take Efavirenz right before going to sleep - Avoid driving a car, motorcycle or bicycle when dizzy 	<ul style="list-style-type: none"> - The dizziness lasts more than two weeks
Skin rash	ABC NVP EFV ETV	<ul style="list-style-type: none"> - Keep the skin clean and dry - Wash with soap and water - Avoid hot baths or showers - Avoid the sun 	<ul style="list-style-type: none"> - Rash is accompanied by a general ill feeling, fever, muscle or joint aches, blisters or mouth sores, inflammation of the inside of the eyelids, swelling of the face, or tiredness
Nightmares, vivid dreams, dizziness	EFV	<ul style="list-style-type: none"> - Take at bedtime (to avoid side effects during the day) and take on an empty stomach. 	<ul style="list-style-type: none"> - If symptoms last more than 2-3 weeks.

Reference: <http://www.bugsanddrugs.ca/documents/HIVARVGuide.pdf> (accessed Jan 12, 2017)

^b if the patient does not have any food, he still has to take his drugs.

Annex 18. Adherence assessment methods through patient self-reporting

Through self-report, we ask the patient about his adherence over a given period (e.g. the last 3 days, over the last week). It could be done through an interview, the Morisky Scale or with a Visual Analogue Scale (0-10 ruler).

Accuracy of self-reporting is maximised by approaching the patient in a neutral and non-judgmental way. The information obtained using these methods can then be taken as a starting point to discuss with patients any difficulties they have concerning taking the medication correctly, and to develop strategies to overcome these difficulties.

Interview

Ask in a respectful and non-judgmental way:

- "Many patients have challenges taking their medications. What challenges are you having?"
- "Can you tell me when/how you take the pills?"
- "When is the most difficult time for you to take the pills?"
- "It is sometimes difficult to take the pills on time? How many pills have you missed in the last 3 days?" [After patient answer] And in the last month?

Morisky Medication Adherence Scale

1. Do you ever forget to take your medicines?
2. Are you careless at times about taking your medicines?
3. When you feel better, do you sometimes stop taking your medicines?
4. Sometimes if you feel worse when you take your medicines, do you stop taking them?

No to all questions: good adherence

Yes to one or more questions: support for improving adherence should be provided

Visual Analogue Scale (0-10 ruler)

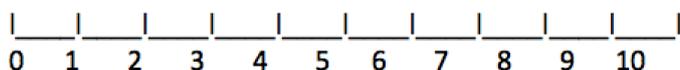
A visual analogue scale, with values ranging from 0 to 10, can be used to indicate how much of each HIV medication has been taken over a specific time period. The use of this tool has been validated in resource-limited settings (Oyugi et al, 2004).

To apply this tool, the patient is asked to indicate on the scale below his/her best guess about how many doses of ARV treatment he/she took in the previous 30 days compared to what he/she is supposed to take.

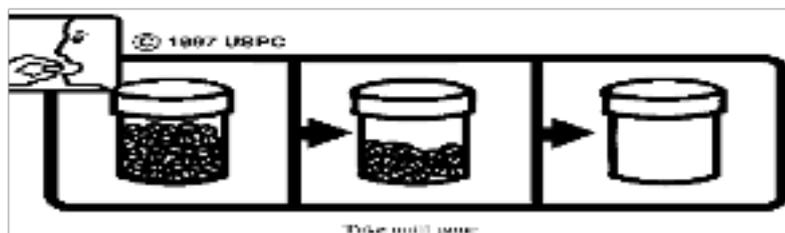
0 means he/she has taken **no** medication at all

.5 means he/she has taken **half** of the doses

.10 means that he/she has taken **every** single dose of the medication.



For illiterate patients, who might have difficulty in interpreting numbers, we could use a visual analogue scale with a pictogram.



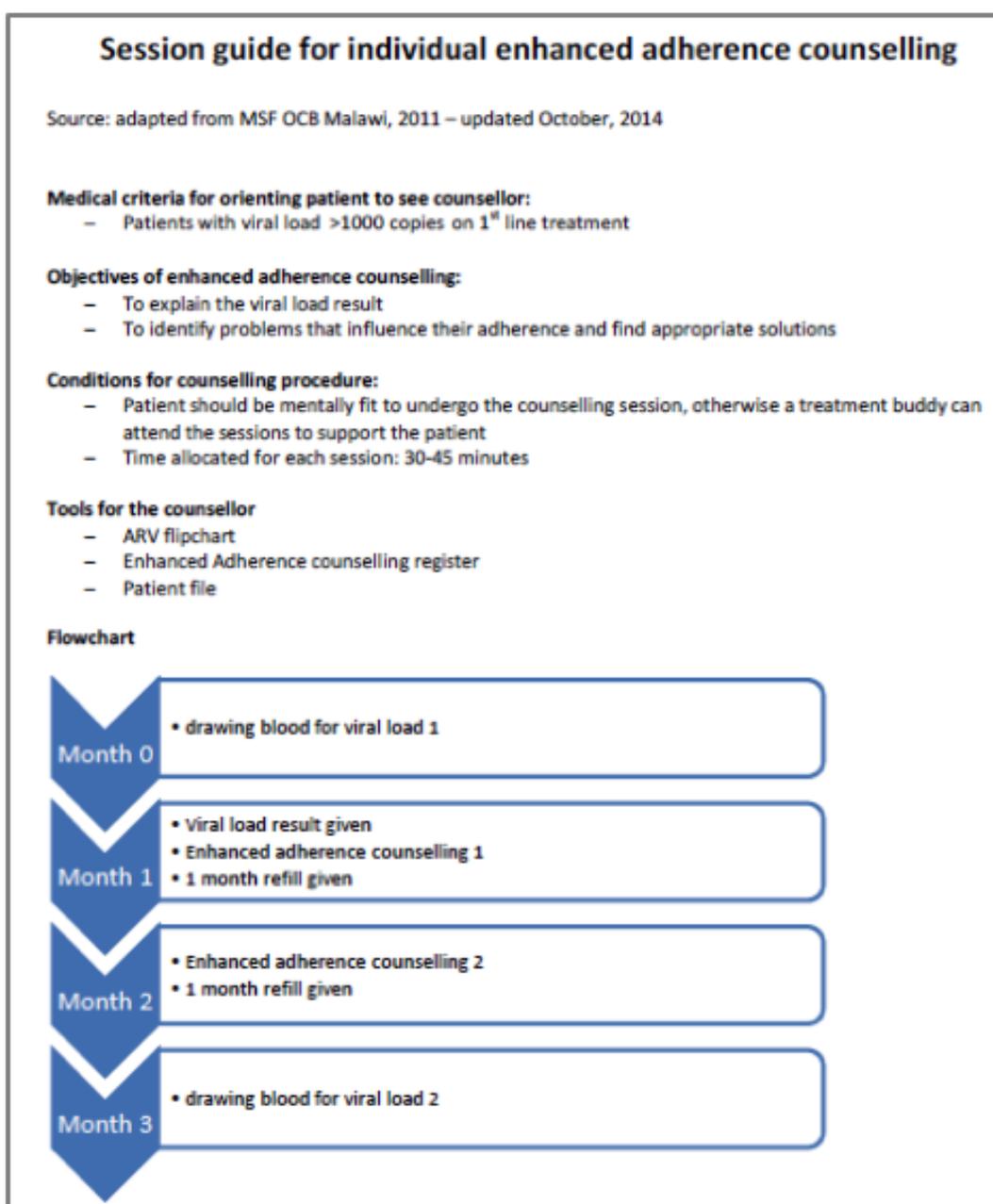
To decide which type of analogue scale to use, it is best to test it with several patients.

Annex 19. PSEC session guide for patients with a high viral load test result

Source: *Enhanced Adherence Counselling session guide, Viral load toolkit, SAMU-MSF, 2015.*

Available in full version on: <https://tukul.msf.org/psec>

Training material, leaflets, posters and other material for EAC and VL education are available on <http://samumsf.org/blog/portfolio-item/viral-load-vl-toolkit/>



Annex 20. PSEC session guide for 3rd line ART initiation and follow-up

Source: MSF-OCP, Nairobi 2015.

The third-line patient support education/counselling sessions are conducted after the “enhanced adherence counselling” session for patients on 2nd line ART (done when there is suspicion of ARV treatment failure) and after the decision to start a third-line treatment.

Objectives of third-line treatment patient support education and counselling:

- To prepare the patient to start 3rd line treatment
- To provide him support in adhering to his 3rd line treatment

Conditions for counselling procedure:

- It is important for patient under third line to be attended by the same counsellor in order to ensure continuity
- Treatment supporter/buddy can attend the sessions to support the patient
- It is also important to write up information collected during the session in the patient’s file in order to ensure good follow-up

A) First session before initiation of third-line ARV treatment

- Look at the patient’s file and prepare a list of problems identified at the previous counselling session, assessing emotional status, social situation, knowledge about HIV/AIDS and ARV treatment, patient behaviour and how the patient takes his treatment;
- Explain the reason for switching to a third-line regimen (repeated high viral load and outcome DST showing resistance to 2nd line drugs, drugs failing due to resistance created by former irregularities in the treatment uptake);
- Explain that the third-line medication is more complex to take (more pills, twice a day dosage);
- Explain the importance of good adherence;
- Assess the possible difficulties regarding taking the treatment every day at the same time;
- Discuss the strategy to adhere to timing of medication, especially in different situations such as when away from home, at the weekend. Does patient have to hide to take his medicine if he has not disclosed his status? ;
- Ask whether patient has a relative or a friend who could support him to take the drugs;
- Discuss with patient if he is ready to start such treatment ;
- Explain that the health consequences are serious if the patient does not fully commit to his treatment. Explain the consequences for the patient and for patients whom he may transmit a resistant form of HIV to.
- Screen for depression and alcohol/substance use.

B) Second session before initiation of third-line ARV treatment (around 7 days after 1st session)

- Look at the patient’s file and prepare a list of problems identified at the previous counselling session, assessing emotional status, social situation, knowledge about HIV/AIDS and ARV treatment, patient behaviour and how the patient takes his treatment
- Make a plan on how to deal with previously experiences adherence barriers
- Verify if information given at the first session has been understood
- Assess if the patient is ready to start a third-line ARV treatment

- Assess the patient's motivation to take ARV
- Assess whether the patient can come regularly to HIV clinic

The clinician prescribes the medication for the third line and sends the patient to the counsellor/nurse to receive information on how to take the medication:

- How to recognise the different drugs prescribed
- According to the regimen prescribed how to take the ARV medication using a daily plan (number of pills, timing, dietary precautions)
- Importance of medication adherence
- Possible side effects of each drug
- What to do if the patient forgets to take one dose
- What to do if the patient vomits after taking the drugs
- Who to contact in case of a problem with the treatment
- That patient should bring the drug stock back on every visit

C) Counselling session 14 days after initiation of the third line ARVs (D14)

- Look at the patient's file and prepare a list of problems identified at the previous counselling session, assessing emotional status, social situation, knowledge about HIV/AIDS and ARV treatment, patient behaviour and how the patient takes his treatment
- Assess patient's adherence to the new treatment (% of doses missed, if the patient has missed a dose, what is the reason?)
- Check if patient is adhering to the timing for taking the drugs
- Ask the patient if he has any side effects and how he copes with these side effects
- Ask about the role of his family or friends in taking the ARV drugs and possibly in the management of the side effect(s)
- Ask if the patient has any questions about the treatment or the disease
- Remind the patient of the importance of adherence

D) Then a counselling session on a monthly basis for the first 6 months (M1-M2-M3-M4-M5-M6)

At each visit:

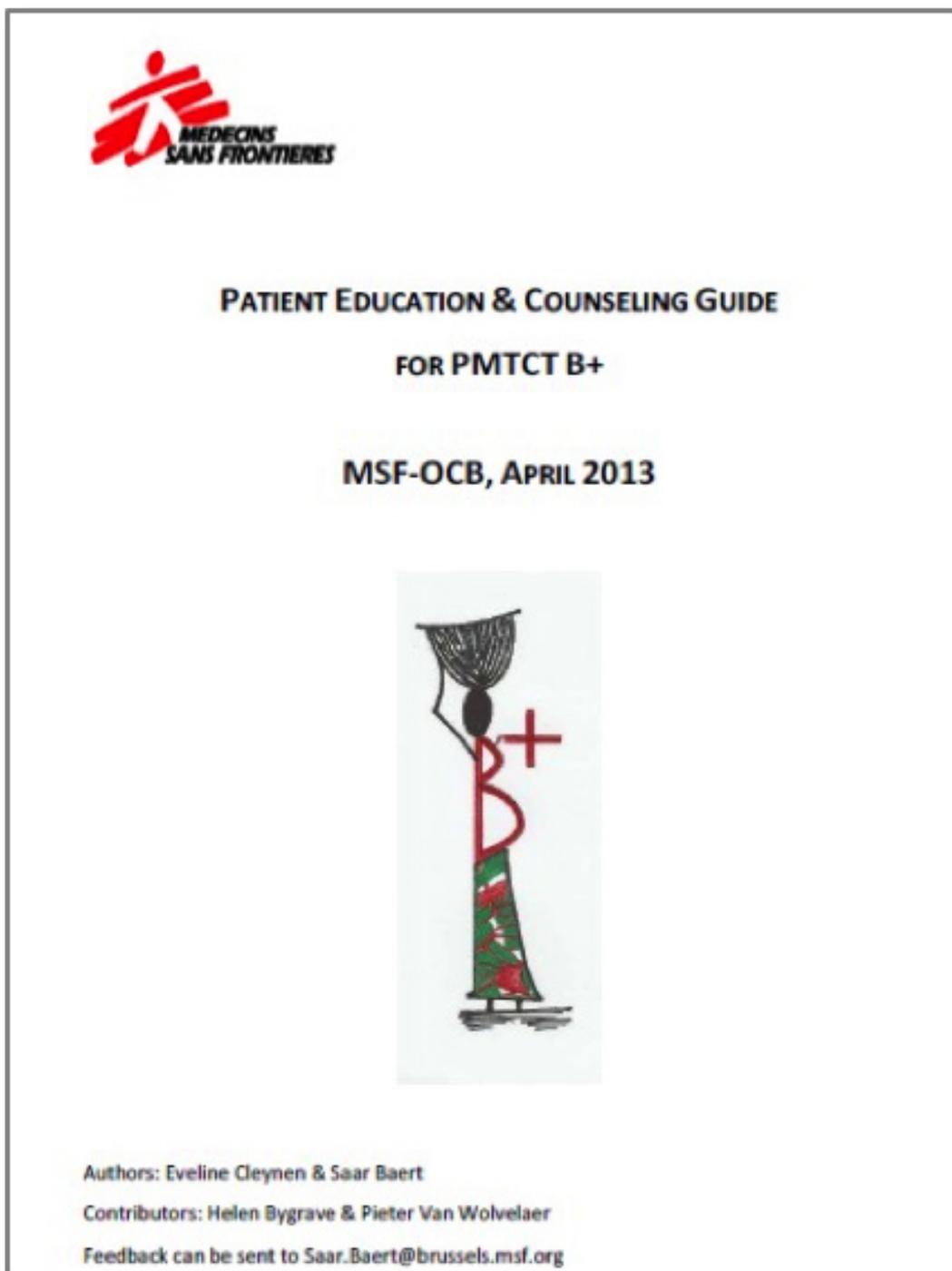
- Look at the patient's file and prepare a list of problems identified at the previous counselling session, assessing emotional status, social situation, knowledge about HIV/AIDS and ARV treatment, patient behaviour, how the patient takes his treatment and how he overcomes barriers to treatment adherence
- Assess patient's adherence to the new treatment (% of doses missed, if the patient has missed a dose, what is the reason?)
- Check if patient is adhering to the timing for taking the drugs

After 6 months a new viral load test is done. Adapt the counselling messages according to the result of the viral load.

Annex 21. PEC session guide for PMTCT

Source: *Patient Education and counselling guide for PMTCT B+, SAMU-MSF, 2013*

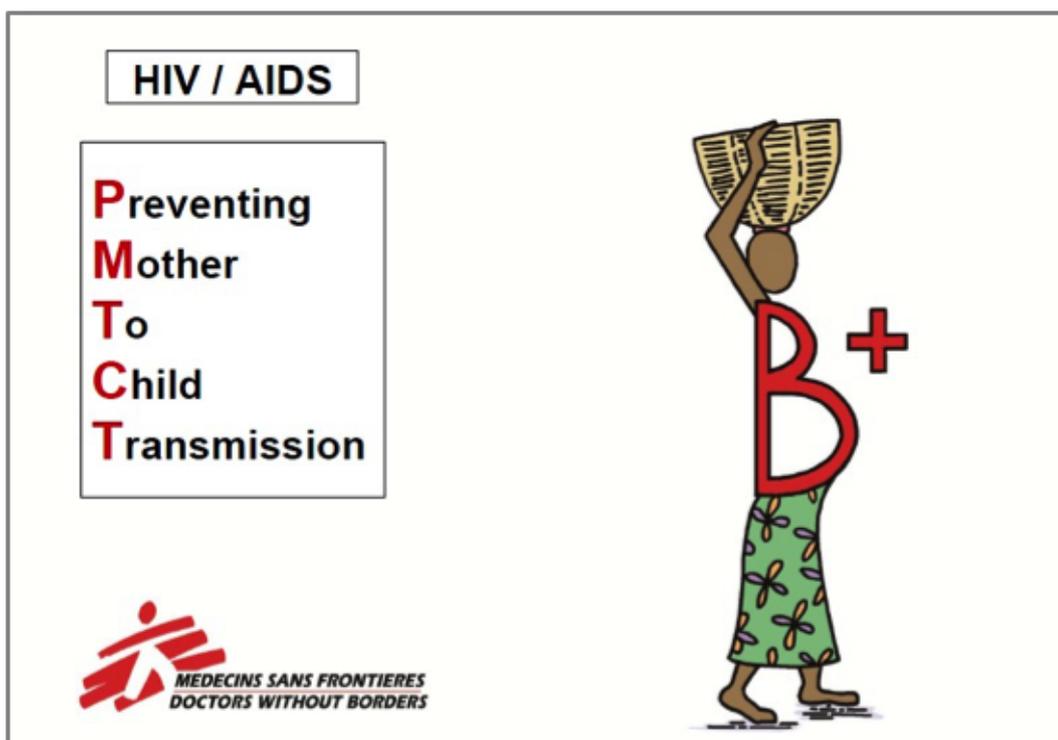
Available in full version on: <https://tukul.msf.org/psec>



Annex 22. Flipchart for PMTCT

Source: Flipchart for PMTCT B+, MSF-OCB Eshowe, 2013

Available in full version on: <https://tukul.msf.org/psec>

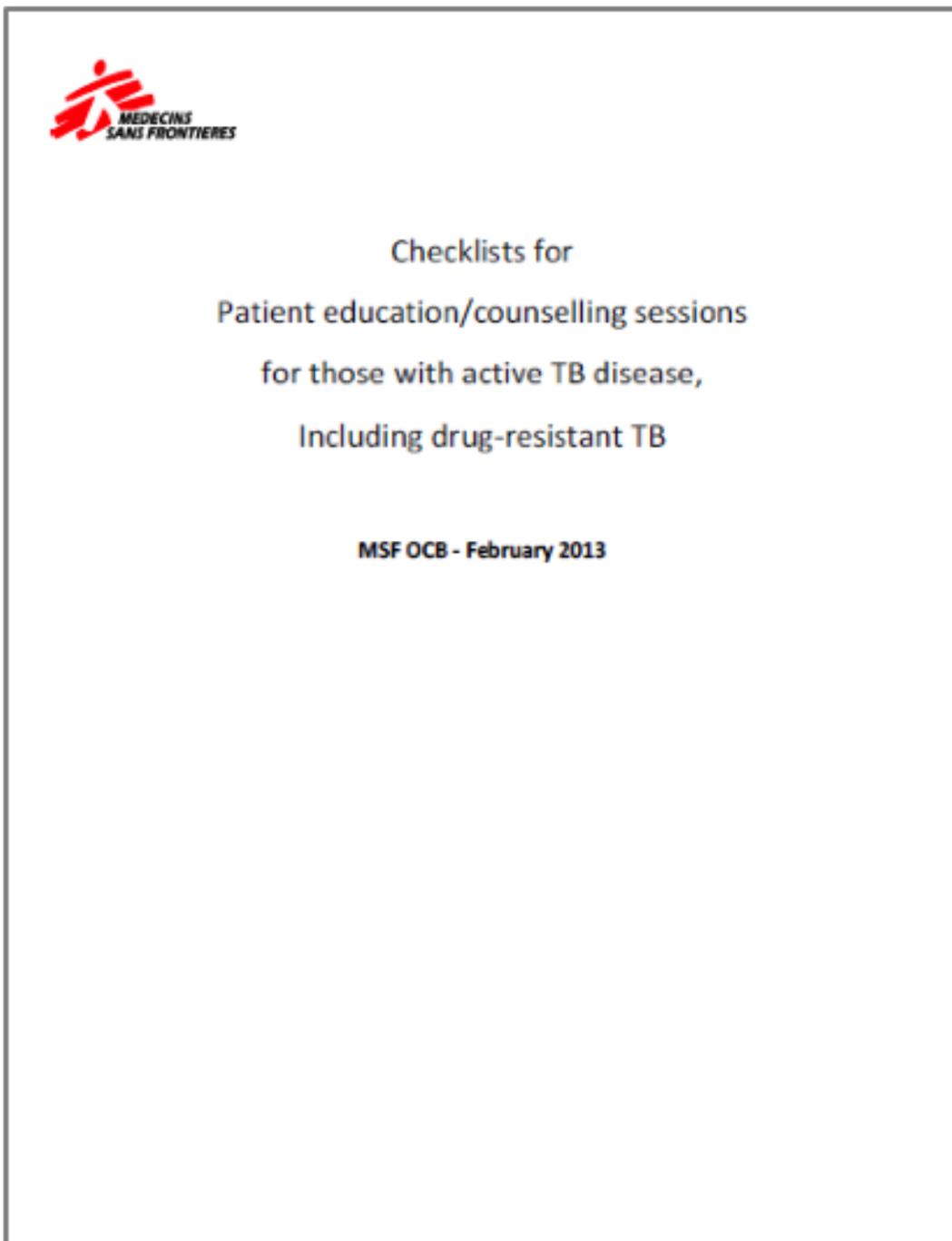


Annex 23. PEC session guide for TB/DR-TB

Source: MSF-SAMU, 2013

Available in full version on: <https://tukul.msf.org/psec>

Details on the treatment interruption sessions, XDR-TB sessions and palliative care sessions can be found at www.samumsf.org (tools of "Patient support interventions to improve adherence to drug resistant tuberculosis treatment: counselling toolkit. MSF Khayelitsha, 2014)



Annex 24. TB Flipchart

Source: MSF-OCG, Swaziland, 2016

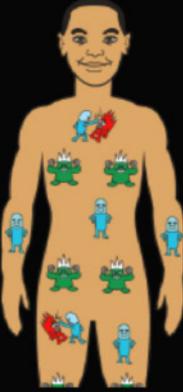
Available in full version on: <https://tukul.msf.org/psec>



Annex 25. Post-Exposure Prophylaxis (PEP) leaflet

Source: MSF-OCB, Rustenburg, 2015.

Available in full version on: <https://tukul.msf.org/psec>

<p>What is PEP?</p> <p>PEP stands for Post-Exposure Prophylaxis. It is an emergency medication that helps preventing HIV, after being exposed (e.g. in case of sexual assault, condom break or unprotected sex).</p> <p>PEP medication has to be taken for 28 days, starting as soon as possible after the exposure - within 3 days (72 hours).</p> <p>PEP is similar to the medication that people infected with HIV take to treat HIV: ARVs.</p> <p>Taking PEP is preventive; if you take PEP correctly it is very likely that you will avoid getting HIV (99% effectiveness if it is taken correctly).</p> <p>PEP does not cure HIV and does not prevent other infections.</p> <p>It is not a substitute of HIV preventive methods, such as condom use.</p> <p>PEP is meant to be used after a high HIV risk event or an uncommon situation of HIV exposure, such as sexual assault, condom break, unprotected sex, etc.</p> <p>If you find yourself frequently exposed to HIV, feel free to come and discuss with us about other possible HIV preventive methods that can be better for you.</p> <p>Before starting PEP you need be tested HIV negative.</p>	<p>How does PEP work?</p> <p>It takes approximately 3 days for HIV to spread in the body.</p> <p>The CD4 cells are like the soldiers of our body, they are part of our immune system and fight against diseases that try to enter the body.</p>  <p>When HIV enters the body, it attacks the CD4 cells (the soldiers of the body) and uses them to multiply.</p>  <p>PEP can help to stop HIV when the virus hasn't yet spread in many of the CD4 cells.</p> <p>The ARV medication has to be taken every day for 28 days as prescribed to reduce the chances of HIV spreading in your body.</p> <p>You will be asked to come back to the clinic for another HIV test after 6 weeks and after 3 months.</p> 	<p>What are the potential side effects of PEP?</p> <p>You may experience side effects while taking PEP. The most common side effects of PEP are nausea, vomiting and diarrhea.</p> <p>You will receive extra treatment to help you dealing with these side effects.</p> <p>If you feel like you cannot handle PEP side effects, you should come back to the clinic to receive appropriate support. You shouldn't stop the medication.</p> <p>PEP works very well if you take it correctly. If you stop, interrupt or skip your medications you reduce the chances of being protected against HIV.</p> 
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Annex 26. Patient Tracing - Some general tips on following up with patients by phone

Source: *Comprehensive Peer Educator Training Curriculum: Trainer Manual*, ICAP, 2009

If consent has been given for an SMS or phone call, we may send an SMS or call the patient who has missed an appointment.

- 1) **If sending an SMS, use the agreed-upon messages. Usually, it is best to keep the messages general in case someone other than the patient receives them. The message could be validated by the patient himself. Never give lab results or specific information about the patient's care in an SMS. Some examples are:**
 - You missed your appointment. Please call us right away (phone number)
 - You missed your appointment. Please come as soon as possible and call (phone number)
 - We need to see you and your child right away at the clinic. Please call us (phone number)
 - The doctor needs to see you and your child at the (name) clinic. Please come as soon as possible.
- 2) **If the patient still does not call back or return to the clinic after sending an SMS, you can follow up with a phone call.**
- 3) **If making a phone call, make sure the phone call is conducted in a quiet room.**
- 4) **Make sure you have all of the patient's information and file in front of you before you call.**
- 5) **Always try to speak with the patient her- or himself, or the treatment supporter if listed in the patient file.**
- 6) **Use scripts to know what to say when you talk with a patient:**
 - Tell patients your name and role
 - Tell patients your reason for calling (that they have missed their appointment)
 - Discuss reasons why the patient should come back to the clinic
 - If the patient refuses, try to determine the reason(s) the patient will not come back. You could also ask if the patient would be willing to accept a home visit so you could talk more in person
 - If the patient accepts, make an appointment at a time and on a day that is convenient for the patient (as soon as possible)
 - Thank the patient for taking the time to speak with you
- 7) **Phone calls should focus on getting the patient to return to the clinic. Never give test results over the phone!**
- 8) **Keep information confidential! If you talk to someone other than the patient, do not say you are from the ARV treatment clinic. Instead, say that you are calling from the clinic and need to speak with the patient, or that the doctor requests that the patient return to the clinic.**
- 9) **Record every call and SMS in a call logbook even if you were not able to speak with the patient.**

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