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Executive Agency for Health and Consumers

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Imp.Ac.T. Project Training Manual

Training manual on HIV/TB rapid testing of DUs/migrants in low-threshold services

Imp.Act.

Executive Agency for Health and Consumers

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HIV and TB Counselling and Testing for DUs and other marginalized groups

A Manual for Providers/Project Managers

INTRODUCTION

This publication has been developed in the framework of the project "Imp.Ac.T. – Improving Access to HIV/TB Testing for marginalized groups", co-funded by the European Commission under the Health Programme 2008-2013 and implemented by the Foundation Villa Maraini (project leader) and four associated partners: Foundation Regeboog Groep (The Netherlands), Sananim (Czech Republic), OZ Odyseus (Slovakia) and Gruppo Abele (IT).

The general aim of the project is to broaden the access to HIV and tuberculosis (TB) testing, prevention, treatment and care for vulnerable groups, such as problematic drug users (DUs) and migrants DUs...
The project's specific objectives are:
• to develop a framework and model to improve the effectiveness of HIV and TB testing and counselling among Target group;
• to increase the percentage of persons into target group, having access to HIV and TB testing;
• to ensure that people living with HIV and TB receive treatment for both conditions;
• to promote healthier ways of life and risk reduction among drug users and migrants;
• to assess the effectiveness of street HIV and TB testing in terms of proportion of new infection identified.

The project will use outreach work as a tool for promoting a new kind of provider-initiated counselling and testing, specifically tailored to hard-to-reach groups. In this way, the project will contribute also to reduce the gap between drug users/migrants and health care services and to reduce inequalities in the access to treatment.

The project can be divided in three main phases:
1 - development of common tools for street HIV and TB testing among target groups;

2 - implementation of HIV and TB rapid tests in low-threshold facilities for marginalized persons into target groups;
3 - comparative analysis and assessment of the effectiveness of such intervention.

The methods used in the first phase include exchange of experience among the partners, analysis of main weakness of current strategies for HIV/TB testing of risk groups and definition of key health determinants to be assessed.
The second phase includes the conduction of training courses for the staff of each partner and then, provision of HIV and TB tests for people attending needle-exchange facilities and drop-in centres managed by each partner organization in Rome, Turin, Bratislava and Prague. Those resulted positive to the tests will be referred to clinical services for confirmatory analysis.
The third phase will include the analysis of all data collected by each partner and the assessment of this kind of intervention in terms of a wider access to test of most-at-risk groups and timely identification of new infections.

This manual has been jointly developed by all the project partners and has been used for training the multi-disciplinary staff in charge of providing the HIV and TB testing in all the four project sites.
On the basis of our experience, we think that this manual can represent a useful tool also for other professionals working with most vulnerable groups and willing to implement HIV and/or TB testing programmes.

The training manual can be used by any person involved in HIV and TB counselling and testing provision among drug users and migrants. Programme managers and planners, health care service providers, other organizations working with drug users and migrants may find this training manual helpful for improving their work.
The manual is intended to be used to train multi-disciplinary staff (social workers, psychologists, doctors/nurses) on how to offer and provide HIV and TB counselling and testing to *drug users and migrant drug users* in low-threshold services such as street units, drop-in centres and night shelters.
The aim of this manual is to ensure that project managers are equipped with the necessary skills, knowledge, attitudes and confidence in order to effectively offer HIV and TB counselling and testing to DUs and migrant DUs and to impart relevant knowledge and skills to others.

By using this manual, project managers will gain or build on the following:
• Better understanding of the concept of integrated services for HIV and TB counselling and testing and methods for providing integrated counselling and services within their organizations;
• Key elements of HIV and TB counselling and testing for DUs and migrant DUs:
  - Pre-test counselling and risk assessment,
  - Post-test counselling for both negative and positive results and risk reduction

• Basic skills on data collection and recording;
• Importance of building and ensuring a quality referral system to treatment centres and other health-care services available in the community.

STRUCTURE OF THE MANUAL

The manual is composed of 7 modules:

Module 1. Recruitment: contains guidance on methods to use when approaching and recruiting DUs for convincing them to do HIV and TB testing.
Module 2. Pre and post counselling: gives a detailed description of what kind of information must be provided in pre and post counselling for HIV and TB.
Module 3. Questionnaire: proposes a model of questionnaire to be administered among DUs and migrant DUs for collecting data.
Module 4. Testing of HIV and TB: gives step by step instructions on how to administer HIV rapid test and TB screening and sputum sample collection.
Module 5. Follow-up: offers specific ideas on how to develop a referral system to clinics and other health care centres for diagnosis, treatment and other related services.
Module 6. Focus groups/interviews: provides a description of two different methods for collecting information from the target groups to be used for monitoring and evaluation.
Module 7. Data recording: gives basic information on how to enter and process data of clients enrolled in the testing.

Each module begins with an introduction of the topic and the main issues to be discussed in the module and with a list of learning outcomes. These should be the basis for evaluating knowledge and skills acquired by the participants at the end of each module.
Then, the content of the module is presented in detail, together with a description of the methods and working material which will be used.

MODULE 1
Recruitment

1. INTRODUCTION

This module provides basic information and guidance on methods to be used when approaching and recruiting DUs for HIV and TB testing. In other words, it contains a description of the first face to face contact and following steps to recruit and motivate drug users/clients of low-threshold services to do the HIV and TB testing.

A basic model of these steps, including approach, selection and recruitment of DUs for testing should be structured as follows:

Step 1 - Approach target group members

The following points should be taken into account before approaching the target group:

- Who will approach participants?
- Are we addressing correct target group? What are criteria and conditions for inclusion and exclusion?
- How to approach target group members in the different cultural and social settings, cities?
- How will the rapid testing be promoted? Will it be promoted as a study or as a service?
- How to assess willingness to take part and be followed up?
- How to assure that the approaching of target group members is completely random?

Step 2 - Check Response Monitoring Sheet

In case the person says YES, I would like to participate: Check gender, age (and also country of birth in case of migrant), and whether the person has been approached before, and continue with selection and inclusion criteria (Step 3).

In case the person says NO, I do not wish to participate: Check gender, age (and also country of birth in case of migrant), whether the person has been approached before, and write down reason for refusal of participation.

Step 3 - Selection: determine whether the person can be included

First of all, it is necessary to check if the person is eligible for the testing, i.e. if he/she matches with the project inclusion criteria. The following questions need to be asked:

- Have you been tested for HIV/ TB before? If yes, when?
- Have you been using drugs in the past 3 months? (If the person has been tested for HIV shorter than 3 months ago, he/she is not eligible for HIV testing)
- Are you willing to consent to a rapid test for HIV and a clinical screening for TB?
- Are you willing to answer a questionnaire for data collection?
- Do you consent to the follow up of your test results and your possible visits to the clinic?

Step 4 - Complete Response Monitoring Sheet

In case the client is eligible for participation, tick 'yes' on the response monitoring sheet and proceed to the informed consent followed by pre-test counselling.

In case person is not eligible for participation, tick 'no' on the response monitoring sheet, apologize for the fact that the person cannot be included, and thank the person for his/her time.

Step 5 - Informed consent

Make sure the client receives information leaflet(s), read and understand the informed consent, as well as all conditions and criteria.
The informed consent form should be identified and signed by interviewer and respondent after that.

1.1 Learning outcomes

By the end of this module, participants must be able to:
- understand the procedure of recruitment of clients for the testing
- know how to use and compile the required administrative documents
- explain benefits, risks, conditions and criteria of testing
  be aware of
- all criteria and conditions for inclusion and exclusion
- study structure, aims and objectives

2. SELECTION AND RECRUITMENT OF THE TARGET GROUP

2.1 Approaching and informing clients

The people to be approached for the testing should be recruited among drug users and migrant drug users attending low-threshold services (drop-in centres, needle-exchange points, street units, night shelters) managed by non-profit organizations and/or public institutions.

With the term drug users we intend both: "problem drug users" according to the definition of EMCDDA: *"Problem Drug use is defined as injecting drug use or long-duration/regular use of opioids, cocaine and/or amphetamines"*, as well as users of other addiction substances, such as alcohol, ketamine, clonazepam,....

Migrants are defined as first generation migrants independent of their nationality, including both documented and undocumented migrants.
The clients of these services can be enrolled in the project through:

- Recruitment by the outreach and social workers, who will offer them the possibility to be tested for HIV and TB or
- Self-request for recruitment, due to personal interest in being tested

Information about the project should be widely disseminated in the low-threshold services involved through an announcement on the notice-board and the distribution of informative leaflets among the clients. It is important to assure that information about HIV and TB testing possibilities will reach a wide spectrum of target group members, in order to raise personal interest in being tested.
The target group should be firstly approached by the outreach and/or social workers of the low-threshold services, who will offer them the possibility to be tested for HIV and TB explaining the benefits and advantages of such service.
During the approaching and recruitment phase, staff members can use techniques typical of "Motivational interviewing", combining elements of empathy and negotiation with the aim to improve patient's motivation toward his/her own health status.
The selection and approach of the target groups must be completely random. This will be assured by standard mechanisms according to the local experience, settings and best practises. Nevertheless, the model of approaching must be defined and clear to all participating parties.
Example: If someone says 'I have been tested already and I was negative', this is not sufficient to exclude the person from the study. Check when the person was tested for the last time and if he/she has risk behaviours since that time.

NOTE: *Don't choose 'suspectable' individuals, but approach people at random!*

Those accepting to be tested will be recorded in the Response Monitoring Form and referred to the staff in charge of conducting the pre-counselling and testing (doctors, nurses, psychologists). Those unwilling or not eligible to be tested will be also recorded in the same Response Monitoring Form, indicating the reason for refusal or not eligibility.

2.2 Response Monitoring Form (RMF)

The Response Monitoring Form (RMF) is an important tool for both recording data and monitoring.
The RMF must be filled in the by staff member approaching the clients. It can be done digitally or manually; in any case, the staff has to assure full understanding of it by the clients, through a clear explanation or "joint" reading of the form.
As explained above, all people approached must be recorded in the form, including both those willing and unwilling, those eligible and not eligible. The variables that need to be reported in the RMF are:

- gender
- age

- country of origin (in case of migrant)
- whether the participant has refused to get tested before
- whether he/she is willing to participate now
- whether he/she is eligible (according to inclusion criteria check, also check for non- responders!)
- in case of refusal, indicate the reason for it.

NOTE: *In the Annex I. to this module an example of RMF is attached!*

In order to fill in the form appropriately, it is important that the target group is fully informed about the scope and need of collecting such data and is asked to cooperate in providing such information.
In particular, it should be explained that the information 'not willing' is a very valuable one, since it serves to outline weakness and limits of the provided service and can indicate how to make it more effective and more widely accessible.
Therefore, it is absolutely crucial that the Response Monitoring Form should be completed correctly for any client approached.

NOTE: *Especially information about why people refuse to be tested is an important data!*

At the end of the day or the week, the data from the RMF should be entered into a digital database, if this not done directly. This can be done by the same person filling in the RMF or by another administrative staff.

2,3 Selection phase: Eligibility

For the clients of low-threshold services willing to get tested, a second important selection step is required: to check their eligibility.
In this regard, clear inclusion and exclusion criteria must be defined, according to the specific characteristics of the target group and the basic requirements for a valid HIV and TB testing.
In order to check eligibility, the recruited clients should be asked the following "supplementary" questions:

- Have you been tested for HIV/ TB before? If yes, when?
- Have you been using drugs regularly in the past 3 months, both injecting and not?
- How old are you?
- Are you willing to answer a questionnaire for data collection, and do you consent to the follow up of your test results and your possible visits to the clinic?
- Do you clearly understand the purpose and procedures of HIV and TB testing?

NOTE: *If somebody is unable to understand the objectives of the intervention and to give the informed consent, he/she must be considered not eligible for the testing!*

Inclusion criteria

Participants will be eligible for testing when they meet all of the following criteria:

- They are regular or occasional Drug Users of any kind of psychoactive substances (see definition in: "2.1 Approaching and informing clients" page 10);
- They are clients of low-threshold services for DUs (drop-in centres, night shelters, outreach/street units, out-patient services for substitution therapy);
- They are over 18 years of age;
- They are able to understand the purpose and procedures of the testing;
- They are able to give theire informed consent (written or oral).

Exclusion criteria

Participants will be considered not eligible for testing when one of the following applies:

- Alcohol users/occasional users, or other clients of the mentioned services, are not part of the target group, but can be eligible in case it has been decided to open the service for other target groups (this has been decided halfway the ImpAcT project);
- They are under 18 years of age;
- They are unable to understand the purpose and procedures of testing and are therefore unable to give informed consent (because under the effects of drugs or due to language barriers);
- They have being tested for HIV in the last three months (only for HIV test);
- They are HIV positive (only for HIV rapid test).

In case the client is eligible for participation, the questioner will tick 'yes' on the response monitoring sheet and proceed to the informed consent followed by pre-test counselling.
In case the client is not eligible for participation, the questioner will tick 'no' on the response monitoring sheet, apologize for the fact that the person cannot be included, and thank the client for his/her time.

2.4 Confidentiality

The staff is obliged to inform the client that all personal data will be stored anonymously under a special code (see chapter 4.1.); this is an anonymous survey, so the client doesn't have to give his/her name; the information that the client gives will not be seen by any health or social services (It is not possible to code the blood and sputum samples anonymously. However this personal information will only be used to get back in touch with you - *the client* -, and not for research or other purposes).
The staff should declare in an appropriate way the confidentiality of all data, e.g. "Please remember it doesn't make any difference to me personally what your answers or test results are". It is important that the social worker underlines that he/she is now not in his/her usual role but performing an interview, and will not 'use' any of the information that has been given

2.5 Training methods, working materials and tools

After the short topic introduction, a brainstorming exercise will be conducted with the participants, in order to cover all the possible situations that might occur during "contact phase" and "recruitment", as well as all possible ways of approaching and motivating clients to testing.
After that, different working groups prepare answers to be presented to plenary and finally concluded.
Working material: power point presentation, flipchart, administrative forms (RMF).

3.0 INFORMATIVE LEAFLETS AND INFORMED CONSENT

The testing will be conducted only after obtaining informed verbal or written consent from the subjects, in line with the national legislation of all participating countries and with the UNAIDS/WHO Policy statement on HIV testing.
The informed consent should be given individually, in the presence of a trained health care provider (WHO Guidance on provider-initiated HIV testing and counselling in health facilities).

The written informed consent will be identified through a barcode or personal code, will be signed by the client and the staff member and then, will be accurately stored by the organization conducting the testing, in order to respect anonymity.

Through the informed consent, the staff member and the client declare that:
- **The interviewer** confirms that he/she has given the respondent a copy of the leaflet entitled 'Information for people taking part' about the study. This written information has been explained to the respondent in person and the respondent has been given the opportunity to ask any questions they wish.
- **The respondent** confirms that he/she has voluntarily agreed to get tested, having been given the above information.
- **The respondent** gives his/her consent:
  - for the HIV rapid test
  - for the TB clinical screening and if necessary, collection of sputum sample
- **The respondent** declares that he/she has been told that:
  - he/she might not be in need of TB testing, in which case no sputum sample will be collected
  - in case of preliminary positive results, he/she should go for a confirmatory HIV and/or TB test in specialized clinical centres
  - he/she can decide not to take part in the study at any time, until after the end of the interview.
  - his/her data will be stored anonymously, coded with a barcode and a personal code that only the respondent can decode.

The signed informed consent will be kept by the staff member and stored together with the tests and the questionnaire which will be administered to the client later.

The client will be requested to sign two separate informed consents: one for HIV testing and one for TB testing.

The informed consent will be provided together with informative leaflets about HIV and TB with basic information about the two infections, reasons for getting tested and interpretation of test results.
The informative leaflets will be given to the clients.

NOTE: *In the Annex II. to this module, examples of Informed consent form and Informative leaflets are attached!*

3.1 Training methods, working materials and tools

After the introduction of the Informative leaflets and the Informed consent with a Power point presentation, the participants will be asked to practice the use of these forms through role plays.
Working material: power point presentation, flipchart, administrative forms (Informative leaflets and Informed consent on HIV and TB).

4. CODING OF CLIENTS

As stated before, all procedures for testing must be conducted with full respect of confidentiality and anonymity.
To assure confidentiality and anonymity of the data, it is necessary to use a clear and simple system for data collection, processing, elaboration, analysis, manipulation and storage.

Each client should be recorded with an anonymous code, which will be indicated on the following items:
- Informative leaflets with informed consent form
- Questionnaire for data collection and risk assessment
- HIV rapid test
- TB clinical screening form
- Sputum sample container (if sputum collection is required)
- Referral paper for clinical centres, in case of HIV and/or TB positive test result.

To avoid the risk of error while recording the same code on so many items, it is highly recommended to use a barcode, consisting of some letters (for example, the initials of the country or city) and a number sequence.
Example: RM0001, RM0002, RM0003, etc… (RM=Rome)

In order to make it possible to identify the clients who will be retested after some time, besides the use of a barcode it is recommended to register each client also on a separate file with a personal code (for example, name/nickname and date of birth), according to the coding system normally used by each organization.
Example: RM0001=Mario 9/1/1971

This will also facilitate the identification of those individuals who will come back after some days for the result of the sputum smear examination and may have lost their barcode.
In cases where the national legislation doesn't allow to test anonymously, clients have to be informed in advance and all protocols, documents and conditions have to be arranged with respect to this (e.g. this is the case of TB testing in Czech Republic).
All the working tools such as the Response Monitoring Form and the signed informed consent must be kept and stored accurately. Staff members must have separate files for keeping these documents as soon as they are collected, in order to avoid to leave any document in a place accessible to other persons (table, chairs, etc…).

4.1 Training methods, working materials and tools

With the use of a barcode machine, the trainer will show how to produce the barcode and where it must be recorded.
After that, the personal coding system normally used by the organization to record the clients will be explained, and participants will be asked to practice it through role plays.
Working material: power point presentation, flipchart, administrative forms (Informative leaflets and Informed consent on HIV and TB, questionnaire, barcode machine).

5. PROPOSED SCHEDULE

Timetable

Time	Content	Method	Material	Remarks
15 min	**Subject introduction**	PP presentation	Data projector	5 steps
60 min	**Approaching target group**	PP presentation; Working groups	Data projector; Flipchart;	Response monitoring form; List of questions; List of inclusion criteria
30 min	**Informative leaflets, informed consent**	PP presentation;	Role plays Data projector; Flipchart;	Informative leaflet and Informed Consent on HIV; Informative leaflet and Informed Consent on TB
30 min	**Coding**	PP presentation; Discussion	Data projector; Flipchart;	Example of coding system; barcode

ANNEX I.

Response Monitoring Form - WORKING DOCUMENT

Date: |_|_| - |_|_| - |_|_|_|_|
d d - mm - y y y y

Time shift: from |_|_|:|_|_| to |_|_|:|_|_|
Name of outreach worker: .....

Organization: .....

Nr	Gender: Female / Male*	Country of birth	Age	Refused before: (Yes / No)*	Willing: (Yes/ No)*	Eligible: for HIV test (Yes / No/)*	Eligible: for Impact project (Yes / No)*	If NOT willing: Why not? (also indicate if person is not willing to take HIV or TB test)
1	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
2	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
3	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
4	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
5	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
6	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
7	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
8	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
9	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
10	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
11	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
12	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
13	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
14	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
15	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
16	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
17	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
18	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
19	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	
20	F / M		|_|_|	Y / N	Y / N	Y / N	Y / N	

* Please **circle** correct answer

ANNEX II.

INFORMATIVE LEAFLET ON HIV RAPID TEST

Information for clients

HIV is the human immunodeficiency virus. It is the virus that can lead to acquired immune deficiency syndrome, or AIDS. This virus is transmitted by infected blood and body fluids, through unprotected sex with someone who has HIV, and/or sharing needles and syringes.

The only way to know if you are infected is to be tested for HIV infection, in order to detect the presence of antibodies.

WHAT ARE THE REASONS TO GET TESTED FOR HIV?

If the test result is negative, you can learn how to protect yourself from the infection. If the test result is positive, you can learn about and adopt behaviors to protect other people from the infection, and you can start a specific therapy and medical treatment to slow down the virus and maintain a healthy immune system.

Nowadays, there are several HIV tests that give a rapid result and do not require laboratory facilities or health centres to be administered.

IN OUR SERVICES, WE OFFER YOU THE POSSIBILITY TO HAVE A FREE HIV RAPID TEST

HIV RAPID TEST

The HIV rapid test consists of a finger-prick in order to collect a blood sample, which will be put on a specific sample pad.
The HIV rapid test for the detection of HIV antibodies produces results within 15 minutes. This test has an high level of sensitivity, so the result is reliable.

Only in case of REACTIVE RESULT, it is necessary to do a confirmatory test in hospital.
We have as collaborating partner the clinical centre …….
You will have the possibility to go there for a confirmatory test and further analysis without the need of reservation. Otherwise, you can go to any other specialized health centre indicated in the last page of this leaflet.

HOW ARE THE RESULTS OF HIV RAPID TEST INTERPRETED?

The HIV rapid test can give this kind of results:

NON-REACTIVE (NEGATIVE): it doesn't need a confirmatory test. However, if in the last three months you have had potential exposure to HIV infection, you are highly recommended to repeat the test three months after the last exposure to HIV.

REACTIVE: it is interpreted as "preliminary positive" and requires a confirmatory testing with a more specific test (Western Blot) to be administered in health centres or laboratory services.
If the confirmatory test is positive, it means you have been infected with HIV.
If the confirmatory test is negative or ambiguous, you should repeat the test four weeks after the first HIV rapid test.

NOT VALID: if no control bar appears, the test must be considered not valid and will be immediately repeated.

Please remember: If you refuse to get tested, you can continue using all the services and facilities provided by our organization!

INFORMED CONSENT

IF YOU DECIDE TO DO THE HIV RAPID TEST

- You will be asked to sign this informed consent

- You will be assigned an identification barcode, which will be reported in this informed consent.

- The personnel will collect a blood sample from a finger prick, and will put it on the sample pad, marked with your barcode.

- While waiting for the test results, you will be asked to complete a questionnaire to collect information about your risk behaviours, in particular related to sex and drug use, and some basic demographical data, such as age, education, employment, etc. The questionnaire will indicate only your identification barcode.

- The medical staff will let you know the results verbally.

- In case of "preliminary positive" result (REACTIVE), you will receive a paper (with your identification barcode) with the indication of the clinical centre where you can do the confirmatory HIV blood test. Following the instructions in this paper, you will have the possibility to go to the clinical centres without previous reservation.

- Copy of the informed consent will be stored in the offices of our organization. The data of the questionnaire and the test result will be recorded and processed using only your identification barcode, so with respect of privacy, confidentiality and anonymity. The identification of your personal data through your barcode will be at the unique disposal of the medical staff of the hospital.

- Your refusal to get tested will not affect your access to the services offered by our organization.

I have received clear answers to all my questions about the HIV rapid test and I voluntarily agree to get tested.

Date___ ___/ ___ ___ /_____ Signature _____

I have given the client a copy of the informative leaflet entitled 'Information for clients' and also the opportunity to ask any questions he/she wishes. I have answered all the questions about the test and have given the client a non-signed copy of this informed consent.

Name of the staff member _____

Signature _____

INFORMATIVE LEAFLET ON TB TESTING

Information for clients

Tuberculosis is caused a bacterium (Mycobacterium Tuberculosis) that is transmitted from an infectious source to susceptible persons primarily through the air (e.g. through coughing).
Most individuals who become infected do not experience clinical illness; infected individuals are usually asymptomatic and non-infectious. Infection can persist for years; however, infected persons remain at risk of contracting clinically apparent disease, especially if the immune system becomes impaired.

WHAT ARE THE REASONS TO GET TESTED FOR TB?

Some people have a higher risk of developing active TB disease (for example, former prisoners, drug users, alcoholics, homeless, and HIV-positive people), but more than 70% of TB patients don't belong to these vulnerable groups. Everybody can get TB!
Symptom clinical screening and sputum smear examination are the best methods to find out if you have active TB disease.
An early diagnosis and the entry into adequate treatment can lead to complete recovery and significantly reduce the spreading of the infection.

IN OUR SERVICES, WE OFFER YOU THE POSSIBILITY TO HAVE A FREE CLINICAL SCREENING FOR TB AND IF NECESSARY A FREE TB SPUTUM TEST

CLINICAL SCREENING

A health professional will conduct a clinical screening, asking you some questions about your health condition.

SPUTUM SMEAR EXAMINATION

On the basis of the clinical screening, the medical staff will decide if a sputum smear examination is needed or not.

In the presence of one or more TB clinical symptoms or other risk factors (HIV-positivity, contacts with TB infected patients, etc.), a sputum sample will be collected and sent to clinical centres for analysis.

The patient himself will spit the sputum sample in a sterile container provided by the staff following the instructions indicated below:

- Rinse the mouth before collecting the sample

- Take a very deep breath and hold the air for 5 seconds. Slowly breathe out.

Take another deep breath and cough hard until some sputum comes up into your mouth.
- Spit the sputum into the container.
- Keep doing this until the sputum reaches the 5 ml line (or more) on the container. This is about 1 teaspoon of sputum.
- Screw on tightly the cap of the container so that it doesn't leak.
- Wash and dry the outside of the container.

HOW ARE THE RESULTS OF TB SPUTUM TEST INTERPRETED?

NEGATIVE: In case of negative result, a second sputum sample will be collected as soon as possible.

POSITIVE: In case of positive result, the staff will arrange a follow-up appointment in a clinical centre for taking the results of the first sputum smear and collecting a second sample. Further diagnostic workup for TB will be performed at clinical centres.

INFORMED CONSENT

IF YOU DECIDE TO DO THE TB SCREENING AND IF NECESSARY THE SPUTUM TEST

- You will be asked to sign this informed consent
- You will undergo clinical screening by your doctor
- If the doctor considers it necessary, further examinations will be conducted.
- The container will be marked with your identification barcode.
- Copy of the informed consent will be stored in the offices of our organization. The data of the questionnaire and the test result will be recorded and processed using only your identification barcode, so with respect for privacy, confidentiality and anonymity. The identification of your personal data through your barcode will be at the unique disposal of the medical staff of the hospital.
- Your refusal to get tested will not have any consequence on the normal provision of services offered by our organization.

I have received clear answers to all my questions about the TB test and I voluntarily agree to get tested.

Date___ ___/ ___ ___ /_____ Signature _____

I have given the client a copy of the informative leaflet entitled 'Information for clients' and the opportunity to ask any questions they wish. I have answered all the questions about the test and have given the client a non-signed copy of this informed consent.

Name of the staff member _____

Signature _____

MODULE 2

Pre and post counselling

1. INTRODUCTION

This module provides basic information about the content of pre and post counselling for HIV and TB.

1.1 Learning outcomes

By the end of this module, participants should be able to:

- Provide HIV pre-test counselling according to international guidelines
- Provide HIV post-test counselling according to international guidelines
- Provide TB pre-test counselling according to international guidelines
- Provide TB post-test counselling according to international guidelines

2. PRE-TEST COUNSELLING FOR HIV

Counselling means a confidential dialogue between client and counsellor with the aim to give the client information that can allow him to take responsible decisions about his own life. It is a process which helps the client to define his/her feelings and to cope with stress. It has also been proven that it prevents the transmission of infections and helps people to cope better with their infection.

These are some fundamental characteristics of counselling:

- In order to make an informed choice, the client needs to have clear, accurate and specific information.
- Counselling differs from education, although education can be an important part of it.
- It does not intend to solve the clients' problems instead of him/her or provide advice on how to solve them.
- It enables the client to better understand the problem/issues, deal with related emotions and fears, find and evaluate different alternatives and make choices.
- It is centred on the needs, desires and reality of the client. It is necessary to recognize that there are two experts in the room: client and counsellor.
- It is an interactive process which actively involves the client, encourages him/her to ask questions, provides feedback and discusses different issues as opposed to giving a lecture or questioning.
- It is private and confidential.
- It is individualized, as every client is a unique human being and the counselling should reflect the particular needs of the individual.
- The environment for counselling must be appropriate.

- The counsellor should be:
  - Trained
  - Empathetic (see the problem as the client sees it while remaining objective)
  - Non-judgemental
  - Cultural-sensitive (respect the client's cultural and belief systems)
  - Able to listen

According to WHO, "HIV testing must always be done with informed consent, adequate pre-test information or counselling, post-test counselling, protection of confidentiality and referral to services." [(1)]

The objectives of HIV pre-test counselling are:
- to help to prepare the client for the HIV test,
- to explain the implications of knowing that one is or is not infected with HIV,
- to facilitate discussion about ways to cope with knowing one's HIV status,
- to discuss sexuality, relationships, possible sex and drug related risk behaviours, in order to help the client understand his/her own risk behaviours and prevent infection.

When providing testing services to the marginalized and vulnerable populations such as problematic drug users and migrant drug users, it is important to stress the voluntarism of the testing component, as well as the right to refuse the testing without further impact on the provided services.

According to international standards, there are three principles/norms of HIV testing (known as "3 Cs"), which must be simultaneously obeyed:
- counselling and information about HIV before and after the test;
- consent to be tested given in an informed, specific and voluntary way by the person to be tested;
- confidentiality of test results and of the fact of seeking a test.

In case of a migrant or a person from a different ethnic group, the use of an appropriate confidential translation service is advised if there are any language difficulties.

The process of testing, including pre and post counselling (adapted from CLIENT'S RIGHTS AND HIV TESTING in the Training manual - Operational plan for comprehensive HIV and AIDS care, management and treatment for South Africa) is:

1 | WHO, Scaling up HIV testing and counseling in the WHO European Region as an essential com1 ponent of efforts to achieve universal access to HIV prevention, treatment, care and support, Policy framework, World Health Organization 2010

2.1 Minimum requirements of the pre-test counselling

The process of VCT pre-test counselling includes:

1. Cross-check code numbers on ALL forms against the client's code.
2. Introduction to the testing:
   - Introduce yourself and the service provided
   - Introduce the basic rules:
     - Confidentiality and anonymity of the information, as well as of the test result
     - Inform about the questionnaire to be filled by the counsellor
     - Inform about informed consent and the right to decline the test after the pre-test counselling.

2.2 Basic facts about HIV and AIDS

Even if the majority of people are aware of the basic information about HIV, a quick assessment of the knowledge about HIV can be helpful. Some written information can also be provided.
The information should include:

- What HIV is and the ways of transmission
- The window period for testing
- Seroconversion
- The difference between HIV and AIDS
- Benefits (clinical and prevention) of knowing HIV status and treatment possibilities,
- The potential risks of knowing HIV status (e.g.: as discrimination, abandonment or violence)
- Legal regulations related to HIV in respective countries

NOTE: . *It is important to stress that HIV is chronic disease, not a death sentence!*

2.3 Risk assessment

While speaking about the ways of transmission, the counsellor can check with the client his/her own risks since the last HIV test.

The counsellor works with the client to:
- Identify his/her risky behaviours
- Understand the reasons why the client continues to engage in them
- Develop strategies for identifying what the client can begin to do to move toward healthier behaviours.

An important aspect is also the risk behaviours of the partner(s), which might affect HIV risk for the client.

2.4 About the test itself

The following elements of testing and counselling should be clearly explained:
- duration and testing procedures
- description of main characteristics of the rapid test, validity of the test
- meaning of reactive, negative and invalid results
- follow-up process in case of reactive result

During this phase, the counsellor should also:
- discuss what result the client is expecting today
- discuss how the client would react to any of the above results
- discuss advantages and disadvantages of having an HIV test

2.5 Informed consent

The informed consent is the authorization of the patient to undergo a medical examination, after having received all the information about risks, advantages and methods of this examination.
It also provides opportunities to refuse to get tested since it informs by telling the client that he/she has the right to refuse to take the test. The client has to be acknowledged of the fact that declining an HIV test will not affect his access to services that do not depend upon knowledge of HIV status.

NOTE: . *If the client is still uncertain about wanting a test, give time to think about it and return!*
In case of refusal of the test, ask and record the reasons of the person. Provide opportunity to ask for questions.

2.6 Training methods, working materials and tools

Activity: brainstorming
Ask trainees to brainstorm their own definition of counselling and HIV/AIDS counselling and on what they think are the qualities of a good counsellor.

Go over the list in the presentation and add any point that have not been mentioned by the trainees.

Complete with a PowerPoint presentation.
Working material: power point presentation, flipchart, markers.

3. POST-TEST COUNSELLING FOR HIV

Post-test counselling is important both in case of reactive or negative result. It aims to help the client to understand and cope with the HIV test result, to provide the client with any further information required, and if necessary refer the client to other services. It is desirable that, where possible, the counsellor who provided pre-test counselling also provides post-test counselling. In this way, the counsellor will already have a relationship with the client, will have laid the ground for any necessary changes in behaviours or planning for the future, and will know quite a lot about the client.
Of course, the content of post-counselling differs according to the result.

3.1 Post-test counselling in case of negative result

• Give and explain the result face to face in a confidential environment.
• Remind any potential exposure risks that occurred within the window period, and in case of risks taken in the last 3 months, advise the client to repeat the test in 3 months.
• Reinforce information on HIV transmission and personal risk reduction plan.
• Review and explore any constraints to the practice of safer sex, infant feeding issues (if breastfeeding) and safer injecting practices.
• In case of pregnant women, inform them about the need to re-test again in the last trimester of pregnancy, as they might be in the seroconversion stage. Even in the case of later start of ART (latest during the labour), this is crucial for mother to child HIV transmission.

3.2 Post-test counselling in case of reactive result

This needs to be done with care and consideration of the importance of such a result for the person.

- Give the result face to face in a confidential environment.
- Give the information and result in a clear and direct manner. Give time to understand and accept the information.
- Explain the meaning of reactivity and that there is the need of laboratory confirmation from the whole blood sample(s), and the distinction between HIV and AIDS.
- Provide (also written) address and contacts of clinics/laboratories for a confirmatory test. Offer the possibility to accompany the person to the clinic, if possible.
- Offer the possibility to have follow-up counselling sessions, if possible.
- Provide information about the treatment possibilities and support systems, as well the preventive measures (also in written form).

- Discuss the social relationships and the disclosure to the partner (benefits and risks) in case of confirmed result.
- In case of pregnant women, provide the information about mother-to-child transmission and that in case of ART during pregnancy, ceasarean delivery and non-breastfeeding the transmission is less than 1%.
- Provide space for asking questions.

3.3 Training methods, working materials and tools

After the presentation in power point, ask participants to practice post-counselling through role-plays.
Organise the class into triads (groups of threes). Each triad will comprise a "counsellor", a "client" and an "observer". Observers are to observe the process of role-play and provide feedback to the counsellor at the conclusion of the role-play.
The groups will play three different cases.
At the end, each group will report the experience, and the main problems will be discussed.
Working material: power point presentation, flipchart, markers.

4. PRE-TEST COUNSELLING FOR TB

The main objectives of TB counselling are:
- prevention of TB transmission,
- emotional support to TB clients,
- motivation of TB clients to complete treatment,
- to helping clients make their own informed decisions about their behaviours and support them in carrying out their decisions.

4.1 Pre-diagnosis counselling

The pre-diagnosis counselling is conducted when the client comes for the first time for TB screening. The objectives of pre-diagnosis counselling on TB include:
- To develop mutual trust and respect between the client and provider.
- To collect necessary medical and psychosocial information about a client.
- To provide information about diagnostic tests, refer the client for further testing, and support the client's decision to be tested.
- To provide basic information on TB and reassure the client that TB is curable.
- To help cope with the stress of being tested and a possible diagnosis of TB.
- To emphasize the importance of the next visit and schedule it.
- To motivate the client to take additional tests, if needed.
- To provide the client with basic information and skills to protect household members and contacts from infection prior to starting treatment.

4.2 Basic facts about TB

It is necessary to stress that TB is a curable disease. Written information can also be provided. Such issues often include:

- What TB is and the ways of transmission
- The different forms of TB, stressing the information about pulmonary TB
- Benefits (clinical and preventive) of early diagnosis of pulmonary TB and treatment possibilities
- The potential risks of being diagnosed with TB (e.g.: discrimination, abandonment or violence)
- Legal regulations related to TB in the country (isolation, etc.)

4.3 About the testing process

Process of testing and counselling outline:
- Explain the testing process: clinical evaluation first, in case of presence of 2 or more suspect symptoms, collection of sputum and repetition of the test twice,
- Explain the meaning of negative or positive results;
- Follow-up process in case of open TB
- Discuss what result the client is expecting today
- Discuss how clients would react to any of the above results
- Discuss advantages and disadvantages of having a TB test

Sample questions to ask clients and statements that demonstrate active listening:

- What have you heard about TB?
- TB has a number of symptoms that could also be caused by other illnesses. These includefor cough more than two weeks, coughing up blood, unexplained weight loss, lack of appetite, fever, night sweats, chest pain, difficulty breathing, and fatigue. Tell me about any of these symptoms or other symptoms you have experienced.
- How long have you been coughing? What kind of cough do you have (e.g., dry, productive, with blood)?
- What questions about TB or your health in general can I help answer before you leave today?

4.4 Key messages to be communicated to patients

The following information should be provided to clients during the pre-diagnosis counselling:
- Your symptoms suggest that you may have TB, but we cannot be sure until we do some laboratory tests of your sputum.
- It is very important to conduct a test on your sputum so that we can know whether or not you have TB. These tests are provided to you free of charge. To do the tests, we will collect and test several samples of your sputum and look at them under the microscope. You can expect to get your results in ____ days.
- An health professional will instruct you on how to collect your sputum. You will give us one specimen now, and if needed we will ask you to collect other specimens at home and bring them to the clinic for testing.

• TB is a disease caused by bacteria (germs). TB is spread from one person to another through the air. It usually affects your lungs, but may also cause illness in other parts of your body. TB is a serious illness that must be treated, but it is important to know that it can be completely cured by taking a combination of medicines.
• Typical symptoms of TB are persistent cough for more than 2 or 3 weeks; fever for more than 7 days; shortness of breath and pain in the chest; decrease in appetite, sudden or unexpected weight loss; fatigue; sweating at night; and productive cough with blood in sputum.
• Early diagnosis of tuberculosis is very important because early treatment can prevent you from getting very ill and will help prevent the spread of your illness to your family and friends.
• If you do have TB, there is a chance you can spread it to other people. While you are waiting for your test results, there are four things you can do to reduce the chances of spreading TB to your family or friends:
- cover your mouth with a handkerchief or tissue if you cough or sneeze.
- Keep the windows open in your house to allow air to circulate, that will also help.
- If possible, sleeping in a separate room will help reduce the chances of spreading TB to others.
- Finally, avoid close contact with young children and other people who may have weak immune systems as they are more vulnerable to illnesses.
• TB cannot be spread by sharing food, eating utensils, or clothes. It is not transmitted through physical (e.g., shaking hands) or sexual contact.

Questions to ask clients to check their understanding:

• Explain to me what you understand about TB from our conversation.
• What will we do to test you for TB?
• Tell me the steps you will take to collect your sputum.
• How will you get your results?
• What have you understood about how TB is spread, and what you can do to prevent spreading it?
• What questions or concerns do you have?

4.5 Screening and tests

After the client provides the sample of sputum:
• Emphasize the importance of the next visit and schedule it. If it is possible ask for the cellular contact of the client (in case she/he agrees to be contacted)
• Motivate the client to take additional examinations such as X-ray, if needed.
• Provide the client with basic information and skills on cough etiquette and how to protect household members. According to CDC recommendations, the basic rules to prevent the spreading of germs are:
- Cover your mouth and nose with a tissue when you cough or sneeze.
- Put your used tissue in the waste basket.

- If you don't have a tissue, cough or sneeze into your upper sleeve or elbow, not your hands.
- You may be asked to put on a facemask to protect others.
- Wash your hands often with soap and warm water for 20 seconds.
- If soap and water are not available, use an alcohol-based hand rub.

4.6 Training methods, working materials and tools

Ask trainees to brainstorm their own definition of pre-test counselling for TB.
Go over the list in the presentation and add any points that have not been mentioned by the trainees.
Complete with a PowerPoint presentation.

Working material: power point presentation, flipchart, markers.

5. POST-TEST COUNSELLING FOR TB

The objectives of post-test counselling for TB are:
- To inform the client about test results and explain what they mean in clear terms.
- To help clients cope with emotional stress and uncertainty.
- To check and reinforce the client's existing knowledge of TB.
- To provide accurate, simple information on TB and TB treatment and correct the clients misperceptions about TB.
- To motivate the client to start and complete treatment.
- To identify and enlist resources (e.g., people, services) that can support the client through the treatment.
- To identify and address potential barriers to treatment adherence and cure.
- To help the client make decisions about his or her TB treatment.
- To strengthen the mutual trust and respect between client and provider as a critical element for treatment adherence and cure.
- To make an agreement or "contract" with the client to ensure follow-up.

5.1 Post-test counselling in case of negative result

Give the result face to face in a confidential environment.
Explain the result. Remind the limits of the testing and the reasons for second sputum.
Reinforce information on TB transmission and preventive measures.
Provide information about the treatment possibilities and support systems.

5.2 Post-test counselling in case of positive result

This needs to be done with care and consideration of the importance of such a result for the person.
- Give the result face to face in a confidential environment.
- Give the information and result in a clear and direct manner. Give time to understand and accept the information.

- Explain the meaning of the result and the need for confirmatory testing, such as a second sputum examination and X-ray.
- Provide addresses and contacts of specialized clinical centres (also in writing).
- Offer the possibility to accompany the person to the clinic, if possible.
- Provide information about treatment possibilities and explain the importance of starting and completing treatment.
- Identify and address potential barriers to treatment adherence and cure.
- Discuss social relationships and disclosure to the partner (benefits and risks) in case of confirmed result.
- Provide space for asking questions.

5.3 Key messages to provide to patients

The following information should be provided to clients in case of positive test results:

- Anybody can get TB. A healthy person can get infected from breathing in infected germs and might develop active TB.
- TB usually affects the lungs, but may affect other parts of the body as well. It is a serious disease, but it can be cured with a combination of medications. Without correct and complete treatment, a patient can become very ill and can die from TB.
- TB treatment is free of charge.
- Taking the medicines as prescribed will help you feel better quickly and will also help you prevent spreading the disease to others. It is important to take all the medicines as directed to keep the TB germs from developing resistance to the drugs, which then requires a much more complicated and longer treatment.
- Taking TB treatment for six to eight months can be difficult. It is very important to do so to avoid getting sick again. To help patients take the treatment properly and get cured, we provide you with treatment support. You have several options how and where you will receive your medicines, and you can choose the best option for you (assuming this is true).
- Anti-TB drugs can have side effects in some people. Most side effects are minor and disappear over time.
- Tell us if you plan to move, so we can arrange that you can continue treatment without interruptions.
- The same type of sputum tests that were used to diagnose your TB will be repeated to monitor the improvement in your condition. They will be repeated at set intervals as needed and at the end of treatment.
- We will be careful about keeping your records in a secure location and not revealing them to others.
- All your family members and close contacts must be examined and treated if needed.

Important: it is very important to pay careful attention to the patient‘s emotions and help him or her deal with the shock of learning that he or she has TB. Having

TB carries a stigma for many people and may lead to feelings of shame, fear of social rejection, or fear of the loss of a job. The main task of the provider at this stage is to give the client a chance to talk, listen actively to his or her concerns, and address questions and concerns through a two-way dialogue.

NOTE: *It is important to stress that TB is curable disease.*

5.4 Training methods, working materials and tools

After the presentation in power point, ask participants to practice the post-counselling through role-plays.
Organise the class into triads (groups of threes). Each triad will comprise a "counsellor", a "client" and an "observer". Observers are to observe the process of the role-play and provide feedback to the counsellor at the conclusion of the role-play.
The groups will play three different cases.
At the end, each group will report their experience, and the main problems will be discussed.

Working material: power point presentation, flipchart, markers.

6. PROPOSED SCHEDULE

Time	Content	Method	Material	Remarks
10 min	Introduction to counselling	Power point Presentation	Pc, beamer	
30 min.	Pre-test counselling for HIV + informed consent	Brainstorming + Power point presentation	Flipchart, markers	
15 min.	Post-test counselling for HIV	Power point presentation	Pc, beamer	
20 min.	Post-test counselling for HIV	Role plays	Flipchart, markers	
30 min.	Pre-test counselling for TB	Brainstorming + Power point presentation	Flipchart, markers	
5 min.	Coughing etiquette	Power point presentation	Pc, beamer	
20 min.	Post-test counselling for TB	Role plays	Flipchart, markers	

MODULE 3

Questionnaire for data collection

1. INTRODUCTION

This module provides basic information on how to administer a questionnaire for collecting data about clients tested for HIV and TB.

1.1 Learning outcomes

By the end of this module, participants should be able to:
- administer the questionnaire (and the follow up questionnaire)
- deal with 'difficult' situations when administering the questionnaire
- entering the data in the data recording sheet in a correct and uniform way

2. HOW TO ADMINISTER THE QUESTIONNAIRE

The questionnaire is a very important tool for data collection and evaluation; for this reason, it must be administered accurately by trained staff.
The questionnaire must be administered to each person tested for HIV and/or TB (when he/she is being tested). This could be done before the testing, after testing while waiting for the test results (preferred option) or after the whole procedure.
It can be administered manually on paper, or on a computer screen using a survey tool (such as LimeSurvey or SurveyMonkey). The survey tool has the advantage that the data will be collected in a database automatically so it saves time. Also, no mistakes can be made in the routing of the questionnaire, since the questions are compulsory and the questions that can be skipped, will be skipped automatically.
The paper questionnaire has the advantage that no internet connection or computer is needed, so it can be used under different circumstances, even on the streets.
In any case, the questionnaire must be administered individually, with respect of confidentiality and privacy.
The questionnaire should be administered by staff members that have received the training for it. They can be outreach workers, psychologists or health professionals (doctors, nurses) who provide the testing as well.

NOTE: *if people will be retested for HIV/TB in the same low-threshold service after some months, it is recommended to administer a follow-up questionnaire!*

2.1 Skills required from the interviewer

Since the interviewer is also a social worker/nurse that could be in contact with the participant outside the interview, it is important that it is clear that the role of interviewer demands a more neutral attitude.

Interviewer skills and attitudes important for administering the questionnaire:
• Never steer or direct a respondent in a certain direction
• An open, non-judgemental attitude
• Empathy versus distance: As an interviewer, the staff member needs to be more distanced than he/she might be when dealing with these clients in his/her usual working role. If clients want to vent emotions or give more information than is needed for the questionnaire, the interviewer should try to keep this short in a respectful manner, e.g.: "that this is very important information. We can get back to this after the interview if you like. For now, we would like to continue with the next question."
• Do not 'translate' questions to your own wording but stick to the original wording of the question. If this is difficult, explain to the participant that you have to do it this way, these are 'the rules' of interviewing.

2.2 How to introduce the questionnaire

A written instruction on how to introduce the questionnaire to the clients can be provided to the staff in charge of it (*see Annex I. of this module*).

It is important to give a good introduction. Explaining your role in advance will help the interviewer to keep the interview within the content and time constraints. If you explain in advance that you cannot go deeper into some issues now, it will not be so much of a disappointment during the interview when you say: 'I'm sorry but we should continue with the questions now'.

Please mention the following content to the participants. This is an example instruction:

The questionnaire will take 10-20 minutes.

When I start asking you the questions, I am an interviewer and not the social worker/ nurse anymore. I have a different role than usually. This means:

- that I will ask the questions as if I don't know anything about you.
- that the things that you tell me here, will not be recorded in any file of the service, and will remain within these four walls (figuratively speaking). Everything you say is totally confidential. Your data will be stored anonymously in a safe place where no-one but the interviewers have access to. They will be enterd in a database and used for evaluation purposes only.
- that some of the questions are quite formal, long, and not 'the way we usually communicate'. It is important that I ask the questions the same to everyone, as they are formulated on paper here. If you do not understand the question, please indicate this to me.

› that some answers require a simple yes or no, and others are more open questions. However, there is not really time to discuss things, it is a structured interview. But if you have questions or want to discuss things further, we can discuss this after the interview.
› Some questions might be very personal or private. All information will be dealt with confidentially. However if you really do not want to answer a question, you have the right to refuse.
› Last but not least : there are no good or bad answers. Please be honest in answering the questions.

NOTE: *Please remember that clients have the right to withdraw from the study at all times, without giving us the reason for their withdrawal!*

2.3 How to complete the questionnaire

While administering the questionnaire, the staff member must keep in mind that he/she is not now in his/her normal working role, but that he/she is now an interviewer.

Even if the interviewer knows the client quite well and knows a lot of information about him/her, it is necessary to hold the attitude 'as if you see each other for the first time'.

The following information must be provided to the interviewer:

- How to answer to yes-no questions: tick or cross with blue or black ink and in case of mistakes, put an arrow next to the final answer.
- How to answer to open questions: use participants words and NEVER use the interviewer' own words to summarize answers. The answers should be as short and accurate as possible, without going into too much detail. The interviewer cannot write down a lot of text otherwise the questionnaire takes too long.
- DO NOT 'TRANSLATE' the questions into your own words. It is important that the questions are always asked in the same manner. You can tell the participant beforehand that some questions might sound a bit formal, but you are supposed to ask them the way they are on paper.
- Explain clients that they don't have to be offended if the interviewer tells them that he/she likes to move on to the next question. This is not because he/she is not interested, but because the interview is very structured. There is room for evaluation or discussion afterwards.
- Some questions will ask for numbers of times, like 'how often did you have sex in the last 12 months?' Apart from these questions being quite private in nature, for most people they are also quite difficult to answer. Explain to the

respondent that if he/she doesn't know the exact answer, he/she can try to estimate it. An estimate is always better than a 'don't know' answer!
- Explain respondent that if he/she really has no idea or doesn't want to answer one question truthfully, it is better not to make up an answer. When a client does not want to answer a question, tick the appropriate answer or use code '999' for open questions.
- When a participant does not know the answer: First, ask the participant if he/she could make a good estimation or guess. If the participant really has no idea, tick the appropriate option (don't know) or use code 99 or 999. Try to avoid the 'don't know' option as much as possible.
- When a client does not understand the question: Repeat the question, clarify if all else fails. Do NOT give examples of answers! It is important that you never steer a participant in a certain direction. Repeat the options again if the client does not use the available categories.
- When a client does not answer the question but says something else: Repeat the question and emphasize the important parts or the available answer categories.
- What to do when a client gets emotional/ defensive: offer a handkerchief, glass of water, ask if he/ she wants a short break. According to experience, most respondents prefer to continue, a break is usually not productive.

2.4 Structure of the questionnaire

The content of the questionnaire is based on similar questionnaires that have been used in research before and on tools of the EMCDDA. For more information on the development of the questionnaire, please contact the ImpAcT project management.
The topics of the questionnaire include:

- **Recruitment (short): this section is completed by the interviewer**
- **Demography**
  - Housing condition: stable, not stable, homelessness
  - Level of education and employment situation
  - Relationship status
- **Drugs**
  - History of drug use
  - HIV risk behaviour: needle and other injecting equipment sharing
  - Type of drugs used/injected
  - Recall periods: last 12 months and last 4 weeks (as for international standard)
- **Prison**
  - (I)DU in prison
  - Number of people in detention cell (to assess TB risk)

- **Sexual partners**
  - Number of sexual partners: stable, casual, prostitution clients, sex work
  - Recall period: last 12 months (as for international standard)
  - HIV and STIs risk behaviour: condom use (be aware of socially acceptable answers)
- **HIV testing**
  - Testing history: date (approx. if not exact) and reported result (terminology: Reactive means Positive)
  - Reason for not getting tested before (this should be asked as an OPEN question. The interviewer than chooses the most appropriate answers. NEVER read out different options, NEVER give examples of possible reasons. This is really important! The interviewer finds the most appropriate category or categories in the list, based on the open answer of the client).
  - Reason for getting tested now. (See former bullet, this should be regarded as an open question in the same way).
- **TB testing**
  - If necessary, explain testing methods
  - See comments under HIV testing

NOTE: *in Annex II. To this module, a copy of the questionnaire is provided!*

2.5 How to deal with the privacy-sensitive material

It is important that the organisation has a safe and closed place where the data can be stored, and that materials are never left lying around somewhere! In case of carrying the questionnaires in a bag (outreach workers), make sure you never leave it standing somewhere. This seems an unnecessary comment, but a lot of mistakes are happening in this field. Everyone needs to be fully aware of the sensitivity of the data and how to handle the data appropriately.

2.6 Training methods, materials and tools

After the questionnaire is introduced in a power point presentation, some time will be spent on discussing possible questions of the participants of the training.
All participants to the training receive a version of the questionnaire for them to make notes. They also receive a short overview of the most important 'difficult questions' in the questionnaire and how to deal with these.

Then the participants should practice with the questionnaire. This can be done using the following interactive methods, depending on group size:

- Role playing with the following roles:
  - Client ('regular' clients could be used as an example, or try to act a bit like a difficult client, give socially acceptable answers or answer with answers that are not one of the options)

- Interviewer
- Observer: feedback on interviewer skills and correct use of questionnaire
  When using this option, divide the questionnaire in 5 minute-chunks and switch roles regularly. Provide feedback.
- 'Buzz group': let people interview each other, two-by-two, and let them write down difficult items. The trainer walks around, listens in with the different couples and provides feedback if necessary. Discuss afterwards.

Working material: laptops, paper version of the questionnaire (powerpoint presentation (available on request).

3. HOW TO RECORD THE COLLECTED INFORMATION

The data of the questionnaire will be entered in an online data entry tool.
This can be done directly while administering the questionnaire, if a computer and internet connection are available, using an online survey tool.
If the questionnaire is administered on paper, the outreach worker/ nurse /other staff member will enter the questionnaire in the online database at the end of the day or once a week.

In this case, it is recommended to select 1 or 2 persons in the organization who will be responsible for data entry, in order to limit the risk of mistakes. (see Module 7 for more information).

3.1 Training methods, materials and tools

If computers are available, short practice session with entering the data should be organized. This is not necessary if the organisation decides that one or two persons in the organisation will be responsible for entering the data (preferred option!).
Working material: laptops, paper version of the questionnaire.

4. PROPOSED SCHEDULE

Time	Content	Method	Material	Remarks
1 hour	Introduction Questionnaire and interviewer Skills	Presentation and discussion	Computer, beamer, screen, powerpoint presentation; paper versions of questionnaire and written instruction for everyone. In case the digital version of the questionnaire is used, some laptops need to be present with internet connection (in case of online administration)	
1 and ½ hour	Practice administering questionnaire	Role play, buzz group, including feedback and discussion	Paper questionnaires, laptops with the questionnaire in case the digital version is used	Trainer needs to check if skills are mastered and everyone is 'ready' to start with the questionnaire

ANNEX I.

INTRODUCTION TO THE QUESTIONNAIRE

Thank you for participating in this study. The questionnaire will take 10 to 20 minutes.
You cannot be tested without taking part in the questionnaire. It is important that we gain knowledge on the people in the project, so that we can find out what kind of people are helped by this project so that we might be able to help more people in the future in other countries, too.

Confidentiality and anonymity

It's important for you to know that all the answers in this questionnaire will remain completely anonymous. Everything that is said now and here, will remain here and will not be reported anywhere else. Even though the interviewer might see you in the low-threshold service, the answers to this questionnaire will not be referred to again. The interviewers are not allowed to do this. Don't worry that the interviewer might remember what you said. They interview so many people that it is unlikely that they remember everything. The questionnaires will be stored in a safe place where no one but the interviewers has access to it. They will be entered into an online database for analysis.
You might be interviewed by a social worker that you know quite well and you know that he or she knows information about you. Please hold the attitude 'as if you see each other for the first time'. The social worker is now not in his/her role as a social worker, but an interviewer for the study.

Personal questions

The questionnaire contains questions about demography, ethnic background, education, and so on; but also drug use, sexual partners, prison, HIV and TB testing. Some of the questions might be very personal or private. As stated earlier, all information will be dealt with confidentially. In case you really do not want to answer a certain question, indicate this clearly to the interviewer. You have the right to refuse answering individual questions. ***You also have the right to withdraw from the study at all times, without giving us the reason for your withdrawal.***

How to answer the questions

A lot of questions have different options, some are yes-no questions, others are open. Please try to answer as accurately as possible and don't go into too much detail. The interviewer cannot write down a lot of text and otherwise the questionnaire takes too long. Don't be offended if the interviewer tells you that he/she likes to move on to the next question. This is not because he/she is not interested, but because the interview is very structured. There is room for evaluation or discussion afterwards.

Some questions will ask for numbers of times, like 'how often did you have sex in the last 12 months?' Apart from these questions being quite private in nature, for most people they are also quite difficult to answer. You probably don't know the exact answer. Please try to ***estimate*** the answer. An estimate is always better than a 'don't know' answer!

However, if you really have no idea or if you don't want to answer the question truthfully, please don't make up an answer. There are ***no wrong or right answers!*** Please be honest in answering the questions, and if you really can't be, say that you do not wish to answer.

In case you have any questions, don't hesitate to ask them. **Good luck!!**

ANNEX II.

QUESTIONNAIRE

Personal code

A01 |_|_| |_|_|_|_|

Example: for Rome: from RM0001 to RM1000
for Turin: from TO0001 to TO1000
for Praga from: CZ0001 to CZ1000
for Bratislava from: SK0001 to SK1000

A. Recruitment

A02 **Date of interview** |_|_| |_|_| 20 |_|_|
day month year

A03 **Initials and signature of interviewer** |_|_|_| .....

A04 **Place of recruitment**

1 on the street/ open air (outreach worker)
2 mobile unit for syringe exchange
3 drop-in center for DU
4 other (specify) ……..
99 not known

A05 **City of implementation**

1 Roma
2 Torino
3 Praha
4 Bratislava

B. Demography

B01 **What is your gender/ sex?** (question not always necessary to ask)

1 man
2 woman
3 transsexual / transgender

B02a **What is your month and year of birth?**

|_|_| |_|_|_|_|
month year

In case respondent does not know, ask him/her to estimate year of birth
don't know= 99, refuse = 88

B02b **Interviewer: Participant is sure about this, or is it an estimation?**
1. sure
2. estimation

B03 **In which city do you currently live?**
1 Prague/ Bratislava/ Rome/ Turin
2 other (say where)……
88 refusal
99 don't know

B04 **Which housing situation best describes yours (in the last 12 months, most of the time)?**
1 stable accommodation (owning, renting or staying with family/ friends for unrestricted time)
2 unstable accommodation (living in a hostel/shelter without a steady address, or on the streets)
3 in institutions (prison, clinic)
4 other, specify: ……..
88 refusal
99 don't know

B05 **Have you been homeless in the last 12 months, that means: staying on the streets or in a hostel without a steady address for one week or longer?**
1 No
2 Yes
88 refusal
99 don't know

B06 **With whom are you living (most of the time), at the moment?**
1 alone
2 with parents
3 with child(ren) alone
4 with partner alone
5 with partner and child(ren)
6 with friends
7 other, specify: ……

88 refusal
99 don't know

B07 **In what country were you born?**
1 CR/ Slovakia/ Italy ® go to question B10
2 Other, say where (country):
88 refusal
99 don't know

B08 **How long have you been living in CR/ Slovakia/ Italy?**

|_|_| years

if shorter than 6 months, answer is 0

B09 **Do you have all the necessary documents and papers to live and work/ study in this country?**
1 No
2 Yes
88 refusal
99 don't know

B10 **Are there any specific ethnic groups that you feel you belong to?** *[e.g., Roma, Sinti?]*
1 No
2 Yes, specify: .....
88 refusal
99 don't know

B11 **What is the highest level of education that you completed?**
1 never went to school/ never completed primary school
2 primary level of education
3 secondary level of education
4 higher education
5 other, specify: .....
88 refusal
99 don't know

B12 **What is your current job status?**
1 regular employment
2 pupil/ student
3 economically inactive (pensioners/ housewives, -men/ invalids)
4 unemployed
5 undeclared/unofficial work

6 other, specify:.....
88 refusal
99 don't know

C. Drugs

C01 **How old were you when you started using drugs - we are talking about injecting drug use or regular use of opioids, cocaine, amphetamines and/or benzodiazepines. Regularly means 1 day per week or more.**

|_|_| years old

don't know = 99, refuse = 88
never used regularly = 00

C02 **Have you injected in the last 4 weeks?**

Persist with questioning, watch out for socially acceptable answers.

1 no
2 yes → go to question C05
88 refusal
99 don't know

C03 **Have you injected in the last 12 months?**

1 no
2 yes → go to question C05
88 refusal
99 don't know

C04 **Have you ever injected drugs?**

1 no
2 yes
88 refusal
99 don't know

C05a **What drugs have you used in the last 4 weeks?**

Read out all options. More than one option is possible.

C05b **Which drugs you just mentioned have you also injected <u>in the last 4 weeks</u>?**

Persist with questioning about injecting because of the possibility of lying or giving socially acceptable answers.

C05a Used	C05b Injected	
_|01	_|01	heroin alone (if in fact Fentanyl, put under 6)
_|02	_|02	cocaine alone
_|03	_|03	heroin and cocaine together
_|04	_|04	heroin and metamphetamines (pervitin) together
_|05	_|05	refinedcoke(freebase,crack,ifrefinedathome,putunder2nothere)
_|06	_|06	Fentanyl ('fake' heroin)
_|07	_|07	methadone
_|08	_|08	buprenorphine (subutex/ subuxon)
_|09	_|09	other opiates (palfium, morphine, opium, burgadin, etc.)
_|10	_|10	amphetamines (speed)
_|11	_|11	methamphetamines (pervitin)
_|12	_|12	benzodiazepines
_|13	_|13	ecstasy
_|14	_|14	ketamine
_|15	_|15	GHB/GBL
_|16	_|16	'pills', please specify:.....
_|17	_|17	cannabis (hashish / marihuana)
_|18	_|18	alcohol ('using alcohol' = more than 4 glasses per day)
_|19	_|19	other substance, please specify:.....

If respondent has NOT ever injected (C04=1)® go to section D

C06 **Have you <u>ever</u> injected <u>with a used syringe or needle</u> from someone else?**

Persist with questioning, watch out for socially acceptable answers.

1 no go to C10
2 yes
88 refusal go to C10
99 don't know go to C10

C07 **With what frequency did you inject with a <u>used</u> syringe or needle from someone else, in the last 12 months?**

1 never
2 occasionally
3 about half the time
4 mostly

5 always
88 refusal
99 don't know

C08 **Have you injected with a used syringe or needle from someone else, in the last four weeks?**

1 no
2 yes
88 refusal
99 don't know

C09 **Thinking about the last time you borrowed a used syringe or needle, what was the most important reason?**

Do not read out! Keep asking, but only one answer possible. If respondent says: 'I did not have a clean one', ask further: 'What was the reason that you did not have a clean one, or could not get a clean one?' Tick the most appropriate answer.

1 too far from needle exchange / machine
2 needle exchange not open
3 needle exchange machine broken
4 someone else did the shot for me
5 unplanned shot, so no syringes available
6 withdrawal symptoms (ill) so wanted to inject as quickly as possible
7 I didn't care (indifference)
8 sharing with partner
9 other (give details) ……..
88 refusal
99 don't know

C10 **Have you ever borrowed any cotton, wool, filter, spoon, flushing water or other items that had been used by someone else?**

1 no go to section D
2 yes
88 refusal go to section D
99 don't know go to section D

C11 **Have you borrowed any cotton, wool, filter, spoon, flushing water or other items that had been used by someone else, in the last four weeks?**

1 no
2 yes
88 refusal
99 don't know

D. Prison

D01 **Have you ever been in prison?** (Do not include police cells or 'migrant identification centres', but do include all other forms of detention, such as pre-trial detention, prison, etc)

1 no go to section E
2 yes
88 refusal go to section E
99 don't know go to section E

Now I'd like to ask you some questions about your time in prison.

D02 **Since you started using, how often have you been in prison?** (Don't count police cells.)

times *don't know = 999; refuse = 888*
never = 0

D03 **Have you ever injected drugs in prison?**

1 no
2 yes
88 refusal
99 don't know

D04 **The last time you were in prison, how many people were with you in the cell?** (at the most)

This is to assess risk for TB. In case the cell was in some periods shared and in some periods not shared, do not write 0, even if this was mostly the case. Choose the maximum amount of people that he/she shared a cell with. If not sure, estimate.

|_|_| persons

E. Sexual partners

I'm now going to ask you some questions on the sexual partners you've had.
- The questions might be private so please let me know if you feel uncomfortable discussing this with me. As I said before, what you tell me, will remain within these 4 walls (so to speak). I hope that you understand that we need to ask these questions, to assess some kind of risk behaviours. If you really do not wish to answer, you can always refuse to answer a question.
- All the questions in this section concern the last 12 months.
- With sexual intercourse or sex we mean vaginal or anal intercourse only (no oral sex or handjobs).

INTERVIEWER: you may say either 'sex' or 'sexual intercourse', as you prefer. The vaginal/anal part does not have to be mentioned, unless participant has forgotten. The 'last 12 months' part is often forgotten, so keep reminding the participant if necessary.

E01 **Have you had any sexual intercourse in the last 12 months?**

1 no go to section F
2 yes
88 refusal go to section F
99 don't know

E02 **Now we will ask you some questions about sex with one or more stable partners in the last 12 months. Have you had sexual intercourse with one or more stable sexual partner in this period?**

(do not include casual partners or sex in change for money, drugs or other benefits)

1 no go to question E05
2 yes
88 refusal go to question E05
99 don't know go to question E05

E03 **How often did you and your stable partner(s) use a condom during sex (in the last 12 months)?**

(do not include casual partners or sex in change for money, drugs or other benefits)

1 never
2 occasionally
3 about half the time
4 mostly
5 always
88 *refusal*
99 *don't know*

E04 **To your knowledge has/have this/these stable partner (s) ever injected drugs?** (not only last 12 months!)

(do not include sex in change for money, drugs or other benefits)

1 no
2 yes
88 *refusal*
99 don't know

E05 **Now we will ask you some questions about sex with casual sexual partners. Have you had sexual intercourse with one or more casual sexual partners in the last 12 months?** (do not include sex in change for money, drugs or other benefits)

1 no go to question E09
2 yes
88 refusal : go to question E09
99 don't know: go to question E09

E06 **With how many casual partners have you had sexual intercourse in the last 12 months?**
(do not include sex in change for money, drugs or other benefits)

|_|_|_| people *don't know = 999; refuse = 888*
none = 0

E07 **How often did you and your casual partner(s) use a condom during sex in the last 12 months?**
(do not include sex in change for money, drugs or other benefits)

1 never
2 occasionally
3 about half the time
4 mostly
5 always
88 refusal
99 don't know

E08 **To your knowledge has your casual partner(s) ever injected drugs?** (not only last 12 months!)

1 no
2 yes
88 refusal
99 don't know

E09 **During the last 12 months have you had sexual intercourse with people who paid you with money, drugs or other benefits for the sex ('clients')?**

1 no ➜ go to question E12
2 yes
88 refusal ➜ go to question E12
99 don't know ➜ go to question E12

E10 **With how many 'clients' have you had sexual intercourse <u>in the last 12 months</u>?**

E10a |_|_|_| Sexual contacts *don't know = 999; refuse = 888*
none = 0

E10b
1 per week
2 per month
3 for the whole year

E11 **How often did you use condoms during sexual intercourse <u>with these 'clients' in the last 12 months</u>?** (Take the average for all clients.) *Persist with questioning because of the risk of socially acceptable answers!*

1	never
2	occasionally
3	about half the time
4	mostly
5	always
88	*refusal*
99	*don't know*

E12 **During the <u>last 12 months</u>, <u>have you paid</u> with money, drugs or other benefits for sexual intercourse with people?** (This means that you were the client)

1	no ➔ go to question E15
2	yes
88	refusal ➔ go to question E15
99	don't know ➔ go to question E15

E13 **How many people in the last 12 months did you pay to have sexual intercourse with you?** (This means that you were the client)

E13a |_|_|_| Sexual contacts *don't know = 999; refuse = 888*
none = 0

E13b

1	per week
2	per month
3	for the whole year

E14 **How often did you use condoms during these types of sexual contacts in <u>the last 12 months</u>?**
(Take the average for all contacts with sex workers.)

1	never
2	occasionally

3 about half the time
4 mostly
5 always
88 refusal
99 don't know

E15 **Have you been diagnosed with sexually transmitted diseases (STD's) like syphilis, gonorrhea, herpes, chlamydia, genital warts or any other sexually transmitted infections in the past 12 months?**

1 no
2 yes
88 refusal
99 don't know

F. HIV testing

F01 **Have you ever done an HIV test?**

1 no ➜ go to question F04
2 yes
88 refusal ➜ go to question F04
99 don't know ➜ go to question F04

F02 **When did you last have a HIV test?** (try to estimate at least the year if uncertain date)

|_|_| |_|_|_|
month year

don't know = 9999
refusal = 8888

F03 **What was the result of that test?**
(If several tests, give result of the last one.)

1 negative
2 positive
3 I never got the result
88 refusal
99 don't know

Go to section G if participant has been tested for HIV before.
Only complete remainder of section F if F01=1, 88 or 99 (not been tested)

F04 **Have you ever been offered an HIV Test before (and not taken it)?**

1 no ➜ go to Question F06
2 yes
88 refusal ➜ go to Question F06
99 don't know ➜go to Question F06

F05 **If yes, by which organisation?**

1 public health service, specify…….
2 service for drug users, specify……..
3 other service, specify: ……
88 refusal
99 don't know

F06 **You have never been tested for HIV before. What was the reason for this or what were the reasons for this?**
IMPORTANT!! DO NOT READ OUT options, but let respondent explain, and tick the most appropriate answer(s). Do NOT mention possible reasons, but ask 'anything else?'
(more than 1 answer possible)

□1 I don't think I am infected
□2 I'm afraid to do the test, because I could be infected
□3 I don't feel comfortable to go to the clinic, because I use drugs
□4 I don't feel comfortable to go to the clinic, because I am (undocumented) migrant
□5 I don't feel comfortable to go to the clinic, because I am doing illegal things (other than DU)
□6 I have no health insurance
□7 It is not something that I think of, I have other priorities (e.g. getting drugs)
□8 I always wanted to get a test, but never got round to it
□9 It is too much of a hassle
□10 other (specify).....

F07 **What made you decide to have the test now?**
IMPORTANT!! Do not read out options, but let respondent explain, and tick the most appropriate answer(s). Do NOT mention possible reasons, but ask 'anything else?'
(more than 1 answer possible)

□1 The test was offered to me, I did not have to go after it myself
□2 The test is free of charge (even if I don't have health insurance)
□3 I will receive a reward for taking part in the study
□4 The results will be given immediately, I do not have to come back
□5 I am not really interested in the HIV test, more in the TB test
□6 I think I could be infected
□7 I feel more comfortable to do the test in this (familiar) setting
□8 I feel more comfortable to have the test here, because the fact that I use drugs is not a problem
□9 I feel more comfortable to have the test here, because the fact that I am (undocumented) migrant is not a problem
□10 I feel more comfortable to have the test here, because the fact that I am doing illegal things (other than DU) is not a problem
□11 other (specify).....

G. TB testing

These questions are about the TB test.

G01 **Have you ever been vaccinated for TB?** *Make sure that participant does not confuse vaccination with Mantoux skin test.*

1 no
2 yes
88 refusal
99 don't know

G02 **Have you ever been tested for TB?**

1 no ➜ go to Question G06
2 yes
88 refusal ➜ go to Question G06
99 don't know ➜ go to Question G06

G03 **When did you last have a TB test?** (try to estimate at least the year if uncertain date)

|_|_| |_|_|_|
month year

don't know = 9999
refusal = 8888

G04 **Which kind of test or tests did you have?** *if necessary, explain testing methods*

(more than one answer possible.)
|_|1 thorax (chest x-ray)
|_|2 sputum
|_|3 skin test (mantoux)
|_|4 blood test
|_|5 other (specify):……
|_|*88 refusal*
|_|99 don't know

G05 **What was the result of the test or tests?**
(If several tests, give result of the last one.)

1 negative
2 positive
3 I never got the result
88 refusal
99 don't know

NOTE: *Go to section H if participant has been tested for TB before.*
Only complete remainder of section G if G02=1, 88 or 99 (not been tested)

G06 **Have you ever been offered a TB Test before?**

1 no ➜ go to Question G08
2 yes
88 refusal ➜ go to Question G08
99 don't know ➜ go to Question G08

G07 **If yes, by which organisation?**

1 public health service, specify….
2 service for drug users, specify….
3 other service, specify: ……
88 refusal
99 don't know

G08 **You have never been tested for TB before. What was the reason for this or what were the reasons for this?**

IMPORTANT!! Do not read out options, but let respondent explain, and tick the most appropriate answer(s). Do NOT mention possible reasons, but ask 'anything else?'

(more than 1 answer possible)

□1 I don't think I am infected
□2 I'm afraid to do the test, because I could be infected
□3 I don't feel comfortable to go to the clinic, because I use drugs
□4 I don't feel comfortable to go to the clinic, because I am (undocumented) migrant
□5 I don't feel comfortable to go to the clinic, because I am doing illegal things (other than DU)
□6 I have no health insurance
□7 It is not something that I think of, I have other priorities (e.g. getting drugs)
□8 I always wanted to get a test, but never got round to it
□9 It is too much of a hassle
□10 other (specify).....

G09 **What made you decide to have the test now?**

IMPORTANT!! Do not read out options, but let respondent explain, and tick the most appropriate answer(s). Do NOT mention possible reasons, but ask 'anything else?'

(more than 1 answer possible)

□1 The test was offered to me, I did not have to go after it myself
□2 The test is free of charge (even if I don't have health insurance)
□3 I will receive a reward for taking part in the study
□4 The results will be given immediately, I do not have to come back
□5 I am not really interested in the TB test, more in the HIV test

□6 I think I could be infected
□7 I feel more comfortable to do the test in this (familiar) setting
□8 I feel more comfortable to have the test here, because the fact that I use drugs is not a problem
□9 I feel more comfortable to have the test here, because the fact that I am (undocumented) migrant is not a problem
□10 I feel more comfortable to have the test here, because the fact that I am doing illegal things (other than DU) is not a problem
□11 other (specify).....

H. Remarks

H01 Would you like to add any remarks or additional information that might be relevant to this study?
1 No
2 Yes, specify: ……
……
……

Thank you for taking part!

I. Remarks interviewer

I01 **Would you as an interviewer like to add any remarks that might be relevant for the interpretation of this respondents information?**
1 No
2 Yes, specify: ……
……

MODULE 4

Testing of HIV and TB

1. INTRODUCTION

This module provides step by step instructions on how to administer HIV rapid test and TB clinical screening and sputum sample collection. In order to give participants a better understanding of these issues, basic information about the biological characteristics of HIV/AIDS and TB and the methods of detection of these two infections is also provided.

1.2 Learning outcomes

By the end of this module, participants should be able to:

- understand the main characteristics of HIV/AIDS and TB and the principles of infection's detection;
- know how to use an HIV rapid test, in particular the Determine HIV ½;
- understand the principles and methods of symptoms screening for TB;
- know how to collect sputum samples for TB detection;
- respect the standard operating procedure for sample collection, packaging, storage and transportation.

2. WHAT IS HIV/AIDS?

Human immunodeficiency virus (**HIV**) is a retrovirus that causes Acquired Immunodeficiency Syndrome (AIDS), a condition in humans in which the immune system begins to fail, leading to life-threatening opportunistic infections. Infection with HIV occurs by the transfer of *blood*, *semen*, *vaginal fluid*, *pre-ejaculate*, or *breast milk*.

The HIV infects cells of the immune system, destroying or impairing their function. The main type of cell that HIV infects is the T helper lymphocyte. These cells play a crucial role in the immune system, by coordinating the actions of other immune system cells. A large reduction in the number of T helper cells seriously weakens the immune system.

Infection with the virus results in the progressive deterioration of the immune system, leading to "immune deficiency." The immune system is considered deficient when it can no longer fulfill its role of fighting infection and disease. HIV infects the T helper cell because it has the protein CD4 on its surface, which HIV uses to attach itself to the cell before gaining entry. This is why the T helper cell is sometimes referred to as a CD4+ lymphocyte.

Once it has found its way into a cell, two pathways are possible: either the virus becomes latent and the infected cell continues to function or the virus becomes

active and replicates, and a large number of virus particles that can then infect other cells are liberated.
Over time, HIV infection leads to a severe reduction in the number of T helper cells available to help fight disease. The process usually takes several years.

There are two species of HIV known to exist: HIV-1 and HIV-2.
HIV-1 is the virus that was initially discovered. It is more virulent, more infective and is the cause of the majority of HIV infections globally. The lower infectivity of HIV-2 compared to HIV-1 implies that fewer of those exposed to HIV-2 will be infected per exposure. Because of its relatively poor capacity for transmission, HIV-2 is largely confined to **West Africa**.
Both forms of HIV are spread through sexual contact, blood, and **mother-to-child transmission**. There is no known cure for either form of HIV and both will eventually progress to AIDS. The symptoms of HIV-1 and HIV-2 are exactly the same and individuals cannot know which type they have without tests performed by a physician.
HIV infection has three basic stages: acute infection, period of "quiescence or latency", AIDS.
• *ACUTE INFECTION*: Once the virus enters the body, it is followed in three to six weeks in 50 to 70 per cent of people by an acute simile mononucleosis or flu-like infection termed a "viremia". The signs of this infection or viremia are sore throat, fever, fatigue and rash. This illness may not be remarked upon since it is similar to other types of brief illness.
• *PERIOD OF "QUIESCENCE OR LATENCY"*: the period from the initial flu-Like episode to the development of constitutional symptoms (a period of increasing immune system degradation). can last anywhere from two weeks to twenty years and beyond. During this time, the only indication that you are infected with HIV is that you will test positive on standard (antibody) HIV tests and you may have swollen lymph glands.
• *AIDS RELATED COMPLEX*: Acquired immunodeficiency syndrome (AIDS) is a surveillance term defined by the United States Centers for Disease Control and Prevention (CDC) and by the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV). The term AIDS applies to the most advanced stages of HIV infection, defined by the occurrence of any of more than 20 opportunistic infections or HIV-related cancers. When CD4+ T cell numbers decline below a critical level of 200 cells per μL, cell-mediated immunity is lost, and various opportunistic infections appear.

How quickly does a person infected with HIV develop AIDS?
The length of time can vary widely between individuals. Left untreated, the majority of people infected with HIV will develop signs of HIV-related illness within 5-10 years. However, the time between HIV infection and an AIDS diagnosis can be 10–15 years, sometimes longer. Antiretroviral therapy (ART) can slow the disease progression by decreasing an infected person's viral load.

2.1 Opportunistic infections and diseases

Infections associated with severe immunodeficiency are known as "opportunistic infections" because they are caused by organisms which do not ordinarily induce illness in people with normal immune systems and take advantage of a weakened immune system.

- Bacterial diseases such as **tuberculosis**, MAC, bacterial pneumonia and septicemia (blood poisoning)
- Protozoal diseases such as toxoplasmosis, microsporidiosis, cryptosporidiosis, isopsoriasis and leishmaniasis
- Fungal diseases such as PCP, candidiasis, Cryptococcus and penicilliosis
- Viral diseases such as those caused by cytomegalovirus, herpes simplex and herpes zoster virus
- HIV-associated malignancies such as Kaposi's sarcoma, lymphoma and squamous cell.

2.3 The window period

It's the period between infection and production of antibodies. This period is asymptomatic and, on an average, lasts for 2 to 12 weeks. However, recognizing the syndrome can be important because the patient is much more infectious during this period. In fact, there is a large amount of HIV in the peripheral blood and the immune system begins to respond to the virus by producing HIV antibodies. This process is known as seroconversion.
If an HIV antibody test is done before seroconversion is complete, it may give a "false negative" result because sufficient antibodies have not yet been developed by the body. That's why, it is recommended to take an HIV antibody test three months or longer after the exposure to the virus.

2.4 Training methods, working materials and tools

Before the introduction of the topic, a brainstorming exercise will be conducted with the participants, in order to get an idea of what they know about HIV and AIDS:

- Ask participants to answer to the following question: What do you know about HIV and AIDS? When they have worked a few minutes, record all their responses on flip chart paper.
- Review all the points listed on the flip chart and ask for comments.
- Introduce the topic showing the Power Point presentation and answer to possible questions from the group.

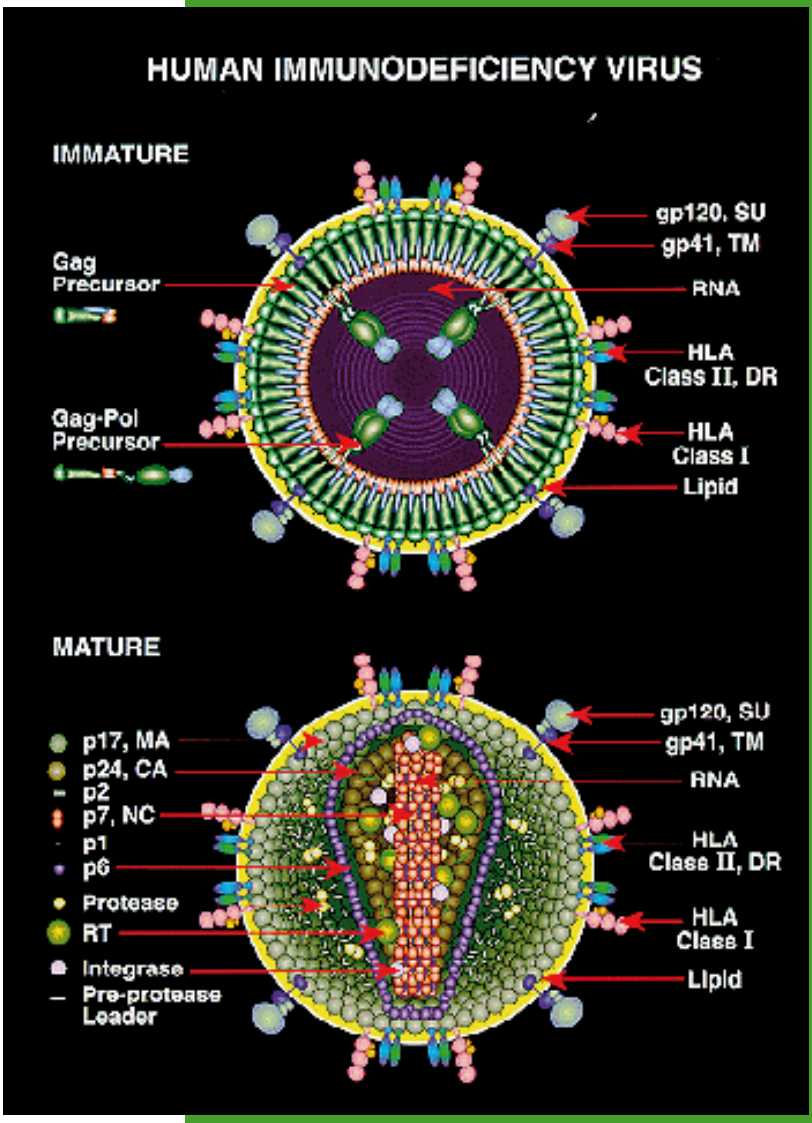
Working Materials: PowerPoint slides; Flip chart and markers

3. HOW TO ADMINISTER THE HIV RAPID TEST

The standard screening test for HIV is a combined HIV-1/2 antibody enzyme immunoassay (ELISA) done on venous blood. A diagnosis of HIV infection cannot be based on a single positive ELISA test alone.
A positive ELISA test should therefore always be confirmed by a Western blot test in the same sample and with ELISA in a subsequent sample collected separately.

Many persons with HIV do not get tested until late in their infection. Approximately 40% to 50% of patients with HIV infection are diagnosed with AIDS within 1 year of first testing HIV-positive.
Many persons who are tested do not return to learn their test results.
Advances in technology have led to the development of a wide variety of rapid HIV tests. These tests have the advantage of giving a result within minute, are easy to use and can be carried out by any health care worker who has received appropriate training. Furthermore, the diagnostic performance of high-quality rapid tests is comparable to that of traditional ELISAs.
Rapid tests can detect HIV antibodies in whole blood specimens. The specimen requires no processing, so the need of equipment and electricity is eliminated. Because the procedures are very easy, involve a limited number of steps and do not require high precision, they can be carried out outside traditional laboratory setting by staff with no formal laboratory training.
HIV Rapid test is interpreted visually and require no instrumentation. HIV antigens are affixed to the test strip or membrane. If HIV antibodies are present in the specimen being tested, they bind to the affixed antigen. The test kit's colorimetric reagent binds to these immunoglobulins creating an indicator that is visually detectable.
So, it can play an important role in HIV prevention activities and expand access to testing in both clinical and nonclinical settings.

The rapid test which is recommended in this manual is the Determine HIV-1/2, third generation.
Determine HIV ½ is an In Vitro, visually read, qualitative immunoassay for the detection of antibodies to HIV-1 and HIV-2 in human serum, plasma or whole blood. The test is intended as rapid test to detect antibodies to HIV-1/HIV-2 from infected individuals.



TB bacterium

BOX 1. SUMMARY OF CHARACTERISTICS OF DETERMINE HIV-1/2 RAPID TEST

- **Accuracy**
  High sensitivity 100 %
  High specificity 99,75 %
- **Specimen type**
  Human serum, plasma or whole blood (finger-prick samples)
- **Little laboratory equipment required**
- **No constant electricity or water supply required**
- **Easy to perform**
  Little technical training required
  Few steps
- **Easy to interpret**
  Visual interpretation of results, without equipment
  Stable end-reading point
- **Rapid** 15 minutes
- **Easy to store**
  Stored in nearly any environmental condition (2ºC-30º C), even where there is no power or water. Refrigeration storage is not required
- **Shelf-life** 14 months
- **Number of tests performed**
  Suitable for individual and small volume testing, e.g. 1–40 samples per day
- **Minimal waste and waste disposal**
- **Kit Components**
  Determine HIV-1/2 Test cards, HIV-1/2 recombinant antigen and synthetic peptide coated, 1 bottle (2.5 ml) of Chase Buffer reagent.

3.1 Biological principles of the procedure

Sample is added to the sample pad. As the sample migrates through the conjugate pad, it reconstitutes and mixes with the selenium colloid-antigen conjugate. This mixture continues to migrate through the solid phase to the immobilized recombinant antigens and synthetic peptides at the patient window site.
If antibodies to HIV-1 and/or HIV-2 are present in the sample, the antibodies bind to the antigen-selenium colloid and to the antigen at the patient window, forming a red line at the patient window site. If antibodies to HIV-1 and/or HIV-2 are absent, the antigen-selenium colloid flows past the patient window, and no red line is formed at the patient window site.

3.2 Whole Blood Collection by Finger stick

Before collecting a finger stick specimen, place a capillary tube on a clean dry surface.

1. Choose the fingertip of the middle, ring, or index finger (whichever is the least callused) for adults and children older than one year. Warm the hand as needed with a warm, moist towel or warm water to increase blood flow.

2. Clean fingertip with alcohol; allow to air dry. Position the hand palm-side up.

3. Use a new lancet for each person. Place the lancet off-centre on the fingertip. Firmly press the lancet against the finger and puncture the skin. Dispose of the lancet in an appropriate biohazard sharps container.

4. Wipe away the first drop of blood with a sterile gauze pad.

5. Hold the finger lower than the elbow and apply gentle, intermittent pressure to the base of the punctured finger several times. Touch the tip of the Capillary Tube to the drop of blood. Avoid air bubbles.

3.4 Test procedure

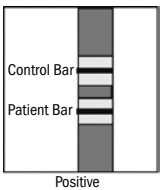
The desired number of test units from the 10-test card can be removed by bending and tearing at the perforation.When opening a new lot of tests, it's recommended to check that the tests function appropriately. This can be done through the testing of a person who knows to be HIV- and a person who knows to be HIV+ and verify that the results are correct.

1. Remove the protective foil cover from each test.

2. For whole blood (finger stick) samples:
   a. Apply 50 µL of sample (by capillary tube) to the sample pad (marked by the arrow symbol).
   b. Wait until blood is absorbed into the sample pad, then apply one drop of Chase Buffer to the sample pad.
   c. Wait a minimum of 15 minutes (up to 60 minutes) and read result.

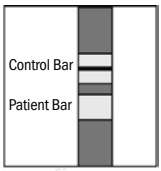
3.5 Interpretation of results

Positive (Two Bars)
Red bars appear in both the control window (labelled "Control") and the patient window (labelled "Patient") of the strip. Any visible red colour in the patient window should be interpreted as positive.



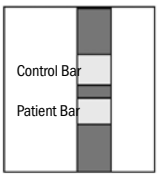
Positive

Negative (One Bar)
One red bar appears in the control window of the strip (labelled "Control"), and no red bar appears in the patient window of the strip (labelled "Patient").

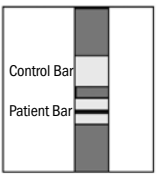


Negative

Invalid (No Bar)
To ensure assay validity, a procedural control is incorporated in the device and is labelled "Control". If there is no red bar in the control window of the strip, and even if a red bar appears in the patient window of the strip, the result is invalid and should be repeated.



Invalid



Invalid

3.6 Training methods, working materials and tools

After the presentation of the HIV test with Power point presentation, for a better explanation and understanding of the procedures of HIV test administration, it will be used the role play technique.

Select two participants and ask one to play the role of an health service provider, and the other the role of a patient. The service provider must administer the test to the patient, using the Determine kit test.
The role play should be repeated with other participants.

Working materials: Power point presentation; rapid test kit

4. HOW TO HANDLE WITH THE TEST

The whole blood sample collected by finger stick can not be stored but should be tested immediately. After the reading of results, the tests with a reactive result will be stored in special containers, such as a polystyrene box, and stored in the offices of the organization until the patient will make the confirmatory HIV test.

The procedures for test administration include also some administrative practices, which allow to keep a file for each patient which include informed consent form, questionnaire for data collection, pre-test counselling, test result, post-test counselling.
Each client will be recorded with a personal barcode. The barcode will be reported in the following items:
- Informative leaflets with informed consent form
- HIV rapid test
- Questionnaire for data collection and risk assessment
- Referral paper for the clinical centre, in case of reactive test result.

Moreover, each individual will be registered manually on a separate file with a personal code (for example name/nickname and date of birth), according to the coding system normally used by each organization.

4.1 Training methods, working materials and tools

Also for this part of the module, the role play exercise will be used.

Working materials: rapid test kit

5. WHAT IS TB?

Tuberculosis (TB) is a common and in some cases deadly *infectious disease* caused by various strains of *mycobacteria*, usually *Mycobacterium tuberculosis* in humans.
Tuberculosis usually attacks the *lungs* but can also affect other parts of the body. It is spread through the air when people who have active MTB infection cough, sneeze, or spit.
Most infections in humans result in an *asymptomatic*, latent infection, and about one in ten latent infections eventually progresses to active disease, which, if left untreated, kills more than 50% of its victims.

5.1 Latent and Active TB

TB germs can live in your body without making you sick. This is called latent TB infection. This means you have only inactive (sleeping) TB germs in your body. The inactive germs cannot be passed on to anyone else. However, if these germs wake up or become active in your body and multiply, you will get sick with TB disease.
When TB germs are active (multiplying in your body), this is called TB disease. People with TB disease may spread the germs to people they spend time with every day.
TB is a major cause of illness and death worldwide. Each year the disease kills almost 2 million people.
The disease is also prevalent among people with HIV.

5.2 Training methods, working materials and tools

Before the introduction of the topic, a brainstorming exercise will be conducted with the participants, in order to get an idea of what they know about TB.

- Ask participants to answer to the following question: What do you know about TB? What are the main risk factors? What are the main symptoms of TB? When they have worked a few minutes, record all their responses on flip chart paper.
- Review all the points listed on the flip chart and ask for comments.
- Introduce the topic showing the Power Point presentation and answer to possible questions from the group.

Then, the methods for TB testing will be presented in Power Point and consequently, for a better explanation and understanding of the procedures of TB clinical screening and sputum collection, it will be used the role play technique.

Select two participants and ask one to play the role of an health service provider, and the other the role of a patient. The service provider must do a clinical screening to the patient, and collect a sputum sample.
The role play should be repeated with other participants.

Working materials: PowerPoint presentation; flip chart, papers and markers

6. HOW TO CONDUCT THE TB TEST (CLINICAL SCREENING AND SPUTUM SAMPLE COLLECTION)

6.1 General comments on screening

Screening is done to identify infected persons at high risk of disease who would benefit from preventive therapy, and to find persons with clinical disease in need of treatment. Therefore, appropriate follow-up, after initial screening, is essential.
Methods to use in screening for latent or current TB disease depend on the epidemiological situation in the country/setting and among DUs with regard to TB and HIV infection.
In addition, screening methods depend on the presence of any symptoms of TB disease.
Initially, DUs should complete a questionnaire and have a clinical examination to identify the presence of signs and symptoms. Then, sputum smear microscopy, culture and chest X-ray should be used in those individuals with symptoms or signs of TB disease.

In order to make a good screening, it's indispensable to know what are the *main risks* for TB infection. The following groups of population should be screened for tuberculosis and tuberculosis infection:

- Persons infected with the human immunodeficiency virus (HIV)
- Close contacts with persons known or suspected to have tuberculosis, sharing the same household or other enclosed environments
- Immigrants from countries with high TB prevalence (most countries in Latin America and the Caribbean, Africa, Asia, Eastern Europe, and Russia)
- People travelling in countries with high TB prevalence
- Alcoholics and intravenous drug users
- Residents of long-term-care facilities, correctional institutions, mental institutions, nursing homes/facilities, and other long-term residential facilities
- Persons with medical risk factors known to increase the risk of disease if infection has occurred.

Besides the risk factors for TB infection, it's fundamental to know what are the *clinical symptoms* of TB.

TB disease should be suspected in persons who present the following signs and/or symptoms:

- Early infection symptoms:
  - Fever
  - Chills
  - Sweating
  - Night sweats
  - Flu-like symptoms
  - Gastrointestinal symptoms
  - Weight loss
  - No appetite
  - Weakness
  - Fatigue

- Symptoms of chronic lung infection (pulmonary tuberculosis):
  - Persistent cough
  - Chest pain
  - Coughing up bloody sputum
  - Shortness of breath
  - Breathing difficulty
  - Recurring bouts of fever
  - Weight loss
  - Progressive shortness of breath

If TB disease is in other parts of the body (extra pulmonary), symptoms will depend on the area affected.

NOTE: *In the Annex I. to this module, a copy of TB clinical screening form is attached.* The clinical screening must be conducted by health professionals!

6.2 Sneeze/cough etiquette and definition

Cough etiquette is a method of personal hygiene to help prevent the spread of infection. Sneezing and coughing are among the mechanisms the body uses to expel bacterial and viral particles in illnesses such as colds and influenza. However, these particles spread the infection to others who breathe them in with the air or touch surfaces on which they land.
Health experts recommend these procedures to reduce the risk of spreading infection through sneezing and coughing.

Cough Etiquette

- Provide tissues and non touch waste containers
- Provide surgical masks to suspects and visitors
- Promote cough etiquette and hand washing
- Provide respirators for staff
- Provide despensers of alcohol based hand rubs/wipes
- Provide clean water, soap, disposable towels

To minimize the spread of TB germe, the persons with TB symptoms should be asked:

- Cover the mouth and nose when coughing, speaking or sneezing
- Avoid coughing directly into hands and use tissue
- Dispose the tissues in the nearest waste container
- Wash hands with soap and water.
- Patients and visitors need to be educated on cough hygiene. This includes instruction them to cover noses and mouths when coughing or sneezing, and providing surgical masks or tissues.

6.3 Instructions for Collecting Sputum for TB

After an accurate screening, those individuals with risk factors and/or clinical symptoms of TB will be required to collect a sputum sample, which will be sent to the clinical centre for microbiological examination.
The diagnosis of TB is confirmed by the presence of acid-fast bacilli (AFB) in sputum smear examination. Repeated sputum smear microscopy may diagnose pulmonary TB in up to two-thirds of active cases.

6.4 How to Collect a Sputum Sample

The procedures for collecting sputum sample involve the production of droplets that are highly infectious if the patient has untreated pulmonary TB. Sputum collection should therefore be organised in areas with good ventilation or, if not available, outside the building.

The sputum sample will be handled with care in order to avoid any risk of infection for the staff, so the patient himself will spit the sputum sample in a sterile container following the instructions of the staff.
The patient will be asked to:

- Rinse the mouth before collecting the sample
- Take a very deep breath and hold the air for 5 seconds. Slowly breathe out. Take another deep breath and cough hard until some sputum comes up into your mouth.
- Spit the sputum into the container.
- Keep doing this until the sputum reaches the 5 ml line (or more) on the container. This is about 1 teaspoon of sputum.
- Screw on tightly the cap of the container so that it doesn't leak.
- Wash and dry the outside of the container.

6.5 How to interpret the results

The sputum samples will be sent to the clinical centres for examination, so these centres will be responsible for interpreting the result and communicate it to the patient.
In case of negative result, the patient will be requested to collect a second sputum sample as soon as possible.
In case of positive result, the staff will arrange a follow-up appointment to clinical centres for taking the results of the first sputum smear and collecting a second sample.
Further diagnostic workup for TB will be performed at clinical centres.
In case there is the risk that the patient will not collect a second sputum sample, it is recommended to make not only microscopy examination, but also the culture of the first sputum smear, in order to increase sensitivity and specificity of the diagnosis.

6. PROPOSED SCHEDULE

Time	Content	Method	Material	Remarks
20 min.	What is HIV/AIDS?	Brainstorming + Power point presentation	Flipchart, markers	
30 min. 30 min.	How to administer the HIV rapid test	Power point presentation + Role play	Pc, projector, rapid test	
15 min.	How to handle with the test	Practical demonstration + Role play	Rapid test, barcode machine	
15 min. 15 min. 30 min.	How to administer the TB tsting (information on TB and clinical screening)	Brainstorming + Power point presentation + Role plays	Flipchart, markers, Pc	
30 min. 30 min.	How to administer the TB testing (sputum collection and cough etiquette)	Power point peresentation + role plays	Flipchart, markers, Pc, containers	

ANNEX I.

TB CLINICAL SCREENING FORM

Who should get tested for TB: questions about risk factors

- Have you spent time with a person known to have TB disease or suspected to have TB disease? or
- Have you HIV infection or another condition that puts you at high risk for developing TB disease? or
- Do you think you might have TB disease? or
- Are you from a country where TB disease is common (most countries in Latin America and the Caribbean, Africa, Asia, Eastern Europe, and Russia); or
- Do you live in a place where TB disease is more common such as a homeless shelter, migrant farm camp, prison or jail, and some nursing homes)? or
- Do you inject illegal drugs?

Clinical symptoms of TB:

• *Early infection symptoms*:

• **Fever** (can be low grade) |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Chills** (usually severe and repetitive) |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Night sweats**(may come and go) |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Flu-like symptoms** |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Weight loss** |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Little or total lack of appetite** |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Weakness** |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Fatigue** |__| YES |__| NO
If YES, since when?: (day/month/year) **|__|__/|__|__/|__|__|__|__|**

• *Symptoms of chronic lung infection (pulmonary tuberculosis):*

• **Persistent cough** |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Chest pain** |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Coughing up bloody sputum** |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Shortness of breath** |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

• **Breathing difficulty** |__| YES |__| NO
If YES, since when?: (day/month/year) |__|__/|__|__/|__|__|__|__|

Note of the medical staff:

Sputum collection required |__| YES |__| NO

Referral to clinical centre for further examination required |__| YES |__| NO

MODULE 5

Follow up

1. INTRODUCTION

This module provides information and concrete indications on how to set up a referral system to clinical centres for diagnosis and treatment of HIV and TB and other related health-care services.

Learning outcomes

By the end of this module, participants should be able to:

- Know how to refer clients to clinical centres for confirmatory diagnosis and entry into treatment;
- Know what kind of information about the referred persons must be provided by the clinical centres.

2. REFERRAL TO CLINICAL CENTRE (schedule of appointment, etc.)

Purpose: To give clear indications on how to set up a referral system to clinical centres

2.1 Set up of collaboration with clinical centres

Any HIV/TB testing programme should include a system of follow-up, which ensure access of tested individuals to specialized services for prevention, treatment, care, support.

This is of particular importance when the target groups are marginalized and vulnerable population such as drug users and migrants. In this case, the testing services can act as a bridge between hard-to-reach groups and public health care institutions, trying to reduce the gap between them and facilitate the access to treatment and care for marginalized and risk groups.

At this regard, it is necessary to establish close collaboration with clinical centres providing HIV and TB diagnosis, treatment and care, in order to set up a referral system to these centres for the people undertaking the testing.

Specific agreement (written or verbal) should be made between the low-threshold service providing rapid testing and clinical centres specialized on HIV and TB. These centres should be considered as "collaborating partners" and should have the following role:

- The collaborating partner should act as the clinical reference centre of the organization, providing all required examinations and treatment for HIV and TB to those individuals referred there by the low-threshold service.

- The collaborating partner will be in charge of conducting HIV confirmatory blood test to those individuals found positive to the HIV rapid test; and conduction of microbiological culture of sputum smear samples, chest X-ray and TB blood test to those individuals found positive to the clinical screening conducted in the low-threshold service.
- The collaborating partner will be in charge of providing all required treatment to those individuals found positive to HIV and/or TB.

NOTE: *it is advisable that the collaborating partner is the clinical centre closest to the low-threshold service where the rapid testing is provided.*

2.2 Referral to clinical centres for HIV

The referral to clinical centre must be ensured for all people tested regardless of test results and should include access not only to treatment, but also to other prevention, care and support services (STI treatment, family planning, antenatal care, opiates substitution therapy, etc.).

In case of *negative result* to HIV and TB testing, the client must be advised to repeat the test after some period, according to the level of risk behaviours of the person. As indicated in latest international guidelines, most-at-risk groups such as injecting drug users and migrants should get tested for HIV at least every six months, but ideally every three months.
In order to facilitate the access to testing and improve the contact between the target group and health-care services, the clients should be encouraged to refer to specialized health facilities for undertaking the testing. At this regard, it is recommended to provide clients with the addresses of clinical centres offering HIV and TB testing, care and treatment in the city.

For those with *reactive HIV result*, a follow-up appointment must be scheduled to the clinical centre (collaborating partner) for confirmatory blood test.
The appointment will be scheduled by the staff according to the working hours and availability of the clinical centres. At this regard, it is recommended to have a referent person from the clinical centres, who will assist in the schedule of appointments for your clients.
The person will be given a *referral paper* indicating the date of HIV rapid test provision and the preliminary test result.
This paper must report the same barcode recorded in the informed consent form, the questionnaire and the HIV test. This barcode will allow the identification of the patient while respecting privacy and anonymity.
In case of patients in need of therapy, it is advisable to make arrangements with the clinics for joint treatment management, in order to give the patient the possibility to receive the therapy in the low-threshold service, for example together with substitution therapy.

2.3 Referral to clinical centres for TB

As for TB, in case of positive clinical screening, the first sputum sample collected by the staff of the low-threshold service will be taken to the collaborating clinical centre for examination.
The container with the collected sputum sample must report the same barcode recorded in the informed consent form, the questionnaire and the HIV test.

In case of *reactive result*, the staff will arrange a follow-up appointment to the clinical centre for the collection of a second sputum sample and further diagnostic workup for TB, according to WHO suggested protocols.

In case of *negative result*, a second sputum sample will be collected by the staff of low-threshold service as soon as possible and only in case of positive result the client will be referred to the clinical centres.
If the person presents several suspected symptoms of TB, even if the result of the first sputum sample examination is negative, it is recommended to refer the person the clinical centres for X-ray.

If the organization has the capacities and resources, every client requiring additional examination should be accompanied to the clinical centres. Otherwise, only for those cases requiring a special attention, the staff will contact the referent person at the clinical centre and will accompany the patient to the appointment. This will be particularly needed for migrants not speaking well the language or not able to reach the clinical centre by themselves.

NOTE: *In the Annex I. to this module, an example of Referral paper is provided.*

2.4 Training methods, working materials and tools

For a better explanation and understanding of the procedures related to the referral to clinical centres, it will be used the role play technique.

- Select three participants and ask one to play the role of the staff member, one the role of the referent person at the clinical centre and one the role of a patient.
- The staff member must contact the referent person for scheduling an appointment, must pass the exact information to the patient and give him the referral paper with the barcode, to be given to the referent person.
- The referent person must receive the patient, take the referral paper and register the indicated barcode.

The role play should be repeated with other participants.

Working material: referral paper.

3. EXCHANGE OF DATA WITH THE COLLABORATING PARTNERS

Exchanging of data between the testing organization and the collaborating partners should be regular and constant. It will serve to collect data about the number of confirmed positive cases and the number of people entering into treatment after the testing.

The clinical centres will register the persons referred there by the testing organizations using the barcode indicated in the referral paper.
For those found *HIV positive* by rapid test, data on confirmatory testing, clinical evaluation and laboratory evaluation (CD4 cells count and HIV RNA) will be collected and exchanged with the implementing organizations.
Moreover, the clinical centres will report also on the number of early infections (person infected in the last 6 months) identified through the **Avidity test**.
Avidity is a measure of the strength of the binding between immunoglobulin G antibodies and the corresponding antigen, a property that increases over a period of months in newly acquired infections. HIV antibody avidity testing provides a reliable method for identifying recently acquired HIV-1 infection.
The identification of newly acquired HIV infection provides important information on the dynamics of the epidemic and transmission networks, and it can serve to develop more specific public health intervention programs.

For those found *positive at TB* symptoms screening, data on results of sputum laboratory examination and final diagnosis will be collected and exchanged.

Moreover, the collaborating partners will provide data also on the number of clients who have entered into treatment after the confirmatory testing.

Data will be exchanged in respect of privacy and anonymity, and according to the local legislation on data protection.
At this regard, every month a meeting will be organized between the staff of the implementing organizations and the referent person of the clinical centres, in order to exchange data and monitor the treatment adherence of the patients.

3.1 Training methods, working materials and tools

The topic can be presented with a power point presentation.
After that, the following two brainstorming can be conducted:
- Which main difficulties could be encountered during the follow-up?
- How can these difficulties been overcome?

Working Materials: PowerPoint presentation, flipchart.

4. PROPOSED SCHEDULE

Time	Content	Method	Material	Remarks
5 min.	Introduction	Power point Presentation	Pc, beamer	
15 min.	Referral to clinical centres	Power point Presentation	Pc, beamer	Copy of Referral paper
20 min.	Referral to clinical centres	Role plays	Flicharts makers	
10 min. 20 min.	Exchange of data	Power point Presentation Brainstorming	Pc, beamer, markers	

ANNEX I.

REFERRAL PAPER FOR HIV AND/OR TB TEST

You are invited to go to the AIDS/TB Centre of the INMI Spallanzani in Rome following the instruction indicated below and presenting this paper to the medical staff of the centre.

NATIONAL INSTITUTE FOR INFECTIOUS DISEASE "L. SPALLANZANI"
Via Portuense, 292 - 00149 ROMA

AIDS CENTRE – room 13 – tel. ……..
Morning: from Monday to Saturday, from 9.00 to 12.00
Afternoon: from Monday to Saturday, from 15.00 to 18.00

Referent person: Dr. ....., tel. ……..

Dr. .....
Foundation Villa Maraini
Tel. …….

Barcode

If necessary, attach indication on how to reach the clinic and a map.

MODULE 6

Focus groups with the target group

1. INTRODUCTION

This module provides basic information about focus group general methodology and adaptation in low-threshold and outreach services.
The choice of the "focus group" technique is based on the fact that it can be relatively simply applied at a low-threshold centre (for example, involving participants within the group who are at the centre at a given time).

1.1 Learning outcomes

By the end of this module, participants should be able to:
- Know what a focus group is all about
- Organize, moderate and observe a focus group with low threshold centres clients, and write a focus group report.

2. HOW TO ORGANIZE THE FOCUS GROUPS

2.1 What a Focus group is

"The focus group has been defined as a "carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment".
The purposes are:
- to gather a group of experts with personal knowledge of substances abuse and addiction-related lifestyles;
- to empower drug users/clients, considering them as experts, and gain first-hand deep-level personal expert information.

In comparison with other methods for data collection, these are the advantages of focus group:
- it allows to gather a lot of information
- it can be organised more easily and at less cost than separate interviews with different respondents
- it is suitable for communities with limited literacy skills
- it provides information about attitudes and opinions that might not be revealed in a survey questionnaire.

The number of participants in a focus group should be limited to allow for an effective discussion, in which everybody has the opportunity to speak.
The recommended size should be between 6 and 10 participants (less than 12).
As for the length, in general a focus group can last max. 2 hours with break.

2.2 Role of Focus groups in testing programmes

Focus groups can be a very useful (often complementary) method for conducting the impact evaluation of a testing programme. In order to assess the impact of an intervention, there should be a baseline measurement and a post intervention measurement which can be compared.
Focus group discussions with target group members can be conducted to assess the situation at the outset of the intervention and after the intervention has taken place.
The goal of the impact evaluation is to assess whether there is a change in the indicators that can be attributed to the intervention, when comparing baseline measurement (T0) with post-intervention measurement (T1).
In the absence of a control group in which the same measurements are done without the actual intervention taking place, a qualitative pre- and post-intervention measurement can be the most appropriate method to show behavioural change and changes in experiences.
The following *Qualitative Indicators* can be measured through focus group discussions with target group members (measured at T0 and T1):
- experienced access to HIV testing
- experienced access to confirmatory diagnosis and treatment of HIV
- experienced access to TB testing
- experienced access to confirmatory diagnosis and treatment of TB
- experienced effectiveness of outreach based HIV testing (only at T1)
- experienced effectiveness of outreach based TB testing (only at T1)
- the rate of use of safe lifestyles and preventive measures regarding HIV and TB

In these focus groups, also some process evaluation topics can be added, in order to get more in-depth information on the level of motivation and support of the different stakeholders at the outset of the project and how the project has been received by the final beneficiaries.

2.3 Overview and planning of Focus Group sessions

Two focus groups should be organized *BEFORE* the starting of the intervention, and two focus groups *AFTER* the testing phase has finished.

Before implementation:
- 1 Focus Group on TB
- 1 Focus Group on HIV

After implementation:
- 1 Focus Group on TB and HIV among people that did not take part in the project
- 1 Focus Group on TB and HIV among people that did take part in the project

Focus Group 1: TB (before implementation)

Main topic and subtopics	Example main question	Follow up questions (only to be asked if the topics don't come up!)
A. Knowledge on TB - Symptoms - Transmission - Protection - Information sources	*" What do you know about TB? What is TB? Who can say something about this?"*	- *"How can we get TB?'* - "How can we protect ourselves from TB?" - "Where did you get this information?" - *"Do you think people in your environment have the same information?"* (Only in case most participants have accurate knowledge)
B. Access to health facilities - Testing - Treatment - Institutional vs. personal barriers	Here, an introduction is helpful: *"Some people in your environment might have been tested for HIV, others have never been tested. What could be reasons that people do not want to get tested?"*	- *"And why do some people not want to be treated?"* - " Do you know where you can get tested/ treatment?" -"What can be personal barriers to refrain from going to the health facility (for testing/treatment)?" - *"What could the health facility change so that more people in your environment would get tested/ treated?"*

Focus Group 2: HIV (before implementation)

Main topic and subtopics	Example main question	Follow up questions (only to be asked if the topics don't come up!)
A. Knowledge on HIV - Symptoms - Transmission - Protection - Information sources	*" What do you know about HIV? What is HIV? Who can say something about this?"*	- *"How can we get HIV?'* - "How can we protect ourselves from HIV?" - "Where did you get this information?" - *"Do you think people in your environment have the same information?"* (Only in case most participants have accurate knowledge)
B. Access to health facilities - Testing - Treatment - Institutional vs. personal barriers	Here, an introduction is helpful: *"Some people in your environment might have been tested for HIV, others have never been tested. What could be reasons that people do not want to get tested?"*	- *"And why do some people not want to be treated?"* - " Do you know where you can get tested/ treatment?" -"What can be personal barriers to refrain from going to the health facility (for testing/treatment)?" - *"What could the health facility change so that more people in your environment would get tested/ treated?"*

Focus Group 3: TB and HIV (after implementation)
ONLY PARTICIPANTS THAT DID NOT TAKE PART IN THE PROJECT, BUT ARE TARGET GROUP MEMBERS.

A combination of Focus Group 1 and 2, with one extra subtopic:

Extra Topic FG 3	Example question	Follow up questions (only to be asked if the topics don't come up!)
A. Experienced change - Knowledge - Access to health facilities	*"Do you think that things have changed, compared to a year ago? Why, or why not?"*	- *"What about what people know about TB and HIV?"* - *"And concerning testing and treatment?"*

Focus Group 4: TB and HIV (after implementation)
ONLY PARTICIPANTS THAT DID TAKE PART IN THE PROJECT.

A combination of Focus Group 1 and 2, with two extra topics as well:

Extra Topics FG 4	Example question	Follow up questions (only to be asked if the topics
A. Experienced change - Knowledge - Access to health facilities	*"Have things changed compared to a year ago, before the project started? Why, or why not?"*	- *"What about what you know about TB and HIV?"* - *"And concerning testing and treatment?"*
B. Short evaluation of the intervention	*"What do you think of the provision of HIV/TB rapid test in this low-threshold service?"*	- *"What was good about it?"* - " What could be improved?"

2.4 Selection of participants

For the first two focus groups before implementation, participants must be selected on the basis of the target group selection criteria indicated in the Module 1.
Recruitment:
• drug users (including documented and undocumented migrants);
• clients of low-threshold services;
• over 18 years old.

Choose people that have more skills and knowledge, that are opinionated and capable to tell you what they think.

In order to get a relatively good and representative sample of the whole target group, try to create a reasonable balance in terms of:
• Age
• Gender
• Ethnic background
However, you should not be too strict, for example if your service has mainly male

clients, don't try to find 50% female participants, but at least look for 1 or 2 women. Also, it is not unlikely that some of the participants will not show up. Then you should be able to find substitutes quickly.

The selected participants should be randomly assigned to one of the two FG sessions. Subjects or participant characteristics should be more or less similar in both focus group sessions.

> **NOTE:** *Try to find 6 to 10 people for the Focus Group. Do NOT start a focus group session with less than 6 participants!!!!*

2.5 Preparation of logistic

The preparation of logistic arrangements must include:

- A *suitable location*: it should be as neutral, comfortable and accessible to participants as possible. Moreover, you should be certain that you can have a meeting free of interruptions.
- A *tape recorder* (not forgetting extra batteries, tapes and labels to number the tapes);
- A blackboard, whiteboard, or paper and pens for taking notes to remember points discussed earlier and structure the results of the discussion;
- A *moderator* to facilitate the discussion and encourage participants to talk about interesting and relevant issues.
- A *note-taker/observer* to observe and record significant verbal and non-verbal details.
- *Drinks/ food* for the participants (if a break is foreseen)
- *One or several dates* and times for the focus groups (preferably when the service is open, so you can find substitute participants if necessary)

Before the conduction of the focus group, both the moderator and the observer must prepare themselves well:

- Go through the topic list together.
- Go through the reporting format together.
- Decide on maximum amount of time that should be dedicated to the different subtopics (divide time evenly over topics).
- Decide when the moderator or observer should intervene (when someone is talking too long or taking over the discussion, etc.).
- Divide tasks in terms of recording the discussion, preparing the location etc.
- Go through the basic skills that are needed for the moderator (be neutral, don't get involved, don't steer, but make sure that everyone gets a chance to vend their opinions, etc.) and the observer/reporter (observe nonverbal signals, keep track of time, listen actively if topics are covered enough or if the level of discussion should be deepened).
- Make sure that you are well-tuned to each other, so that you can keep discussion between the moderator and observer during the session to a minimum!

2.6 Training methods, materials and tools

Before the introduction of the topic, a brainstorming exercise will be conducted with the participants, of the training (social workers, nurses), in order to get an idea of what they know about focus group:

- Ask participants to answer to the following question: What do you know about focus groups? When they have worked a few minutes, record all their responses on flip chart paper.
- Review all the points listed on the flip chart and ask for comments.

Then, introduce the topic showing the Power Point presentation and answer to possible questions from the group.

Working Materials: PowerPoint slides; Flip chart and markers

3. HOW TO CONDUCT THE FOCUS GROUPS

3.1 Role of the moderator and the observer

The moderator is the facilitator of the discussion. He/she has the control of the session and is responsible for the direction that the focus group takes.
The moderator should use all the techniques to help participants feel comfortable and to encourage a lively and natural group discussion. At this aim, he/she should have the following characteristics:
- Adequate knowledge
- Listening skills
- Leadership skills
- Relationship with the participants
- Patience and flexibility
- Observation skills
- Right "*Clothing*" (adequate to the environment)

The observer has several functions. The main task is to observe the session and to take notes.
In addition to noting responses, the observer is also looking at any nonverbal sign or body language that the group demonstrates. This can tell you a lot about how the group feels about the topic under discussion as well as give some indication of how many people hold the same idea. Observing these signs can add a lot to the written notes of the responses.

The observer also acts as a "back-up" moderator. He or she can quietly pass notes to the moderator to point out any major question not asked, any area that could be followed up, or anything they think may help.

The observer is also responsible for any equipment that is being used, such as tape recorders or cameras.

3.2 How to run the Focus Groups

The focus group must be introduced as a group discussion on TB/ HIV among drug users, without mentioning the purpose of conducting an evaluation of the testing programme. Participants should be totally unaware of this. Tell them that we need 'experts' and that you will only moderate, but not be part of the discussion.

At the very start of the session warmly welcome the participants (thank them for coming) and introduce yourself, possible colleagues, and their functions (chair person, note-taker, etc.).

- Inform participants about:
  - The purpose of the focus group, and what you would like to gain from it;
  - Agenda and timetable;
  - Rules of behaviour: these include that only one person should speak at a time, and that people should not interrupt each other. Emphasise that you are interested in everyone's view, that each participant's contribution is valued and that everyone will get a chance to speak;
  - How information will be treated and used. Naturally it is of vital importance to stress that all personal information will remain absolutely confidential.
- Allow participants to introduce themselves.
- Listen well and, if necessary, ask for clarification.
- Do not express your own opinion on a topic.
- When closing a topic or subtopic, summarize in a few sentences what has been said, and ask if participants have understood it correctly. Then introduce the new topic.
- Encourage passive participants to speak and curb the enthusiasm of overly dominant participants. This can be done by addressing passive participants directly, like asking them for their opinion. You can also interrupt overly dominant participants by simply stating that you would like to hear the view of other people on a certain issue. Or you could ask all participants to speak, one after the other.
- Allow sufficient breaks for refreshments.
- Encouraging and controlling the discussion (making pauses, rephrasing, etc).
- Observing non-verbal messages.

General rules:

- Main topics are introduced with OPEN questions. **Do not introduce the questions or elaborate on them**, because you might guide the participants that way. Keep it short and don't explain or provide examples like 'for instance, what kind of symptoms…' This is very important!.
- Subtopics are only introduced if they don't come up in the discussion. Wait with

posing sub-questions until after approximately 10-15 minutes of discussion.
- Do not be tempted to provide information yourself within the focus group session. There will be a short education session at the end of the focus group.
- Avoid interpreting the participants directly: 'so, actually you are saying that…' Don't do this, you are steering the participant this way.
- The observer should make basic notes on a print-out of the reporting format, e.g., non-verbal signals, important remarks or inconsistencies. However, do not make notes of the whole meeting since you will miss the non-verbal signals.
- The observer should also take note of what's happening in terms of power dynamics, hypo- and hyper representation of participants, leadership level of participants. Some of the information should be reweight in terms of this.

Debriefing/ education session
At the end of the Focus Group sessions, a short debriefing/ education session is provided, in which:
- people are asked what they thought of the discussion
- gaps in knowledge on transmission, testing etc. are closed; people are educated (if necessary). It is important that the observer takes note of the gaps/ mistakes in knowledge on TB/ HIV so that they can be corrected after the session.

3.3 Training methods, materials and tools

After the presentation of the topic with Power point presentation, for a better explanation and understanding of the procedures of HIV test administration, role play techniques will be used.

- Select a "moderator", an "observer" and six "FG participants" and ask them to role one of the four focus groups planned within the project.

Working materials: Power point presentation.

4. HOW TO RECORD THE COLLECTED INFORMATION

The focus groups must be recorded digitally (mp3 audio-material) and transcribed by the observer/ reporter, using a specific reporting format and taking into account the following instructions:

- Fill out the participants characteristics table (in the reporting format) at the beginning of the focus group session. The report should remain anonymous, don't include names or personal details.
- Transcription should be done *literally,* without interpreting the words of the focus group participants. The exact wording of the participants should be used and never changed to other vocabulary!

- For every subtopic, do the following:
  - summarize the most important information. If applicable write down the level of (dis)agreement in the group (mention every opinion).
  - write down at least 1 exact quote (literal transcription!) per subtopic. Choose a quote that underlines the general opinion. In case there are more different opinions, every opinion needs at least 1 exact quote.
  - After the quote add the *exact time* of the quote, so that it can be checked if necessary (minutes/seconds in your digital recording, e.g. 31:22).
  - Add *initials of the participants* to make clear who said what.
- The observer can make some basic notes on a print-out of the reporting format, e.g., non-verbal signs accompanying statements, or important remarks or inconsistencies. This will aid the reporting later on. However, do not make notes of the whole meeting, because the observer might then miss important nonverbal signals.
- In case the observer/ reporter would like to add information that might clarify a statement or passage, or perhaps non-verbal signals are given, place the comment of the reporter in square brackets, as follows: "I think this [offering TB tests] is very important, really. [participant winks, showing that he is not serious]."
- The observer must also describe of power dynamics (by time, voice tone, leadership level) to correct hyper- or hypo representation in order to be able to *re-weight* concepts in function also of "histrionic" level of participants.
- Do the transcription **as soon as possible**, preferably immediately after the focus group. Information on non-verbal signals is still fresh in memory and the transcription process can be shortened.

> **NOTE:** *in the Annex I. to this module, a copy of the reporting format is provided.*

4.1 Training methods, materials and tools

Power point presentation.

Working materials: Power point presentation.

5. PROPOSED SCHEDULE

Time	Content	Method	Material	Remarks
15 min	What a Focus group is	Brainstorming	Flip chart, markers	Plenary sharing
45 min.	Focus group methodology: how to organize a FG	Power point presentatiopn	Projector	
1 hour	Facus Group conduction: how to conduct a FG	Power point presdentation + Role play simultion	Projector, Flip chart, markers	Re-adaption and fix problems
30 min	How to record the collected information	Power point presentation	Projector	Reporting form

ANNEX I.

CONCEPT REPORTING FORMAT - Focus Group 1 and 2

Organization/ city :	
Focus group facilitator:	
Focus group observer/ reporter:	
Translation done by:	
Location of focus group:	
Date of focus group:	
Number of participants:	

	Initials	Age	Gender	Nationality / bith country	In case of migrant how long in IT/SO/CR?	Remarks
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						

Initials of participant	**Topic 1: knowledge on (depending on focus group theme, TB or HIV)** - Symptoms - Transmission - Protection - Information sources
	Summary of discussion:
	Transcripts of exact quotes of prevailing opinions/ ideas:
	<Add rows according to number of opinions/ideas>

Participant descriptives (no less than 6 participants!)

Initials of participant	**Topic 2: Access to health facilities** - Testing - Treatment - Institutional vs personal barriers
	Summary of discussion:
	Transcripts of exact quotes of prevailing opinions/ ideas:
	<Add rows according to number of opinions/ideas>

	Extra notes and observations, e.G.: - power dynamics - timing - extra remarks - general atmosphere - information from education session - etc.
	<Add rows according to number of opinions/ideas>

MODULE 7

Data recording

1. INTRODUCTION

This module provides basic information about how to enter the data of people tested in an online database.

1.1 Learning outcomes

By the end of this module, participants should be able to:

- Enter the Response & non-response data
- Enter & save the questionnaire data (see also module 3)
- Enter & save the test results data
- Enter & save the follow up data

2. DATA TO BE ENTERED IN THE DATABASE

The following data should be entered in the online database:

- The Response Monitoring Form
- The Questionnaire (including the follow-up questionnaire, if provided)
- The Testing Results (including confirmatory testing conducted in clinical centres)

It is highly recommended to select 1 or 2 persons in the organization who will be responsible for the data entry, in order to limit the risk of mistakes. It can be any staff member involved in the testing programme (outreach worker, psychologist, nurse).

2.1 Response Monitoring Form

The Response Monitoring Form is filled in during the recruitment phase (see Module 1.).
It is filled in every day that the testing is conducted and then it can be entered in the database weekly or monthly.
The variables that need to be reported are:

- gender
- age
- country of origin (in case of migrant)
- whether the participant has refused to get tested before
- whether he or she is willing to get tested now
- whether he or she is eligible for HIV testing and for the ImpAcT project (through the check of inclusion criteria; also check for non-responders!)

- in case of REFUSAL, what is the main reason why the person does not want to get tested.

To record the daily data in the database, an excel sheet form can be used.

The response monitoring sheet must be recorded in a separate database, since this data covers ALL people that are approached, not only those that are tested!

2.2 Training methods, working materials and tools

This part of the training could be integrated with the part on the recruitment and the questionnaire.
The RMF and the questionnaire can be introduced to the participants on screen with power-point, but also on paper.
If any interactive methods are used to practice recruitment and the questionnaire (module 1), data entry will be part of that. It will not be necessary to do another role play for this part.
A short discussion as a part of the presentation could be valuable, so that everyone fully understands what they are supposed to ask.
Working material: laptop, power-point, paper version of RMF and questionnaire

3. DATA-ENTRY SYSTEM

As already explained in Module 3, the data collected through the questionnaire can be entered directly online while administering the questionnaire (one action), or after administering the questionnaire on paper (two actions, the data entry can be done once a week).

> **NOTE:** *not every outreach worker needs to be trained in data recording. It is better to give this task to one or two persons per organization, so that it is done in a consistent manner by well-trained people.*

The data are entered in the data entry system at different times and by different people, see the table below.
It should be clear who is going to be responsible for entering the data in the data entry system (one person or two people per organisation), and how the clinical and laboratory data are handed to the organisations providing the rapid testing.

	Data	Sample	Source/ Responsible
1	Questionnaire data	All those attending T1 (first interview)	Outreach worker/nurse
2	Results of TB clinical screening	All thos attending T1	Nurse/Medical Doctor/(trained outreach worker - in case this is in line with local laws, rules and conventions)
3	Results of HIV Rapid Test	All thos attending T1	Nurse/Medical Doctor/ (trained outreach worker - in case this is in line with local laws, rules and conventions)
4	Result of Sputum Sample 1	Those with high TB risk (positive to TB screening)	Collaboratin clinical centre
5	Result of Sputum Sample 2	Those with negative sputum sample 1	Collaborating clinical centre
6	Date of presentation for confirmatory TB test (thorax)	Those with positive TB sputum test	Collaborating TB Clinic
7	Date of presentation for confirmatory HIV test	Those with reactive HIV rapid test	Collaborating HIV Clinic
8	Results of confirmatory HIV diagnostics		
9	Results of HIV Avidity Test	Those with confirmed positive HIV diagnostics	Collaborating HIV Clinic
10	Date of presentation for TB treatment	Those with confirmed positive TB diagnostics	Collaborating TB Clinic
11	Date of presentation for HIV treatment	Those with confirmed positive HIV diagnostics	Collaborating TB Clinic
12	Date of entry into TB treatment	Those with confirmed positive TB diagnostics	Collaborating TB Clinic
13	Date of entry into HIV treatment	Those with confirmed positive HIV diagnostics	Outreach worker / nurse
14	Follow-up questionnaire 2 (HIV risks)	Those that show up for second HIV rapid test (after min. 3 months)	Outreach worker / nurse
15	Follow-up questionnaire 3 (HIV risks)	Those that show up for third HIV rapid test (min. 3 months after second test)	Nurse / MD / outreach worker
16	Follow-up rapid test HIV 2	Those that show up for second HIV rapid test (min. 3 months after second test)	Nurse / MD / outreach worker
17	Follow-up rapid test HIV 2	Those that show up for third HIV rapid test (min. 3 months after second test)	Nurse / MD / outreach worker
18	Follow-up risk assessment TB 2	Those that show up for second TB assesment (after min. 6 months)	Nurse / MD / outreach worker

The best solution should be that these organizations collect regularly all the data required from the collaborating clinical centres and enter them into the system by themselves.
It is important that the system of linking all the data should be as easy as possible, and should not be mistake sensitive when entering identifier codes.

In the first interview (T1), all participating clients get an identifier barcode, consisting of 2 letters and 4 numbers. This code is printed on the questionnaire and reported in the database.
The same code is indicated on the HIV rapid test and the container of sputum samples (if collected) that will be sent to the laboratory for examination.

Those individuals with preliminary positive HIV and/or TB test results will be referred to the collaborating clinical centres with a referral paper indicating the same barcode.
In this way, the test results coming from the clinics will report the same barcode used for the questionnaire, and it will then be possible to link all the data referring to one individual.
Since the results of confirmatory testing will be available some days after the first testing provision, these barcodes need to be paired with the personal codes used for each client, in order to be able to analyse the data later. (*see also Module 1*).
Therefore, all organisations will need to create a (protected) file that has both the personal codes and the bar codes and some personal details. This file provides the key and should be stored on a different computer so that privacy can be guaranteed.

NOTE: . *in Annex I. to this module, a detailed list of variables to be entered in the database is provided!*

3.1 Training methods, working materials and tools

The data-entry system will be introduced by power-point slides. The different data-entry sheets will be discussed and worked through. If possible, some laptops should be provided to participants, in order to practice the use of the online database.
Working material: laptop, power-point, paper version of RMF and questionnaire.

4. PROPOSED SCHEDULE

Time	Content	Method	Material	Remarks
½ hour	Introduction of Response monitoring form	Presentation and discussion	Example of response monitoring form	powerpoint possible but not necessary
1 hour	Introduction to data entry system	Presentation and discussion	Laptops with data entry system (in case of online tool, internet access needed)	Only with those that will do the data entry
1 to 1,5 hour	Practicing with data entry system	Computer practice	Laptops with data entry system (in case of online tool, internet access needed)	Only with those that will do the data entry

ANNEX I.

LIST OF VARIABLES FOR DATABASE TOOL

Database 1. Respondents

For each respondent, the following items:

- City (Prague/ Bratislava/ Rome/ Turin)
- month/ year of birth
- date of inclusion in the study
- informed consent signed? yes/no
- 1st time Questionnaire (main Q)
  - A01
  - A02
  - A03
  - A04
  - B01
  - B02
  - Etc…….
- 2nd time Questionnaire (follow up Q)
  - A01
  - etc.
- 3rd time Questionnaire (follow up Q)
  - A01
  - etc.
- 4th time Questionnaire (follow up Q)
  - A01
  - etc.
- 1st time HIV rapid test done correctly (y/n)
- 1st time HIV rapid test result (reactive/ negative/invalid)
- 1st time TB risk assessment screening result (negative – positive)
- 1st time TB sputum sample 1 collected (y/n)
- 1st time TB sputum sample 2 collected (y/n)
- 1st time TB sputum sample 3 collected (y/n)
- 1st time result of TB test sputum sample 1 - lab (positive/ negative)
- 1st time result of TB test sputum sample 2 - lab (positive/ negative)
- 1st time result of TB test sputum sample 3 - lab (positive/ negative)
- 1st time date of receiving TB test result (date)
- 1st time date of confirmatory HIV test – clinic (date)
- 1st time confirmatory diagnosis HIV – clinic (positive/negative)
- 1st time date of receiving confirmatory diagnosis result – clinic (date)
- 1st time date of presentation for treatment of HIV – clinic (date)
- 1st time date of receiving HIV avidity test results from lab (date)
- 1st time result of HIV avidity test – lab (infection occurred in the last 6 months/ infection occurred before the last 6 months)

- 1st time date of receiving confirmatory TB diagnosis - clinic (date)
- 1st time date of presentation for TB treatment – clinic (date)
- 2nd time HIV rapid test done correctly (y/n)
- 2nd time HIV rapid test result (reactive/ negative/invalid)
- 2nd time TB risk assessment screening result (positive/ negative)
- 2nd time TB sputum sample 1 collected (y/n)
- 2nd time TB sputum sample 2 collected (y/n)
- 2nd time TB sputum sample 3 collected (y/n)
- 2nd time result of TB test sputum sample 1 - lab (positive/ negative)
- 2nd time result of TB test sputum sample 2 - lab (positive/ negative)
- 2nd time result of TB test sputum sample 3 - lab (positive/ negative)
- 2nd time date of receiving TB test result (date)
- 2nd time date of confirmatory HIV test – clinic (date)
- 2nd time confirmatory diagnosis HIV – clinic (positive/negative)
- 2nd time date of receiving confirmatory diagnosis result – clinic (date)
- 2nd time date of presentation for treatment of HIV – clinic (date)
- 2nd time date of receiving HIV avidity test results from lab (date)
- 2nd time result of HIV avidity test – lab (infection occurred in the last 6 months/ infection occurred before the last 6 months)
- 2nd time date of confirmatory TB test – clinic (date)
- 2nd time result of confirmatory TB test – clinic (positive/ negative)
- 2nd time date of receiving confirmatory TB diagnosis - clinic (date)
- 2nd time date of presentation for TB treatment – clinic (date)
- 3rd time HIV rapid test done correctly (y/n)
- 3rd time HIV rapid test result (reactive/ negative/invalid)
- 3rd time TB risk assessment screening result (positive/ negative)
- 3rd time TB sputum sample 1 collected (y/n)
- 3rd time TB sputum sample 2 collected (y/n)
- 3rd time TB sputum sample 3 collected (y/n)
- 3rd time result of TB test sputum sample 1 - lab (positive/ negative)
- 3rd time result of TB test sputum sample 2 - lab (positive/ negative)
- 3rd time result of TB test sputum sample 3 - lab (positive/ negative)
- 3rd time date of receiving TB test result (date)
- 3rd time date of confirmatory HIV test – clinic (date)
- 3rd time confirmatory diagnosis HIV – clinic (positive/ negative)
- 3rd time date of receiving confirmatory diagnosis result – clinic (date)
- 3rd time date of presentation for treatment of HIV – clinic (date)
- 3rd time date of receiving HIV avidity test results from lab (date)
- 3rd time result of HIV avidity test – lab (infection occurred in the last 6 months/ infection occurred before the last 6 months)
- 3rd time date of confirmatory TB test – clinic (date)
- 3rd time result of confirmatory TB test – clinic (positive/ negative)
- 3rd time date of receiving confirmatory TB diagnosis - clinic (date)
- 3rd time date of presentation for TB treatment – clinic (date)

- 4th time HIV rapid test done correctly (y/n)
- 4th time HIV rapid test result (reactive/ negative/invalid)
- 4th time TB risk assessment screening result (positive/ negative)
- 4th time TB sputum sample 1 collected (y/n)
- 4th time TB sputum sample 2 collected (y/n)
- 4th time TB sputum sample 3 collected (y/n)
- 4th time date of result TB test (date)
- 4th time result of TB test sputum sample 1 - lab (positive/ negative)
- 4th time result of TB test sputum sample 2 - lab (positive/ negative)
- 4th time result of TB test sputum sample 3 - lab (positive/ negative)
- 4th time date of receiving TB test result (date)
- 4th time date of confirmatory HIV test – clinic (date)
- 4th time confirmatory diagnosis HIV – clinic (positive/ negative)
- 4th time date of receiving confirmatory diagnosis result – clinic (date)
- 4th time date of presentation for treatment of HIV – clinic (date)
- 4th time date of receiving HIV avidity test results from lab (date)
- 4th time result of HIV avidity test – lab (infection occurred in the last 6 months/ infection occurred before the last 6 months)
- 4th time date of confirmatory TB test – clinic (date)
- 4th time result of confirmatory TB test – clinic (positive/ negative)
- 4th time date of receiving confirmatory TB diagnosis - clinic (date)
- 4th time date of presentation for TB treatment – clinic (date)

Database 2: Response/ nonresponse
for each week:
- send standardised excel sheets every month to the researcher.


Hit

Lesson learned on Conflicting roles: Social worker versus interviewer

A barrier in data-collection in implementation research

1. Introduction

In three of the four cities, the interviews were done by social workers[1] or medical staff of low threshold services. In one of those cities, Turin, the conflicting roles of being a social worker one moment, and an interviewer for the ImpAcT project another moment, were perceived as quite problematic. In order to prevent/ minimize these kinds of conflict in future projects like this, the situation is described here, as well as lessons to be learned.

2. Goals and perspectives of researchers and social workers

For the social worker, to listen and help clients is the most important and most rewarding aspect of his or her[2] work. Tasks like providing basic needs, counseling, medication, company, will always come before filling in a form, preparing a report, or administration of a questionnaire; even though he knows that research could give strength to his work, enhance it with respect to the stakeholders and ultimately strengthen it in terms of advocacy.

For the researcher involved in these kind of projects, to 'help' these clients of low threshold services is also a strong motivation for his work, but on a different level: to collect information that is useful in order to get a clear picture of the situation for these kind of target groups on a wider scale (for instance, European), and ultimately, to improve the situation, if needed.

The social worker and the researcher in these kinds of projects have the same goal, but different perspectives. Their work demands different roles but are each valuable in their own way. The different perspectives can be polarized on scales, for example:

- helping individuals *directly* on the spot, versus helping larger groups of people, *maybe*, in the future
- providing help versus asking for participation
- showing empathy versus being more neutral/distant

[1] The term 'social worker' might also refer to 'operators in low-threshold services' or 'medical staff in low-threshold services' or other terms used for the people that work with the target group of this project.

[2] in the remainder of this chapter we will only use 'he / his / him', this should be read as 'he or she / his or her / him or her'.

• trying to get people in the project that need it most, versus random recruitment
• trying not to reopen old wounds with those who have already suffered, versus getting as much information as possible, also on sensitive issues.

When these differences are overemphasized and gaps are not bridged, this could lead to resistance or mistrust regarding the data collection among social workers. This could be highly counterproductive, possibly leading to lack of attention, omissions or mistakes. This is a risk that should not be underestimated. Adherence and compliance to research protocols can be reached only if the alliance between researchers and social workers is firm and both parties are convinced of the usefulness of the tools used and benefits that will come from them, so that using those tools is not a waste of valuable time.

3. Research barrier: Conflicting roles in Turin

The prejudices that departed from the aforementioned considerations, at least in the experience of Turin, came forward in the form of direct and indirect "resistances", already during the preparation/training phase but also during the administration of questionnaires:

"The questionnaire is too long and heavy"
"The questions seem too intrusive"
"I do not feel to ask certain things to a man"
"A Muslim would be offended"

It was decided to give it a try and use the simulation and the pilot phase to test these assumptions, since they were not shared by all participating organizations. In the beginning, the fears seemed to be largely contradicted. Only later in the implementation stage it became clear that there were problems with the questionnaire administration. Apparently, to simulate the questionnaire in the (very short) training, and to have a pilot phase of 10 to 15 real interviews, was not enough to show the problems that the workers had with their role as interviewers. Therefore it did not lead to a discussion in the beginning of the implementation phase, which could have lead to change certain things (e.g., adaptation of the tools, or organization of extra training sessions).

Halfway the implementation phase, the local project leader became aware of gaps in the questionnaires, and organized an extra meeting with all the interviewers. It became apparent that sometimes the interviewers noted the first (possibly socially acceptable) answers of the participants, and had not continued questioning when they had their doubts, without reporting these doubts. The interviewers reported that they did not do this, because of the following reasons:

"I sincerely believe that they have the right to declare what they think."
"How can they trust you, if you doubt what they say?"
"Administration of the questionnaires in the mobile units is difficult: there is not enough time and space."

"I think the pre-counseling and especially the post-test counseling in the case of reactive results are more important."

The first two remarks illustrate the difficulty of the combined role of social worker and interviewer. If an unfamiliar researcher would have interviewed these people, doubts about the correctness of the answers would probably not have come up at all. Because the interviewers know most of the participants, they are more prone to *notice* incorrect or socially acceptable answers. Also, as social workers, they do not want to press and continue questioning, because they do not wish to jeopardize the relationship (trust) they have developed with their clients. According to the researcher, it is good that the interviewers chose not to push to get more accurate answers. In the training, the interviewers were instructed to treat the participants as if they see them for the first time, not questioning their answers based on your own knowledge of their situation. This is precisely what the interviewers did.

However, the last two answers of the interviewers suggest that the interviewers might have also deliberately skipped certain sections, or perhaps preferred to choose the quick answers over the ones that require more extra questions and, eventually, prolong the interview. Even though this happens in 'regular' research as well, it is more problematic than the above mentioned role conflict. We have however not found evidence that this kind of 'data-adaptation' has taken place. Extra information of the local project leader confirmed only that first answers were often taken at face value.

It is important to realize that the above mentioned problems did not occur in all four cities. In Bratislava, the interviews were done by a nurse specifically hired for the testing. This created other difficulties since the nurse was not familiar with the clients (like what?). In the other two cities, Rome and Prague, the combined role of interviewer-social worker seemed to be less of an obstacle. It seems likely that the culture and the attitude towards research within an organization are important factors in a possible conflict between roles.

4. Actions taken and lessons to be learned

The problems with the data collection in Turin did not become clear in the beginning of the implementation, when the questionnaire could have been adapted. Halfway the project implementation it was decided to do extra focus groups with staff members, to identify possible problems in the project implementation and develop extra training to deal with these. In Turin, role playing was used (with 'real' clients) to train the interviewers further. Furthermore, the interviewers were called to an additional meeting to discuss the conflicting roles (social worker versus interviewer).

For future projects that might decide to involve social workers into data collection for research purposes, the following considerations should be taken into account:

Be fully aware of the fact that social workers cannot 'turn off' their knowledge of

their clients and do not want to jeopardize their relationship of trust with these clients. This need not always be a problem. In the case of collecting of highly sensitive data, it *could* be difficult.
One of the main advantages of involving social workers as interviewers in a project like the ImpAcT project, is that they are used to working with the target group. They are in touch with the target group, even hard-to-reach clients, and they (usually) have learned conversation skills that are tailored to the target group. Having social workers as interviewers can bridge the gap that exists between (most) researchers and clients of low threshold services.
The culture within organizations seems an important factor in how research activities are perceived and fulfilled. In some organizations, a (slightly) negative attitude towards research exists - based on earlier experiences, expectancies regarding involvement of the government, or other ideas regarding data collection and privacy. Sometimes these organizations use other ways to gather and spread knowledge. Often, qualitative methods (open interviews, focus groups) are preferred over quantitative methods, because they focus more on empowerment; thereby providing more immediate 'evidence'. The value of these kinds of tools is perceived in a more immediate way and therefore seems to be more functional and useful, according to the people that are involved in collecting the data. However, the data of focus groups alone are not always strong enough for evaluation purposes.
The decision of choosing between quantitative or qualitative measures (or using both) should not be taken lightly. It is important that project leaders are aware of the possibilities and drawbacks of different research methods, and develop the research questions or indicators accordingly.

The following actions could be taken to prevent problems with conflicting roles (social worker versus interviewer) in projects like the ImpAcT project:
When developing the indicators, it is advisable to involve both social workers and researchers, so that feasibility of the (quantitative or qualitative) methods in practice is clear at the outset of the project.
For each location, it could be helpful to set up an alliance between a social worker/ local project leader and a researcher, who are both responsible for the implementation and the data collection at the site.
Training of staff should preferably be done by one of the main researchers, first-hand, not second-hand; preferably together with a social worker, and include multiple role playing sessions.
After the pilot phase, the data collection should be monitored regularly by the researcher. It is important that not only the actual database entry is monitored, but also the experiences of the interviewers with the data collection.
In case of problems with conflicting roles, have extra focus groups among the interviewers, so that problems will become clearly defined, and actions can be chosen.
Use experiences of interviewers to improve the data collection tools (shorten questionnaires, adapt wording, etc), if possible.

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