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Assessment on HIV and TB Knowledge and the Barriers Related to Access to Care Among Injecting Drug Users and Service Providers

Report on focus group discussions
among injecting drug users
and service providers

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TUBIDU 2011–2014

Empowering the Public Health System and Civil Society to Fight the Tuberculosis Epidemic among Vulnerable Groups

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ABBREVIATIONS

ARAS	Romanian Anti-AIDS Association
ART	antiretroviral treatment
ARV	antiretroviral
AIDS	acquired immunodeficiency syndrome
DoL	Dose of Love Association, Bulgaria
DOT	directly observed treatment
DOTS	directly observed treatment, short-course
ECDC	European Centre for Disease Prevention and Control
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EU	European Union
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HAV	hepatitis A virus
HBV	hepatitis B virus
HCV	hepatitis C virus
HIV	human immunodeficiency virus
HPP	HIV Prevention Point
IDU	injecting drug user
IH	Institute of Hygiene, Lithuania
LTBF	Tuberculosis Foundation of Latvia
LTBI	latent tuberculosis infection
MDR	multi-drug resistant
NGO	non-governmental organisation
NIHD	National Institute for Health Development, Estonia
NSP	needle and syringe point
OST	opioid substitution treatment
PLHIV	people living with HIV
RAA	Romanian Angel Appeal Foundation
STI	sexually transmitted infection
SW	sex worker
TB	tuberculosis
UNODC	United Nations Office on Drugs and Crime
VCT	voluntary counselling and testing
WP	work package

INTRODUCTION

Even though the incidence of tuberculosis (TB) has reduced in many European countries, it is on the rise among people living with HIV (PLHIV). The critical risk group consists of injecting drug users (IDUs) with HIV who often lack sufficient knowledge about tuberculosis and its spread; neither have they any information about where to turn for treatment and care.

TUBIDU is an EU-funded (Public Health Programme) project with seven participating organisations from six EU countries (Bulgaria, Estonia, Finland, Latvia, Lithuania, Romania). TUBIDU also includes five collaborating partners, all from non-EU countries (the Leningrad Oblast AIDS Centre from the Russian Federation, the International HIV/AIDS Alliance in Ukraine, the National Centre for Tuberculosis and Lung Diseases from Georgia, World Vision Albania and World Vision Bosnia-Herzegovina).

The general objective of the project is to contribute to the prevention of the IDU- and HIV-related TB epidemic in the project area. The strategic objectives include empowering the public health system and civil society and enhancing collaboration between various stakeholders in the field in order to tackle TB.

In the framework of the project, all the associated partners conducted research to describe and define TB- and HIV-related knowledge and risk factors as well as the use of and barriers to access to TB- and HIV-related health care services among IDUs and PLHIV. The first stage included focus group discussions conducted among IDUs and professionals working in harm reduction in order to gain background knowledge regarding the above-mentioned issues. A cross-sectional study among IDUs will be conducted in the second stage to identify TB- and HIV-related knowledge and the barriers to access to TB and HIV health care services among IDUs and PLHIV.

The current report summarises the results of the first stage, i.e. the focus group discussions in partner countries, and provides a few recommendations for the provision of TB and HIV services for IDUs. The report consists of a general overview of the focus group methodology, followed by discussions and conclusions. Considering that specific countries differ in terms of their epidemiological situation as well as service provision, the discussion notes and conclusions only include the main outcomes. The appendixes present the individual country reports of the focus groups in more detail in order to contextualise the results. General overview of the HIV and TB situation prevention and treatment systems including overview of the previous research is available at <http://www.tai.ee/en/tubidu/publications>.

GENERAL OVERVIEW OF THE FOCUS GROUPS

Rationale and methodology

The main aim of the focus groups was to describe problems related to access to TB and HIV services among IDUs and explore the possible ways of improving access to these services. The results were expected to provide input for developing a quantitative study protocol and instrument, as well as for preparing guidelines on TB prevention for injecting drug users and training programmes for specialists (the latter two are the tasks of the other work packages of the TUBIDU project).

A focus group is generally considered to be a good method to generate ideas for new initiatives and programmes, since results can be obtained fairly quickly. This methodology helps to explore the questions under study in more detail, and thus complements the quantitative data.

Two focus groups (7 to 12 participants each) were assembled in every country, consisting of:

- 1) Injecting drug users. They were purposely sampled to include those with no experience, recent experience and established experience of HIV and TB testing and treatment. In addition, they were sampled according to gender, age, ethnicity and duration of IDU.
- 2) Professionals (social workers, counsellors, outreach workers, etc.) working with injecting drug users in syringe exchange programs, low-threshold centres or harm reduction services.

Participants were recruited through the NGOs and the focus groups conducted in the premises of local NGOs or other organizations working with IDUs. The focus groups were conducted in local languages. They lasted between 60 and 90 minutes, were coordinated and conducted by specifically hired interviewers trained by local TUBIDU research team, and audio-recorded. Participation was voluntary and anonymous; no personal data were collected or recorded. Participants received local supermarket gift vouchers as the compensation for the time and effort.

The TUBIDU research team prepared guidelines for carrying out focus group sessions (Appendix 1) and specific questions (interview outlines) to be asked from focus group members (Appendix 2). Interview outlines included information about the participants' background, knowledge and attitudes about HIV and TB, experiences with their testing, treatment and care systems, as well as contacts with people with HIV and/or TB.

Recordings of the focus group discussions were transcribed and analysed to identify the main themes and issues. The preliminary analysis was done by the project partners (Appendix 3) and the final analysis by NIHD. The findings are presented as a descriptive

summary and direct quotations from the participants have been used to illustrate the discussion. Every quote is marked with a code reflecting the country (BUL – Bulgaria; EE – Estonia; LAT – Latvia; LIT – Lithuania; ROM - Romania) and study group (IDU – injecting drug user; SP – specialist). Thus BULIDU means an injecting drug user from Bulgaria; EESP – specialist for Estonia; etc. If some of the text from the quotation has been left out, it is marked with /.../. Interviewer comments are marked with “[]”.

FINDINGS AND DISCUSSION

The detailed overviews of the focus groups by countries are provided in Appendix 3. Each country report is organised into two sections – one presenting findings from the focus group session conducted with injecting drug users and one from the session involving professionals working with IDUs, The following is a short summary of the main outcomes across the countries.

Knowledge

The results indicated that in general, people's knowledge about HIV- and TB-related issues varies by countries and target groups. For example, the participants (both IDUs and specialists) in some countries had better knowledge about HIV, in others — about TB.

More specifically, **all IDUs** who participated in the focus groups of all six countries were aware of HIV, how it spreads and how to prevent infection. IDUs were aware of sexual and parenteral transmission as well as mother-to-child transmission of HIV. In general, HIV was considered a serious disease and people felt they were in danger of infection because of their behaviours.

BULIDU: We know almost everything about HIV of course... HIV is transmitted by blood and unprotected sexual contacts. It is easy to get infected for us, as we are injecting drugs and have compromised immune system and sometimes risky behavior... The other issue is being in a prison. In the prison you cannot choose your behavior sometimes. There are closed environment, rules and violence... HIV is a serious disease... HIV is more dangerous than other diseases because people cannot be cured from HIV ...

EEIDU: It [HIV] is a virus... It spreads sexually, with drugs, with syringes... It is easy to get infected... It is easier to get infected through blood than through sex... It spreads more easily from a man to a woman than from a woman to a man.

LITIDU: HIV is transmitted through contaminated needles, sexual contacts and mother can infect new-born... HIV is fatal disease. [Is it easy to get infected?] For me yes, because I am a drug user... Risk is big because of drug injections.

Many participants had friends or acquaintances who were infected with HIV. IDUs were mostly aware of the basics of HIV infection, but knew much less about the progression and treatment of the disease. The lack of available information was not considered to be a problem, on the contrary — it was suggested that anyone interested in the subject could find information quite easily. It was also pointed out that people may not be actively looking for additional information about HIV themselves and therefore targeted information campaigns as well as mass media campaigns for the whole population are needed.

BULIDU: *We don't have enough information about the ART treatment or other details. Mainly because HIV cannot be treated the information never seems enough. We have not enough information for the progression of HIV and AIDS, support services for HIV-positive people...*

EEIDU: *I have more than enough information about HIV... Who is interested, has no problems finding information...*

LITIDU: [What kind of information about HIV would you like to have?] *Well, to know how HIV works in human body and how affects organs.*

Many participants considered their TB knowledge to be poorer than their HIV knowledge and the available TB information to be more limited than HIV information. TB was considered a serious disease. Some thought is more dangerous than HIV because it spreads by air, some thought it is less dangerous because it can be treated. In general people felt at risk of TB, especially because it can be transmitted by air. Misconceptions about the spread of TB (for example it was thought to be transmitted sexually and by blood) were frequent and participants did not always know how they could protect themselves against contracting TB.

BULIDU: *TB is a serious disease... TB is not so dangerous than HIV anyway because you can get treated... We don't have enough details for everything. For example MDR and XDR — are they treatable? Why cannot you diagnose it with one test – positive or negative result. It is not so clear like HIV testing...*

EEIDU: *Tuberculosis? It is a lung disease... Very contagious... I know practically nothing about it... It spreads sexually and by the blood... It spreads like HIV and if it is open TB then also through air... I have very little information about tuberculosis... I know very little because I do not want to know about it...*

LATIDU: *Theoretically everybody has some knowledge. But the real understanding arises when the problem touches yourself, the closest people. Nobody can tell precisely how a person can get tuberculosis, even doctors are not able to ensure for 100% that in this or that way it is not possible to get the infection.*

LITIDU: *TB disease is more dangerous in comparison with HIV which cannot be transmitted through air... It is transmitted from one person to another when you are sneezing, coughing or laughing. It would be interesting to know what happens when you have TB... You cannot eat together with a person with TB. [Do you feel that you are in danger of contracting TB?] Yes, TB can transmit through air...*

Only a few had friends or acquaintances who had contracted TB, and even fewer knew people with a TB and HIV co-infection. TB-HIV co-infection was considered to be a serious and often fatal condition, although many of the participants knew that TB is treatable. Misinformation and stigma related to TB was named to be one of the reasons why people with TB symptoms are resistant to get tested for TB.

BULIDU: *Three of us have had friends who were TB patients... No, we have not heard of somebody with both HIV and TB. We have no idea what happens with them, but we suppose they will just die and nobody will want to help them. The HIV will kill the person finally...*

EEIDU: *People with TB and HIV can be treated... The treatment regimen is crazy... It is strong hit against the immune system... Antibiotics weaken the body...*

LATIDU: *Tuberculosis is the second disease for those who are HIV infected. This is like two shoes in one pair. Usually both go together. It is rare than one disease is present in the body alone, without this second disease.... If a HIV infected person gets tuberculosis, the life expectancy becomes shorter.... I know persons who have both diseases and some of them are dead already.*

LITIDU: *My friend spent several months in the hospital and felt bad... They [people with HIV and TB] are very depressed... Many TB cases are in prison.*

ROMIDU: *I got ill [with TB] one month after I quit heroin and enrolled in the methadone substitution treatment... Years ago one could die from TB. Many are afraid, they do not acknowledge they have the disease; they say "I have pneumonia". They are ashamed of their illness. But [TB] is treatable; you don't have to be ashamed. Because of the shame [attached to it] TB is dangerous: you can catch it from people who are not open about their illness...*

Specialists also knew the basics of the infections — transmission and treatment —, but much less about more specific issues such as the pathogenesis of HIV and TB, drug resistance and vaccination. Compared to HIV, there is less information available about TB, and yet people are more afraid of contracting TB than HIV, since the former is an air-borne infection. Interest in all these topics was high among the participating specialists and thus, continuous education for professionals and the distribution of information among target groups should remain a priority. In addition to paper-based materials, the Internet can also be used as a source of information. Discussing IDUs, the specialists asserted that they know more about the transmission channels and testing opportunities of the infections, and less about treatment and how to access it.

BULSP: *The clients ask a lots of and different kind of questions. Most of them ask for the statistical data about HIV in the town, confidentiality and anonymity issues, and the testing procedures... The people working mainly in the HIV prevention don't have enough information about TB. The additional information that we need is connected with a lot of issues: testing, treatment and rehabilitation. Everything about TB.*

EESP: *There should be more public information about tuberculosis because it is more dangerous disease than HIV. People travel in public transportation.*

LATSP: *When I studied at primary school there were these AIDS days. And each year you got new and new knowledge. And this gives you a feeling of safety, that they [people living with HIV] are not monsters, but just persons with damaged immunity. But about tuberculosis...there were no such activities... [TB is a] very serious disease. Because this person really can infect others... this is like a chain reaction... One can infect family members, other people. There is an alarm not only about himself but also about the other people.*

LITSP: *It is dangerous that this disease [TB] spreads by air, and everyone can become infected... We have seen in our patients the increase of the disease.*

Many specialist had had clients with HIV or TB, very few with HIV-TB co-infection. In general, clients talk about their infections and diseases with specialists, but the fear around confidentiality remains. Also, some differences regarding talking openly about their diseases could also be noticed between organizations and countries, but no specific conclusions can be drawn based on this study.

BULSP: *Yes, we had clients with TB in our programs. Just a few – not more than five persons... Yes, the clients talk about TB openly, but still there are considerations and fears in the vulnerable groups for the confidentiality. There are fewer fears about TB than about HIV...*

EESP: *Approximately 75–80% of the clients are HIV-positive... They talk about their infection peacefully and without shame... Some do not talk unless you direct the discussion towards this topic... We have suspected TB [in our clients] many times, referred for screening, but there has been no case, everybody has been fine... Clients do not talk about tuberculosis as openly as about HIV, I think they despise it more...*

LITSP: *We do not always specifically know what infections patients have, because even they aren't always aware of them.*

ROMSP: *We had a situation with a pregnant patient with HIV and TB, who had no identity papers, lived in extreme poverty, used "legal drugs" and whose HIV and TB treatment heavily interfered with the pregnancy. This is one example of how multiple-risks patients don't have access to proper integrated services and the existing ones are not enough.*

Perceptions about the occupational risk of contracting HIV and TB varied among the specialists. Some considered themselves to be at a higher risk (especially for TB) due to their regular contact with infected patients; some did not as they thought they knew how to protect themselves. Lifestyle and personal hygiene were listed as important factors to protect from TB disease. It must be stressed that the actual knowledge and skills regarding occupational risk reduction were not tested among the focus groups.

BULSP: *We don't feel we are in danger of contracting HIV on our working places, because we know how to protect ourselves...Yes, it is easy to contract TB. Everybody is in danger and could contract TB... Yes, we also are in danger of contracting TB in our working place. We know what we could do to protect ourselves. Mainly good lifestyle, no smoking and drinking and ventilation in the working place...*

EESP: *I am more afraid of tuberculosis than HIV, because I can regulate more if I get infected with HIV or not... I feel just a little danger of occupational transmission of HIV... If I was afraid it would be difficult to work... We are not in danger unless the clients attack... I have some risk because I work in syringe exchange and if I stuck myself with a needle I may contract HIV, but I test every time this happens... For us here it would be easy to get tuberculosis... We should eat well, wash hands, air the rooms...*

LATSP: *Regarding HIV... there are concrete, practical things. And if I'm not contacting with these things [blood etc.], then I'm not worried about it... it is not flying in the air [like TB bacteria].*

LITSP: *No, there is no risk... I think if there is blood from the wound on handlers or other surfaces, we will never know where virus can be.... We have a very high risk of contracting TB... We should use masks, but to provide social help with it would be unprofessional... We don't use masks because it would seem weird.*

Some participants had attended several trainings that handled TB and HIV issues in general, but failed to touch upon the specifics of the prevention, diagnosis, and treatment of TB among IDUs, especially from the point of view of non-medical professionals working in outreach services and low-threshold clinics/centres. The participants voiced the need for continuous HIV/TB training (see the section on training below) as well as for clear guidelines and algorithms of action to identify individuals with TB (in harm reduction services) and refer them to screening.

BULSP: *Yes, we have a lot of knowledge for HIV. Still we lack knowledge for: innovations and modern practices for HIV/AIDS; advanced knowledge for medical aspects of the disease; enough information for treatment and services provided PLHIV...*

EESP: *I think we have enough information... I have plenty of information about HIV as we have had many trainings... I would like to know more about HIV treatment and antiretroviral drugs... There is very little discussion about short course treatment after sexual exposure... We have had many trainings, also about hepatitis and tuberculosis... We do not have enough information about tuberculosis...*

LATSP: *We as non-medics don't have so broad information. We are not informed about what proportion [of the drug price] is covered by state...*

LITSP: *We have had no trainings on HIV and TB... [I would like to know] whether it is safe living together with person infected by HIV?... Sometimes we have a lack of knowledge to explain which situations are not dangerous [with regard to getting infected]... We have lack of information about personal safety in work place... If we get information that patient is sick, we don't know what to do.*

Services

Both IDUs and specialists in all countries considered access to **HIV testing** to be quite adequate. Most IDUs had tested for HIV. In many cases HIV testing is provided within the community (services offered by both NGOs and public clinics), which makes testing easy. The only exception was Lithuania, where HIV testing is mostly a fee-charging service, which may hinder the uptake of testing. The main testing-related problems faced by many people are their personal attitudes and fears about the potential loss of their privacy and anonymity, which was confirmed both by specialists as well as drug users themselves.

BULIDU: Yes, testing for HIV is very accessible. We can easily make HIV test in the NGO that is working directly where we are spending our day... Yes, it was very easy; almost every day of the week there is a nurse in the NGO, so you can get tested if you need it. There are also rapid tests that give you an answer quickly.

BULSP: We have referred clients to Regional Health Inspectorate Cabinet for anonymous and free testing in the town and NGOs that provide free and anonymous testing... We consider that the HIV testing services are very good and convenient for clients in the region, especially in the town...

EEIDU: Of course I have tested for HIV... I do not have a regular schedule for testing but I test quite often... I am positive, but I have acquaintances who are negative and if they feel at risk for HIV they go testing immediately...

EESP: There are not so many testing opportunities anymore... Rapid testing is free of charge but for STI testing one must pay... It would be very helpful to provide HIV testing in syringe exchange programs and low threshold centers... So they could test right in our centre, because if they leave our centre not everybody goes to testing site...

LITSP: It is harder to diagnose HIV than TB... HIV testing is completely inaccessible.

ROMIDU: When I was using [heroin] I was taking the HIV test at the Centre regularly.

TB screening services were also considered to be quite readily available in most of the participating countries. In Bulgaria, for example, TB clinics organize open door days annually, which enable everybody to get screened for TB if needed. In Latvia, however, clients are charged for testing for TB, which is also considered as an obstacle for IDUs who often have a very low or no income. Confidentiality and discrimination of IDUs were also mentioned as barriers to screening.

BULIDU: It was easy to get TB screening. The TB nurse was coming to DoL every week. BULSP: Yes, it is easy to get a TB screening in Bulgaria. Even if there is no contact with NGOs there are Open Days Doors in the TB clinic for everybody at least once in the year. The IDUs could have easy access when the NGOs are working. If they are not working and offer services inside the groups it will not be easy, because of the discriminative attitudes to IDUs in the country. It is very important for the offered already TB services for vulnerable groups to be continued.

EEIDU: It was easy to get screened for tuberculosis... There were no hindrances...

EESP: *There are plenty of places where to get screened for TB...*

LATSP: *I think HIV [testing] is more accessible, because there are cities in Latvia where you can go for a testing anonymously. But regarding tuberculosis, he must tell his personal data... Second thing – rapid tests, they does not exist for detections of tuberculosis. Thus HIV testing is more accessible... the procedure per se.*

LATSP: *X-ray costs 3 lats, they don't have this money. Ok, in Riga outpatient clinic it is free of charge, but he is saying to me – you know how much money I need to go there? One lat. I was thrown out three times because I don't have ticket. I'll not go anymore.*
LITIDU: *Everyone can check for TB in a TB hospital if they have a referral from a doctor.*

LITSP: *We send all patientts to TB hospital for TB testing... We are asking for patients who have symptoms to take the tests... IDUs unwillingly visits TB services, and its hard to motivate them.*

The situation is more complicated when it comes to the **treatment and care of HIV and TB**.

In general, **HIV-treatment** was considered to be accessible and effective. Participants knew that adherence is important for successful treatment outcomes. Stigma (especially IDU related) and confidentiality issues were mentioned as barriers to treatment. Negative attitudes were also sensed from the medical personnel. Also, people who do not have complaints or symptoms, may not be interested in treatment as they do not perceive the need for it.

BULSP: *The clients are aware that HIV treatment is free and accessible for everybody that needs it, but they have fears and bad attitudes regarding the discrimination and confidentiality in the country...*

BULIDU: *Also as IDUs we think that even if HIV treatment was available then because of the discrimination nobody would provide it to us – we are junkies and HIV-positive, nobody will want to take care for us. If we needed treatment we'd ask first in the NGO. It is anonymous and trustful there. If they don't exist we'll try to go to family doctors and institutions, but it is not trustful there.*

EESP: *HIV treatment is readily available... Once the person goes, treatment is available... One has to take drugs regularly, so people do not want to get involved in treatment... The attitudes of the doctors are problematic...*

EEIDU: *Access to HIV treatment is easy... Not everybody goes for treatment because some do not feel that they need it... The two doctors I got are very indifferent...*

LITSP: *Treatment is succesfull when you countinue your treatment till you get well...*

ROMIDU: *[HIV treatment] prolongs your life... stops the microbe... maintains the virus at a certain level... it boosts your immunity...*

Some participants were not sure whether they could get HIV treatment and there were also some misconceptions about the effectiveness of treatment and side-effects.

TB treatment was also considered available, accessible and effective both by the specialists and IDUs, although not in all countries Participants were aware of the long duration of the treatment and the importance of adherence.

BULSP: *Yes, we had clients that received TB treatment. It was effective and they were cured.*

BULIDU: *TB is treated and the treatment is available, effective and free of charge...*

EEIDU: *Of course I would get treatment, people are socially dangerous when they have tuberculosis... There is even involuntary treatment*

EESP: *To get treatment is easy, you do not have to stay in the hospital too long, and you'll get food... They do everything to motivate people to get treatment... In our county a medical nurse takes drugs and food to the homes of patients every day...*

LITIDU: *TB treatment is long and complicated... [Would you be able to receive treatment in case you contracted TB?] I don't know.*

LATIDU: *You should go for tuberculosis drugs every single day. This is sad that doctors are not interested whether the patient is able to come this day or not. Maybe he is feeling unwell today...*

LITSP: *TB is curable, but you have to take the treatment... Most important thing is not to dismiss the treatment.*

ROMIDU: *The Koch bacillus is very strong. The treatment does not kill the bacillus, just puts it to sleep... [the Koch bacilli] are like little worms in a sack.*

Even though participants (both IDUs and specialists) were mostly aware of the basics of the treatment, services available as well as the preconditions for access, many of them still wanted to know more about the health care system in their country, i.e. regarding the specific steps that are required to access the services (both HIV and TB testing and treatment). It became evident that service providers, especially in harm reduction, may not know enough about institutions providing HIV and TB treatment or the ways of accessing treatment. The systems were considered to be complicated and confusing, since patients are required to visit several institutions to access different medical services. One concern voiced by the focus groups in all the countries was the lack of cooperation between medical service providers: services are available but they do not actually function in a common network, which makes it more difficult for the clients to access them.

The main barriers obstructing access to HIV/TB services were considered to be (summary of focus group discussions):

- The negative attitudes of medical and other staff towards drug users (the most frequently mentioned barrier and problem).
- The doctors' lack of interest in spending a sufficient amount of time on educating patients and solving their problems (which may discourage people from seeking out the services).

- Internal stigma (self-stigma) was also considered an important factor preventing people from accessing treatment services. The participants felt stigmatised and discriminated against due to their IDU status, which may hinder their access to treatment.
- The low motivation of the people themselves to be tested or treated.
- In some cases the need to pay (or misinformation about the need to pay) for the services can become an obstacle.
- The complicated nature of service provision and the lack of cooperation between different service providers may make the system very difficult for people to navigate.
- The lack of identity documents (citizenship) and/or national health insurance.

BULIDU: For us if the services are based in the NGOs like testing and HIV treatment would be most easy to reach. Also if there are combined services like testing and treatment based in one place it would be the best... If we could change something it would be to provide everything for HIV in one structure – easy to get, close, free of charge and confidential and anonymous if possible. If is not possible in one structure that at least all the structures should to have an easy path and communication channels, so the person would not have to go to five structures to get what they need. ... Just there should be also good communication between structures, rehabilitation and social advantages if you were a TB patient. The conditions [food and premises] in TB clinics should be better and methadone should be provided if we have to stay in the hospital.”

BULSP: There are problems in offering TB services in the smaller towns. The services need to be expanded in a geographical aspect... The good thing is that most of the services are available. What could change – better and active communication between the different structures that offer services... The main issue that would make easier for the people to get treated is some free food vouchers and social support

EEIDU: It would help if the treatment centers were opened during the weekends...

EESP: There is only one place in the city where to get the drugs, if they were available at family doctors then access would be better... The biggest issue is how to motivate people to go for HIV treatment. Our clients have many other things to do than to think about their health... HIV treatment should be provided were methadone is provided – so you would not get methadone unless you have taken [HIV] drugs...

LATSP: It would be nice if these centres who are working with tuberculosis patients, HIV patients could collect the information and not to spend the money for brochures, but to send out the information via e-mail to [social] departments, where to refer the patient... thus the social worker should not spend the time in searching via internet... There is a necessity for an algorithm, guidelines... like Stop TB. I have a small book, like visit card. There are first symptoms listed and on the other side – five steps what should be done. First – tuberculosis out-patient clinic, second – family doctor... What I should do if a tuberculosis patient is visiting my office...

LITSP: The system [for TB treatment] is difficult, all institutions requires for something. Patient has minimal social skills, uneducated. Have to bring many documents and papers, and it demotivate patient to get treatment.

In general, there were no major contradictions among IDUs and specialists regarding the barriers. One specific barrier only outlined by service providers concerned neurocognitive problems (related to long-term drug use or the use of a certain type of drug, e.g. ethnobotanical drugs in Romania) and being under the influence of drugs, both of which affect the likelihood of achieving contact with the client as well as the client's ability and motivation to accept the service or participate in the process of service provision.

Training

One of the aims of the focus groups was to discuss the training and continuous education needs of specialists. The following subjects were mentioned during the discussions as possible topics for trainings:

- TB — all issues related to infection, progression, vaccination, diagnosis, treatment (including the management of side effects) and prevention.
- TB risk groups, screening methods (including the reliability of screening methods) and frequency. TB screenings and referrals by non-medical staff (in case of an outreach or low-threshold clinic for IDUs).
- Occupational health — how can service providers protect themselves against contracting TB when coming into contact with a TB patient?
- HIV — treatment, side effects and the management thereof. HIV and chronic diseases, simultaneous treatment of an HIV infection and a chronic disease.
- Post-exposure prophylaxis of HIV, both after sexual contact and unsafe injection.
- Adherence to TB and HIV treatment as well as OST, HCV, etc.; adherence counselling.
- Counselling offered to clients/patients: attitudes; barriers to communicating with HIV and TB patients; the reasons why people are reluctant to talk about HIV and TB; communication with clients/patients; appropriate disclosure of a TB diagnosis; motivating clients/patients to undergo regular screening and take responsibility for their own health as well as for the health of other people.
- Inter-institutional cooperation and teamwork.
- Legislative issues regarding the patients' rights and the rights of other members of the public.

RECOMMENDATIONS

The main recommendations applicable to all countries striving towards the aim of improving access to health care in the field of HIV and TB, as outlined by the focus groups, include:

- **Introduce user-friendly services.** Adjust services according to the needs of drug users, e.g. by establishing more flexible opening hours for HIV clinics (including the option of getting tested and receiving ARV drugs over the weekend), and open additional service provision sites in different geographical locations.
- **Provide integrated HIV and TB services.** Ensure better collaboration between HIV and TB service providers, also regarding the issue of the party responsible for informing target groups.
- Develop a **support system** to help clients to undergo regular health screenings. Strengthen and improve the system of **referral and accompaniment** services for the successful referral of clients.
- Prepare cooperation guidelines for **different governmental, municipal and non-governmental organisations** in order to promote the provision of (integrated) services.
- Revise **administrative issues and legislation** in order to grant access to HIV/TB services even for those IDUs who do not have identity documents and/or health insurance.
- Continuously provide **information to clients** about specific services and the possibilities of accessing them by means of various information channels and visual aid materials.
- Improve the **capacity of medical professionals** for work with vulnerable groups through training (and other forms of continuous education). Apart from screening, treatment and care, other topics that should be covered include attitudes, understanding information and making it available to vulnerable groups.

Limitations

The limitations of our work include small sample sizes and no more than two focus groups per country. The experiences of children/adolescents and women who inject drugs were not treated as a topic of special significance in the focus group discussions.

APPENDIX 1. Focus group guidelines

Guidelines for focus groups concerning the assessment of TB knowledge and barriers related to access to TB and HIV services among injecting drug users

General information on forming a focus group

A focus group is a type of a group interview. Focus groups are considered to be a good method of generating ideas for new initiatives/programmes/projects.

Aim of the focus group

The aim of the focus group was to describe problems related to access to TB and HIV services among IDUs and to get the input of the representatives of IDUs on how to improve access to these services.

Participants

Participants should be chosen carefully. They should be familiar with the subject discussed in the focus group, have personal experiences with it and be able and willing to provide information and insight.

One group should consist of people who resemble each other, since composing a group of highly dissimilar individuals decreases the quality of the information obtained. People tend to censor themselves in the presence of those who differ greatly from them in terms of power, status, income, or personal characteristics. For example, one group should consist only of IDUs of similar socio-economical backgrounds – if some are unemployed IDUs who live on the streets and inject opiates every day, while others work and use amphetamine for recreational purposes during weekends, then they may not feel comfortable around each other.

Ideally, the participants of a focus group should be unfamiliar with each other. Another option is to choose people who know each other well or are friends. In this case it is important to avoid a power imbalance and to make sure that every participant is given the chance to speak. Generally, we do not recommend adding drug dealers (who do not inject drugs themselves) to the focus group.

Make sure that:

- Everyone participates voluntarily and that nobody is forced to participate; if a person refuses to participate make sure they understand that this does not influence the future provision of services to them in your organisation (that they are still welcome despite of their reluctance to participate).
- The participants know that their privacy is respected and that they cannot be identified in any report. There is no need to ask the participants to state their real names.

Size

A focus group should be small enough to allow all participants to express their opinions and large enough to capture a diverse range of perspectives. A typical focus group usually includes 7 to 12 people.

Duration

A single focus group session usually lasts for a maximum of 2 hours. We recommend keeping the duration of a session between 1 hour and 1.5 hours.

Compensation

Focus group participants are often compensated for their time. We recommend offering coffee/tea/water and biscuits during focus group discussions and also giving condoms/information materials/syringes and/or anything else available to the participants at the end of a session.

Moderating the focus group

A moderator has to lead the discussion but remain impartial and not express any personal opinions. The moderator has to ensure that all participants get the chance to say what they wish and that one person does not dominate the discussion. The moderator may need an assistant to take notes.

A good focus group is like a good conversation. People may laugh, share personal stories, disagree, interrupt each other etc. The moderator's duty is to make sure that the participants stay focused on the topic instead of discussing issues irrelevant to the subject.

Recording

Record the discussion on audiotape, if possible (so that it could be listened back). If not, have an assistant moderator take notes. The participants' consent to take part in the focus group should also be recorded.

Process of the focus group discussion

1. Introduction – the moderator introduces himself/herself and the assistant moderator and then explains the goals of the focus group. The moderator assures the participants that their privacy will be respected and that they cannot be identified in any report.
2. The moderator then asks the participants to introduce themselves – no real names are necessary; the participants can use aliases. The aliases, ages and backgrounds of the participants (how long have they injected drugs, what kind of drugs they inject, are they currently employed) should be recorded or written down.
3. Questions and discussion. The questions are rather like broader themes that can be used to guide the discussion. As two distinct infections (TB and HIV) will be covered,

please make sure that the group members talk about them one by one without combining their answers/opinions about the two.

4. Short conclusion – at the end of the focus group session the moderator summarises the main points of the discussion (the main obstacles to receiving services as identified by the group, the main recommendations of the participants on how to improve access to the services) to make sure that everything was understood correctly.
5. The participants are thanked once more for their contribution and receive the promised incentives.

Report

We recommend drafting the report immediately after the focus group session, as the information gathered will soon start to fade from your memory. The report should not be longer than 2–3 pages and include the following:

- Information concerning the participants – age, gender, background (e.g. how long have they worked in the sex industry or how long have they injected drugs).
- Short summaries of the discussion related to all key questions. The barriers, problems and solutions mentioned should be listed in their order of importance. For example, if all the participants agreed that the distance that needs to be travelled to access the services is the most significant barrier, while the opening hours of clinics are the least important one, then this should be noted in the report accordingly.

APPENDIX 2. Focus group questions

For people who inject drugs:

1. Do you know about HIV? What do you know?
2. How is HIV transmitted? Is it easy to get infected? Is HIV a serious disease?
3. Do you feel that you have enough information about HIV? Why do you think so (that you do (not) know enough about it)?
4. What kind of information about HIV would you like to have? To whom would you turn in order to get more information?
5. Do you know anybody who has HIV?
6. Do you feel that you are in danger of contracting HIV? Why do you think so?
7. Have you ever needed to get tested for HIV?
8. Do you know where to go for an HIV screening?
9. Was it easy or difficult for you to get an HIV screening when you needed it? Why was it easy/difficult?
10. Are there any treatments available for HIV? Are these treatments effective? Why do you think so? Can you get an HIV vaccination?
11. Would you be able to get treatment in case you contracted HIV? Why? Where would you go in order to get treatment?
12. What are the things that would make it easier for you to get tested and treated for HIV? What would you change about these services and what are the aspects that are already very good?
13. Do you know about tuberculosis? What do you know?
14. How is TB transmitted? Is it easy to get infected? Is it a serious disease?
15. Do you feel that you have enough information about TB? Why do you think so (that you do (not) know enough about it)?
16. What kind of information about TB would you like to have? To whom would you turn in order to get more information?
17. Do you know anybody who has had TB?
18. Do you feel that you are in danger of contracting TB? Why do you think so?
19. Do you know how TB is diagnosed? Have you ever needed to get a TB examination? Where have you gone in order to get help?
20. Do you know where to go for a TB screening?
21. Was it easy or difficult for you to get a TB screening when you needed it? Why was it easy/difficult?
22. Are there any treatments available for TB? Are these treatments effective? Why do you think so? Can you get a TB vaccination?
23. Would you be able to receive treatment in case you contracted TB? Why?

24. What are the things that would make it easier for you to get tested and treated for TB? What would you change about these services and what are the aspects that are already very good?
25. Have you heard about people who have both HIV and TB? What happens to them? Can they be treated?

For service providers:

1. Have you had clients with an HIV infection in your services? How many? Do clients talk about HIV openly? Why (do they (not) talk about it openly)?
2. Is it easy to get infected with HIV? Is HIV a serious disease? Do you feel that you are in danger of contracting HIV in your workplace?
3. Do you feel that you have enough information about HIV? Why? What kind of information about HIV would you need?
4. When was the last time you received an HIV training?
5. What kind of questions do clients ask you about HIV?
6. Where have you referred clients for an HIV test? Do you consider the HIV testing options available in the region to be adequate for your clients? What do your clients think about testing? What should be done to improve testing?
7. Are there any treatments available for HIV? Are these treatments effective? Why do you think so?
8. What do clients think about HIV treatment? What would make it easier for clients to receive HIV treatment?
9. What are the things that would make it easier for people to get tested and treated for HIV? What would you change about these services and what are the aspects that are already very good?
10. Have you had clients with tuberculosis in your services? How many? Do clients talk about TB openly? Why (do they (not) talk about it openly)?
11. Is it easy to contract TB? How serious is the disease? Do you feel that you are in danger of contracting TB in your workplace? How can you protect yourself from TB? What are the signs of tuberculosis? How can it be diagnosed?
12. Do you feel that you have enough information about TB? Why do you think so (that you do (not) know enough about it)? What kind of information about TB would you like to receive?
13. When was the last time you received a TB training?
14. What kind of questions do clients ask you about TB?
15. Do you know where to go/where to refer your clients in order to get a TB screening?
16. Do you think it is easy to get a TB screening in your country whenever people need it? Why do you think so? Is it easy (or especially difficult) for people who inject drugs to access these services? Why? What would make it easier for people to get tested for TB? What would you change about these services and what are the aspects that are already very good?

17. Are there any treatments available for TB? Are these treatments effective? Why do you think so? Can you get a TB vaccination?
18. Have you had clients who have received TB treatment? Were they cured? What would make it easier for them to get treated for TB?
19. Have you had clients with both HIV and TB? What happened to them? Can they be treated?

APPENDIX 3. Focus group reports

BULGARIA

I Report on the injecting drug user focus group discussion

METHODS

Time: March 12, 2012

Organised by: Dose of Love Association

Venue: NGO Dose of Love Association, Burgas, Bulgaria

Conducted by: Antoaneta Radeva, NGO Dose of Love Association; observer – Nela Ivanova, NGO Dose of Love Association

Procedure of the focus group discussion (methodology)

The participants were selected by the NGO Dose of Love Association (DoL). They had to be injecting drug users. In the beginning of the focus group session, the participants were informed about the aim of the study, its objectives and course. All the participants read the informed consent form and filled in a short anonymous questionnaire concerning their background data. The focus group discussion was conducted in Bulgarian. Coffee, tea and biscuits were provided during the focus groups session. The observer took notes and a short summary was prepared by DoL.

RESULTS

Background information of the participants

The ages of the participants ranged from 23 to 33 years; three were women and four were men (this approximately corresponds to the gender ratio in the target group). The participants resided in different areas of the city (Burgas) and had various networks of friends and subgroups, but they all knew each other. All the participants were the leaders in their groups.

Results of the focus group discussion

Participant knowledge about TB and HIV.

People did not have equal levels of knowledge; some were better informed than others.

- All of the participants had heard about HIV and TB, mostly in the context of infection transmission. The participants were aware of the higher risks faced by drug users due to their weaker immune system.
- 85% of the participants knew about TB and HIV transmission channels as well as the mechanisms of how HIV affects the immune system. The participants considered HIV and TB to be serious diseases. HIV was deemed more dangerous than TB since people cannot be cured from HIV.
- The participants confirmed that they were aware of HIV and TB, but the level of their information was not as high as it could have been. They had high-quality information, but still considered it to be insufficient.
- The participants agreed that they were not actively looking for additional information. They were of the opinion that if people were interested in the topic then they could find out about it easily and thus a lack of information was not a problem. The participants mainly lacked information about the progression of the disease and the support services available for HIV-positive people.
- One of the participants had an HIV-positive friend who had died of an overdose. Three people had friends who had contracted TB.
- The participants had not heard about people with a HIV/TB co-infection. No one personally knew anybody with a HIV/TB co-infection.
- 80% of the participants thought that they could contract HIV/TB due to their compromised immunity as IDUs, or in a closed-environment prison.
- All of the participants had felt the need to test for HIV and TB and had been tested several times either in DoL or in other institutions.
- The participants considered the testing services to be easy to access, as the NGO provides testing directly within the IDU community.
- The participants believed that TB could be treated, but HIV could not. They were aware of the fact that TB treatment is free of charge, available and effective if the patient

follows the requirements, but the efficiency of treatment depends on how far the disease has progressed.

- The participants did not have any information about HIV treatment. Only one participant had heard about antiretroviral treatment (ART). The participants did not believe HIV treatment to be adequate, but were aware of the fact that in Bulgaria it is free of charge.
- The participants did not believe that treatment was actually available, especially in light of the discrimination against those who are HIV-positive.
- If they did not have access to the services of the NGO they would seek information from family doctors (as the first choice), followed by the Regional Health Inspectorate, TB clinics, private clinics and others.
- The participants thought that there were no good communication channels between them and the service providers in the field of HIV and TB and because of that, there is a lack of information about treatment.

Knowledge gaps

- Information regarding risk factors and TB and HIV infection in general were of high quality.
- Information regarding testing was of mid-quality (the participants only knew about the types of testing that were available, but nothing more).
- Information about the institutions that offer support and the steps necessary to access treatment was limited.
- In general, knowledge concerning TB treatment was better than knowledge about HIV treatment.

Barriers hindering access to TB and HIV services

- It was not clear for the participants how to access HIV treatment after testing. They knew more about it in case of TB.
- The participants felt stigmatised and discriminated against because of their IDU status; this may also hinder their access to treatment.

Recommendations on improving the level of knowledge and access to health care in the field of HIV and TB

- Advertise treatment and rehabilitation services more.
- Distribute information about HIV/TB services more actively in the course of group discussions and conversations.
- Provide free or very affordable sanatorium stays after TB treatment.
- Set up a unit with integrated services and better communication to make TB and HIV services more widely known.

II Report on the service provider focus group discussion

METHODS

Time: March 16, 2012

Organised by: Dose of Love Association

Venue: NGO Dose of Love Association, Burgas, Bulgaria

Conducted by: Antoaneta Radeva, NGO Dose of Love Association; observer – Nela Ivanova, NGO Dose of Love Association

Procedure of the focus group discussion (methodology)

The participants were selected by DoL. They had to be professionals in the field of disease prevention among injecting drug users. In the beginning of the focus group session, participants were informed about the aim of the study, its objectives and course. All the participants read the informed consent form and filled in a short anonymous questionnaire concerning their background data. The focus group session was conducted in Bulgarian. Coffee, tea and biscuits were provided during the focus groups discussion. The observer took notes and a short summary was prepared by DoL.

RESULTS

Background information of the participants

The focus group involved seven participants, six women and one man. The age of the participants ranged from 28 to 44 years. Professional experience in the field of health promotion among drug users remained between two and ten years.

Results of the focus group discussion

Participant knowledge about HIV

- All of the participants considered HIV to be a serious disease. In their opinion, HIV was not a huge problem in Bulgaria because of its low incidence, but they were aware of the high risks of a potential spread of infection. They thought that prevention among vulnerable groups was of a high level and there were good treatment options, but there was also a lack of optimum prevention and intervention.
- Participants revealed that their knowledge about HIV and the disease was moderate, mainly concerning the disease, its prevention and testing. The level of knowledge was lower regarding HIV treatment. The specialists did not deem themselves competent in the medical aspects of the disease.
- The participants did not see themselves as being more at risk of contracting the infection than anyone else in society, because they knew how to prevent it.

- In their opinion, HIV screening and testing are easily accessible for the whole country; people know where to go and how to get tested. The only testing-related problems faced in the society at large are the personal attitudes of people and their fears about confidentiality and losing their anonymity. The participants considered this problem to be cultural rather than institutional.
- Screening and prevention services are accessible to drug users thanks to the Ministry of Health programme HIV/AIDS Prevention and Control, which has been running in Bulgaria for as long as eight years already.

Problems regarding HIV

- Lack of knowledge in the professional circles regarding the innovative and modern practices related to HIV/AIDS. Better knowledge about these aspects would make the professionals more confident and successful in their work.
- Lack of advanced knowledge about the medical aspects of the disease.
- Lack of social support for PLHIV.
- Lack of information about treatment. Four participants, excluding the DoL team, did not have sufficient information about the services offered to PLHIV.
- Lack of awareness regarding the necessity of multidisciplinary support for HIV-positive clients – focussing also on health-related, social and psychological aspects, not just the medical ones.
- All the participants were certain that there were HIV services but that every structure functioned independently instead of being joined in a common network.

Participant knowledge about TB

- The participants considered TB to be a serious disease. The strength of the system lies in the availability of free treatment, preventive activities and vaccination. More information could be provided to society, although some positive steps have been taken under the programmes organised by the Ministry of Health and the Global Fund. The same can be said about screening services available to the population and vulnerable groups. It is possible that there is still some drug resistance due to the patients' non-adherence to treatment.
- The participants knew how to recognise the symptoms of TB and where to refer their clients for testing.
- They had good knowledge about TB (including where to refer their clients for screening and testing), except when it came to the more specific medical aspects. They knew the risks of infection and how to protect themselves.
- The participants thought that drug users have sufficient information about TB risks and the services available to them. There have been cases where health professionals have expressed discriminative attitudes towards injecting drug users.

- Screening and testing have been made available thanks to outreach programmes and Open Doors Days in TB hospitals.
- Problems related to service provision are more serious in smaller towns and villages.

Participant knowledge about HIV and TB co-infection

- The participants knew about the connection between HIV and TB and the risks of co-infection.
- They thought that they did not have enough practical experience regarding HIV and TB co-infection.
- Lack of knowledge regarding places where drug users with TB and HIV could be treated.
- They knew about TB vaccination and were also aware that there was no vaccine against HIV.

Knowledge gaps

The participants' level of knowledge and the information they possessed were not equal. People who actively work with TB-related problems did not have enough knowledge about HIV and vice versa, although they were aware of the connection and consequences of both diseases.

Barriers hindering access to TB and HIV services

Service providers in harm reduction did not know enough about the steps that need to be taken to access institutions treating HIV and TB. They were not confident about the ways in which they could provide help to their HIV-positive clients or offer social and psychological support to them. They knew that such services are available in the country, but do not function under a common network, which makes accessing them more difficult for the clients.

Recommendations on improving the level of knowledge and access to health care in the field of HIV and TB

- Distribute information about the services available in the country, both about individual services as well as cooperating HIV and TB services.
- Create a main national or local unit that would unify HIV information services.
- Create a system for distributing information about the diseases and increasing the capacity of professionals.
- Work with medical structures with the goal of decreasing discriminative attitudes towards drug users.
- Improve communication between service providers.
- Improve prevention programmes and the quality of TB/HIV interventions.
- Improve communication between providers of medical, social and psychological services intended for people with HIV and/or TB.

- Develop a manual to describe the course of services offered to people with TB and HIV.
- Increase the capacity of work amongst medical professionals who work with vulnerable groups (attitudes, understanding information and presenting it to the clients).

ESTONIA

I Report on the injecting drug user focus group discussion

METHODS

Time: April 10, 2012

Organised by: National Institute for Health Development (NIHD)

Venue: NGO Convictus Estonia, Tallinn, Estonia

Conducted by: Victoria Vinckler, NGO Estonian Network of People Living with HIV

Procedure of the focus group discussion (methodology)

The participants were selected by NGO Convictus Estonia and NGO Estonian Network of People Living with HIV. The participants had to be injecting drug users. In the beginning of the focus group session, the participants were informed about the aim of the study, its objectives and course. All the participants read the informed consent form and filled in a short anonymous questionnaire concerning their background data. The focus group discussion was conducted in Russian. Coffee, tea and biscuits were provided during the focus group discussion. Participants were compensated for their time – everyone was given a supermarket voucher (value €10). The focus group discussion was recorded and later transcribed and translated into Estonian. A short summary was prepared by NIHD.

RESULTS

Background information of the participants

The average age of the participants was 32 years (range 23–43); two women and eight men; nine were Russian and one was Estonian. Three had acquired vocational education, three upper secondary school education, and four had acquired secondary education or less. All had been tested for HIV at least once. Only one had ever had TB (a 23-year-old woman).

Results of the focus group discussion

Participant knowledge about TB and HIV

- The majority of the participants had heard about HIV; they knew it was an infectious disease that destroys the immune system. Most had HIV-positive friends. Most were aware that HIV could be transmitted through blood, sexual contact, and during pregnancy. Some said that women were more prone to infection than men, and that it was easier to get infected through shared syringes than sexual intercourse.
- Some considered HIV to be a serious disease. Some thought that it was not that serious – if you get treated, you might live. One person considered influenza to be more serious, since more people have died of it.
- Everybody agreed that they had enough information about HIV and did not need any more. They believed that if people were interested in the topic then they could find out more quite easily, and there was no lack of information.
- Most participants would have visited an infectious disease specialist to get information, or a support group. One person thought that it would be a good idea to turn to your family doctor, since they are the first contact point with medical help for most. Some people were concerned about their privacy and thus did not think that visiting a family doctor was a good idea.
- The Internet was considered to be a good source of information, especially for someone who wanted to stay anonymous. However, one participant said that there are Internet sources that state there is no HIV at all; the information available on the Internet is too varied, so it would be wiser to go to a doctor to get information.
- Most people thought that if they followed precautions they would not be in any danger of contracting HIV.
- All the participants had been tested for HIV; most had even been tested several times. All the participants knew where to go to get tested and considered the available testing possibilities to be sufficient.
- All the participants knew that HIV-positive people could be treated and believed the treatment to be effective. They knew that treatment was free of charge and there was no need for health insurance, and thought that getting treatment was likely and uncomplicated. But not everyone gets treatment because they simply do not care. The participants had no specific thoughts on how to improve access to treatment, because

it was “already easy”, and it all depended “on the person”. It was suggested that clinics could be open for a few hours over the weekends as well, since those who work may find it difficult to visit a clinic on a weekday. Some thought that doctors were too indifferent towards patients, while others began defending doctors.

- The participants considered their knowledge about TB to be poorer. TB was deemed very contagious. A TB and HIV co-infection was regarded as an especially complicated situation.
- Some people thought that TB could be transmitted through blood and during sex.
- Some people thought they did not have enough information about TB. Some thought they had enough for everyday situations and they did not need more until they had a reason to.
- Three people knew somebody who had had TB.
- People felt more at risk of contracting TB than HIV.
- People knew that an X-ray scan is the most common way of diagnosing TB. Some remembered BCG vaccination and a Mantoux test done at school. There was some confusion around whether or not people are vaccinated against TB.
- People would turn to a family doctor or an infectious disease specialist if they suspected they had TB. Nobody had experienced problems related to testing for TB.
- They knew TB could be treated and that the treatment was quite effective. They believed they could get treatment. A few knew about compulsory treatment. Some thought there was no need for health insurance, while some were unsure about it.
- They had heard about people with an HIV and TB co-infection; treatment was considered possible but only if a very strict regimen was adhered to.

Knowledge gaps

No major knowledge gaps were detected. Generally, the participants had better knowledge about HIV than about TB, as they themselves readily admitted.

Barriers hindering access to TB and HIV services

In general, access to services was considered good. Some of the barriers mentioned included the attitudes of doctors and the low motivation of the patients themselves.

Recommendations on improving the level of knowledge and access to health care in the field of HIV and TB

- Ensure that HIV clinics operate at more flexible opening hours (and that the patients have the option to receive drugs over the weekend).

II Report on the service provider focus group discussion

METHODS

Time: April 11, 2012

Organised by: National Institute for Health Development

Venue: NGO Pealinna Abikeskus, Tallinn, Estonia

Conducted by: Victoria Vinckler, NGO Estonian Network of People Living with HIV

Procedure of the focus group discussion (methodology)

The participants were selected by NIHD. They had to be professionals working with injecting drug users in syringe exchange programmes and low-threshold centres. In the beginning of the focus group session, participants were informed about the aim of the study, its objectives and course. All the participants read an informed consent form and filled in a short anonymous questionnaire concerning their background data. The focus group session was conducted in Russian. Coffee, tea and biscuits were provided during the focus group discussion. Participants were compensated for their time – everyone was given a supermarket voucher (value €10). The focus group discussion was recorded and later transcribed and translated into Estonian. A short summary was prepared by NIHD.

RESULTS

Background information of the participants

The focus group involved seven participants, four women and three men; their age ranged from 28 to 56 years. Three had acquired vocational education, three higher education, and one had acquired secondary education. Two had worked with IDUs for 1–3 years, two for 3–5 years, and three for more than five years.

Results of the focus group discussion

Participant knowledge about TB and HIV

- All the participants had worked with people with HIV; up to 75–80% of their clients were considered to have an HIV infection. Most clients are frank and usually talk about their infection themselves without any questions needed; some only mention their infection if asked about it.
- HIV was considered to be a serious disease and contracting the infection was deemed easy, especially among drug users who share syringes. HIV treatment was considered effective, but it was pointed out that HIV could not be cured.
- Most of the participants did not feel they were in danger of contracting HIV in their workplace, unless of course a client attacks, but this happens very rarely.

- Most of the participants believed that they had good knowledge about HIV and had participated in several trainings over their careers.
- Most of the participants said that their clients are interested in HIV treatment; they ask about health insurance fund benefits, about treatment and the effects of HIV on their health.
- The HIV testing options available for clients were not considered adequate (as one testing location had been closed recently). The fact that STI testing is a fee-charging service was also considered to be a problem. Testing would be easier if provided under syringe exchange programmes.
- Clients have some misconceptions about testing: for example, they believe that because of their immune system dysfunction, HIV testing is not always reliable. Some are suspicious of rapid testing, since it is reliable only when three months have passed from contracting the infection.
- Clients sometimes think that HIV treatment is a conspiracy organised by pharmaceutical companies. Drug users find it difficult to adhere to treatment. Some clients have been afraid of treatment-related lipodystrophy, since this is something they have heard a lot about.
- Access to HIV treatment was considered to be good. The only problem mentioned was the attitudes of service providers toward drug users, which are not always friendly. Another problem was related to motivating clients to seek treatment. The internal stigma and barriers of the people were considered to be important factors keeping them from accessing treatment services.
- The solutions that could make treatment even more accessible included providing treatment not only in one site in Tallinn (the capital), but in several (for example also by family doctors), and providing ARV treatment in the same location as methadone treatment.
- Contacts with TB patients were less common. Clients do not want to talk about TB as openly as about HIV.
- The participants had heard much less about TB than HIV, even though it is a global problem. They said that they did not have enough information about TB.
- The participants considered TB to be a serious disease and its treatment to be long but effective, while the vaccine wears off after a certain amount of time. The participants knew how TB spreads and how it is diagnosed. They knew where to refer clients for TB testing.
- They thought that there were many myths about TB and its treatment among their clients, and that their clients believed that TB treatment came with a plethora of side effects.
- When it comes to TB services, everything has been made as straightforward as possible for patients. For example, countryside nurses visit patients on DOTS at home and deliver their medicine themselves. However, the specialists thought that patients had to

take some of the responsibility, too. They should do something in addition to simply swallowing the tablets put in their mouth.

Knowledge gaps

No major knowledge gaps were detected. Topics covered by further training organised for the personnel could include:

- Tuberculosis – all issues related to infection, diagnosis, treatment, etc.
- HIV treatment, side effects and the management of side effects, improving adherence to treatment. HIV and chronic diseases, receiving simultaneous treatment for HIV and chronic diseases.
- HIV post-exposure prophylaxis, both after sexual intercourse and unsafe injection.

Barriers hindering access to TB and HIV services

In general, access to services was considered good. Some of the barriers mentioned included:

- Few HIV testing locations, no regular HIV testing in syringe exchange programmes.
- The health care workers' negative attitudes towards patients.
- The patients' self-stigma and low motivation to get tested and seek treatment.

Recommendations on improving the level of knowledge and access to health care in the field of HIV and TB

- Provide more HIV testing locations and offer HIV testing in syringe exchange programmes.
- Provide HIV and/or TB treatment in more locations (e.g. at family doctors' offices) and implement the one-stop-principle.
- Provide free of charge STI testing for risk groups.

LATVIA

I Report on the injecting drug user focus group discussion

METHODS

Time: March 5, 2012 from 4:30 to 7:00 p.m.

Organised by: Latvijas Tuberkulozes fonds (Tuberculosis Foundation of Latvia) (LTBF)

Venue: Centre for Tuberculosis and Lung Disease, Riga Outpatient Department. 5 Nicgales Street, Riga

Conducted by: Evita Biraua (head nurse, Centre for Tuberculosis and Lung Disease, Riga Outpatient Department; co-ordinator of a HIV Prevention Point (HPP)); Inga Bulmistre (public health organiser of the HIV/AIDS counselling cabinet of the Centre for Disease Prevention and Control)

Procedure of the focus group discussion (methodology)

The number of participants invited to the focus group discussion was 12; the actual number of participants was 12 (clients of the HPP and the TB outpatient department). The participants were informed about the aim of the study, its objectives and course. Before the interview the participants filled in an anonymous questionnaire containing some general participant information.

RESULTS

Background information of the participants

The focus group discussion took place among 12 participants: four women and eight men aged 26–46 years. The average age was 35 years.

The preferred language of communication: five participants indicated Latvian and 10 participants Russian as their preferred language; this shows that three participants communicated equally well in both languages.

Among the focus group participants four had acquired elementary education and eight had secondary or secondary vocational education. The participants with secondary and secondary vocational education showed a greater interest in the subject matter and their ability to improve the knowledge.

Only two of the participants had a permanent position, seven were temporarily employed and five of the participants received state benefits.

Data on the health checks and risky behaviour of the participants was as follows:

- Seven participants (i.e. 58%) had been screened for TB over the past 6 months;
- 83% were aware of their HIV status;
- Over the past six months eight participants (67%) had repeatedly taken a HIV test;
- 75% (nine participants) were injecting drug users;
- 17% (two participants) had been users before, but not at the moment;
- 8% (one) had never used drugs (this person was a TB patient).

Results of the focus group discussion

Participant knowledge about TB and HIV

- The participants differed in their knowledge level; those participants who had been exposed to the infection to some extent (had suffered from the diseases themselves, had one at the moment or had close ones who suffered from these diseases) were better informed.
- HIV and TB are equally important, but there is less information about TB than HIV. The perceived reason for that was the lack of information in mass media.
- TB has always been a serious problem in Latvia, especially among prison inmates.
- It is easier to contract TB, since the disease is airborne.
- TB can be cured, but HIV cannot.
- There was more confidence about the effectiveness of TB treatment than about HIV treatment. 83% of the participants agreed that TB treatment is effective, but only 50% of the participants would take HIV medication in case of need.

- The participants understood that TB is contracted more easily in case of weaker immunity, making HIV-positive people much more prone to contracting TB.
- The respondents voiced the personal responsibility principle: if you wish to live, you have to be interested in getting information. There is never too much information. The more you learn the better are your chances of understanding the situation.
- The sources of information referred to were: personal experiences, school and HPP; the participants emphasised that the above-mentioned institutions should provide information on a broader scale and offer various levels of training.
- The respondents spoke about attitudes and sympathy and the willingness to take an interest in other people's problems; however, they noted that there was a gap in their general ability to approach someone with an HIV or TB infection without hurting their feelings.

Knowledge gaps

- The participants stressed that HIV is more prevalent in Latvia (even though the statistics indicate the opposite).
- People lacked sufficient knowledge about the ways in which TB is contracted. The answers given about the transmission channels of TB showed that people were not aware of the differences between LTBI and TB, as well as other forms of TB, which are more widespread among people with immunodeficiency.
- There was no clarity in terms of preventive measures that could reduce the risk of infection; the opinions of the participants differed on issues such as the survival of the *Mycobacterium tuberculosis* in the environment, the endurance of the infection in the air, airborne particles and dust, and situations in which the bacteria could cause an infection.
- Those who had not been exposed to TB or HIV lacked sufficient knowledge about the kind of screening that is needed and places where to turn in case of such infectious diseases.

Barriers hindering access to TB and HIV services

- Information is not readily available and easy to understand, which makes it more difficult for people to protect themselves from the infections.
- People are not convinced they need to be examined.
- There is not enough information about the possibilities of services or the locations where TB screening is performed; the participants noted that it is considerably easier to get tested for HIV.
- Participants lacked knowledge concerning the frequency and cost of screening. They did not have any resources to see a doctor or go to a screening.

- Doctors display a lack of interest and devote an insufficient amount of time to educating patients and solving problems. Health care staff lack kindness.
- Fear on the part of the patients of telling other people about their disease; the respondents indicated that the public at large is not yet ready to accept and understand people with such a condition. The participants shared their negative experiences.
- Fear that the duty of confidentiality will not be observed.
- Hearsay and negative information about the side effects of HIV treatment makes it difficult to decide whether or not to take medication; this means that there is a great need to explain the importance of HIV treatment and the expected gains to the public.

Recommendations on improving the level of knowledge and access to health care in the field of HIV and TB

- Increase the involvement of the state in intensified TB diagnostics through expanding the populations to whom the annual TB screening is provided.
- Offer anonymous TB screening; ensure anonymity and confidentiality, like in the case of HIV.
- Spark interest in the matter; people do not pay attention to a problem until they themselves are faced with it.
- Provide easily understandable information that is visualised like a real life story, a positive example; also give facts about the mortality rates of TB.
- Provide more information about healthy lifestyles and the essential symptoms that must be paid attention to.
- Provide information about screening locations, where to turn to for the advice and options offered to socially vulnerable groups.
- The participants would like to see a support system to help HIV-positive patients to undergo their regular medical examinations.
- Mass media were mentioned as an important source of information that has not been sufficiently exploited; it could help to raise awareness about the gravity of the situation and the topicality of the issues.

II Report on the service provider focus group discussion

METHODS

Time: March 8, from 9:30 to 11:00 a.m.

Organised by: Latvijas Tuberkulozes fonds (Tuberculosis Foundation of Latvia) (LTBF)

Venue: Radisson Blu Hotel Latvija, 3 Eliabetes Street, Riga

Conducted by: Evita Biraua (head nurse, Centre for Tuberculosis and Lung Disease, Riga Outpatient Department; co-ordinator of the HIV Prevention Point); Inga Bulmistre (public health organiser of the HIV/AIDS counselling cabinet of the Centre for Disease Prevention and Control)

Procedure of the focus group discussion (methodology)

The number of the participants invited to the focus group discussion was 12; the actual number of participants was 11 (the invited participants were HPP staff as well as professionals engaged in social work and work with TB patients). The participants were informed about the aim of the study, its objectives and course. Before the interview the participants filled in an anonymous questionnaire concerning some general background information.

RESULTS

Background information of the participants

The focus group discussion took place among 11 participants: ten women and one man aged 23–58. The average age was 38 years.

Among the focus group participants seven were employed in the field of social work and four in health care. In addition, one participant noted that he/she works in rehabilitation. By profession, three of the participants were medical nurses and seven were social workers. Eight participants had acquired higher education and three had secondary/secondary vocational education. All participants were employed; one participant indicated that he was also a self-employed person.

Seven participants permanently lived in Riga, three in another municipality and two in the Riga region.

Summary of the participants' work experience:

- 30% of the participants were experts with more than 10 years of work experience with TB patients;
- 40% did not have any experience in relation to TB;
- 18% had no work experience with IDUs;
- 9% had no work experience in relation to HIV.

It could be concluded from the data that 67% of the participants had no experience (or had partial experience), since the questions of all the three groups (TB+HIV+IDU) are frequently interrelated.

Results of the focus group discussion

Participant knowledge about TB and HIV

- The participants differed in terms of their knowledge level.
- Information sources: educational institutions, seminars, health day campaigns, AIDS day events, inter-institutional communication.
- There is less information about TB, yet people are more afraid of contracting TB and suffering from the disease than in the case of HIV, since the former is an airborne infection.
- Information about HIV is more readily available, but it is of a general nature, intended for the public at large rather than professionals.
- HIV screening is more accessible than TB screening; unlike in case of TB screening, people undergoing HIV screening can retain their anonymity.
- TB can affect people from different social groups; however, the low-income groups and the poor are more exposed to the risk.
- A strong immune system is very important to avoid contracting TB.
- TB is a very serious and dangerous disease; if left untreated the infection could be transmitted to other people, who could die.
- TB is dangerous because it is an airborne infection; contracting it is easy, and there are patients who deliberately infect other people. There is a multiresistant form of TB.
- People with TB cough excessively, cough out blood-tinged sputum, have grey skin, lose weight and feel exhausted.
- TB is diagnosed by an X-ray scan or fluorography, sputum analysis or the Mantoux test in case of children.
- Treatment is free of charge for TB and HIV patients; AIDS treatment is much more costly for the state.

Responses to the questions regarding attitudes highlight the psychological aspect – fear of contracting TB and criticising the conscious transmission of infection to other people. This was mentioned in reference to TB patients in particular.

Knowledge gaps

- Among the participants 67% had no experience in working with injecting drug users infected with both HIV and TB (co-infected patients), since they had not been aware of these situations in their everyday work.
- All the participants of the discussion noted that they had become aware of their poor knowledge and identified their information gaps regarding both HIV and TB, especially in the socially vulnerable groups.
- There were information gaps about the medical aspects of the disease such as available treatment, side effects and care.
- The participants did not have sufficient knowledge about the different ways in which to protect themselves from contracting TB when seeing a TB patient.

- People were not sure if all cases of TB could be diagnosed by an X-ray scan. They were not aware of any reasons that could complicate making a diagnosis.
- There was only some information about places where to refer clients for TB and HIV screenings.
- There was a lack of knowledge concerning the degree of protection against TB provided by vaccination.

Barriers hindering access to TB and HIV services

- Anonymity may not be preserved when screening for TB.
- HIV screening is more accessible than TB screening.
- Psychological barrier: fear of becoming infected in an outpatient department visited by TB patients.
- Fear that confidentiality will not be preserved; stigmatisation of HIV and TB patients.
- Low awareness of the need to promote good health and health care; patients do not seek out the options of having a medical examination.
- Lack of motivation and shifting responsibility: from the staff to the client, i.e. staff members fail to make an effort to motivate clients to undergo a medical examination; and from clients to the staff, i.e. clients are not concerned that they may infect the staff.
- No money for patient co-payments even to see a family doctor.
- TB is insufficiently discussed among members of the public.
- Lack of a single set of guidelines or an action plan for mutual cooperation among separate governmental, municipal and non-governmental organisations.

An analysis of the questions reflecting the participants' knowledge and skills in relation to TB, HIV and co-infection lead to the conclusion that there are knowledge gaps and a definite need for training in the following areas:

- In-depth training on TB: the infection and disease, treatment, side effects and prevention.
- A clear algorithm of action to identify individuals with TB and refer them to a screening.
- The risk groups, the necessary screening and the frequency thereof.
- More information on TB as a problem in Latvia, statistics.
- Legislative issues on patient rights and the rights of other members of the public.
- Vaccination against TB.
- Reliability of the results obtained by different methods of examination; cases in which TB is more difficult to diagnose.
- HIV treatment, side effects and the availability of care.
- Patient adherence to treatment.
- Motivating clients to undergo regular screening.

- The better motivation of both parties (clients and the staff) and explaining the need to take responsibility for one's own health as well as the health of other people.
- Attitudes; barriers in communicating with HIV and TB patients; the reasons that keep people from talking about HIV and TB; mutual communication.
- Inter-institutional cooperation.

In addition, the identified **target groups** in need of training were:

- Staff members working with people from social risk groups.
- Medical staff including family doctors.
- Staff of different services offering help to IDUs – narcological assistance, HIV prevention points, social services.

Recommendations on improving the level of knowledge and access to health care in the field of HIV and TB

- Educate specialists who work with people from social risk groups on how to recognise a TB patient, how to protect themselves from infection and how and from where to obtain health care for those affected by TB and HIV.
- Prepare a brochure with an algorithm, i.e. an action plan for contacting a potential TB patient in need of screening and providing information on where and how the screening can be performed.
- Make sure that information on TB and HIV screenings is available in places that the risk groups visit; indicate the addresses of the closest testing locations.
- Develop persuasive arguments to motivate clients to undergo regular examinations.
- Include HIV and TB screening in the “patient participation” plan for the clients of social services as a mandatory requirement for obtaining social services.
- Use mass media channels to disseminate information on the prevalence of HIV and TB and educate all groups of the public.

LITHUANIA

I Report on the injecting drug user focus group discussion

METHODS

Time: May 28, 2012, from 2:00 to 3:10 p.m.

Organised by: Institute of Hygiene

Venue: Association of HIV/AIDS Affected Women and their Families Demetra

Conducted by: Loreta Stoniene, TUBIDU researcher (Institute of Hygiene); Jurga Dapkeviciene, psychologist of the Association Demetra

Procedure of the focus group discussion (methodology)

The focus group included ten participants who were current IDUs, either Demetra's needle and syringe programme (NSP) clients or their friends who had the time and motivation to participate. Supermarket coupons were used as incentives (value 30 LTL (approx €8.7)).

RESULTS

Background information of the participants

Eight participants were men and two were women. Five were Lithuanians, three Polish, and two Russians. The average age of the participants was 32 years (age range 25–45 years). The average duration of heroin injection – 6.8 (1–22) years. Two participants had acquired basic, four secondary, two vocational, and two higher education. One of the participants had suffered from TB. Eight had been tested for HIV, two did not know the test results as of yet.

Results of the focus group discussion

Participant knowledge about TB and HIV

- The respondents stated that they knew more about HIV than about TB. They were aware of the three main ways in which HIV could be transmitted, and understood that the risk of HIV is higher when contaminated syringes are used. The participants also knew that HIV is a fatal disease and that no vaccine has been created for it. They knew very little about TB, only that it could be transmitted through air (when sneezing, coughing or laughing in case of open TB) from one person to another and that healthy people should not eat together with those infected with TB. In addition, they knew that TB as a disease is more dangerous compared to HIV, which cannot be transmitted through air.
- They expressed their need to learn more about TB, since they were only aware of how the infection could be transmitted. The participants also had little information about what happens to people if they contract TB. They were interested in finding out how HIV functions in the human body and how it affects the organs.
- The participants stated that there was no vaccine for either TB or HIV.
- The respondents knew that TB and HIV can be treated but did not know much about the effectiveness of treatment.

HIV and TB risk

- The participants considered themselves to be at risk for TB and HIV, as injecting drugs increases the risk of TB/HIV. However, when compared to HIV they thought that their risk of contracting TB was higher due to the transmission channels of the infection.
- More than half of the respondents personally knew people infected with HIV and TB or had had friends with TB who had spent months in hospitals, used medication and were not very healthy anymore. Those with HIV feel depression and desperation; they do not have any future plans. They do not want to be treated or make changes in their lives.
- The respondents were aware of the fact that there are very many TB cases in prisons.

Access to HIV and TB testing and treatment

- For hospitalised patients, HIV testing is available for free in the Vilnius Centre of Addictive Disorders. HIV testing is also free of charge for all people in Demetra NSP

(community based). However, people need a doctor's referral to undergo TB screening in a TB hospital.

- The respondents knew that TB could be treated but also that the treatment was long – four to six months in hospital – and complicated. Only a few respondents knew that TB and HIV treatment is free of charge.
- The respondents thought that access to TB and HIV testing was better than treatment. They hoped that should they fall ill, treatment would be available, especially since the cost of ART and TB treatment is covered by the state. Drug use, abstinence and this “vicious circle” were mentioned as the main barriers standing in the way of treatment.

Suggestions for an RDS study

- The respondents agreed that TB screening is very useful as a part of the TUBIDU project and an incentive is enough to visit a TB hospital in Vilnius for an X-ray scan.

Main outcomes

- The knowledge level regarding HIV is higher than in case of TB. The participants stated their need for information about how TB and HIV affect the human body/organs.
- Access to testing is better than to treatment. Not everyone knows that treatment is free of charge.
- More than half of the respondents had friends with TB or HIV.
- A person's level of education is in correlation with his/her knowledge about TB and HIV; however, better education does not necessarily lead to safer behaviour.

II Report on the service provider focus group discussion

METHODS

Time: March 23, 2012, 1 h 30 min

Organised by: Institute of Hygiene

Venue: Institute of Hygiene

Conducted by: Loreta Stoniene, TUBIDU researcher (Institute of Hygiene)

Procedure of the focus group discussion (methodology)

The session was attended by seven participants from institutions working with vulnerable groups – the Vilnius Centre for Addictive Disorders, the Association of HIV/AIDS Affected Women and their Families Demetra, the Lithuanian Red Cross Society, the Vilnius City Municipality Social Support Centre, the Vilnius Region Correctional Inspection, the Vilnius Lodging House, the Vilnius City Home for Mother and Child – and two from the patient organisation Association STOP/TB Lithuania. Supermarket coupons were used as incentives (value 20 LTL (approx €5.8)).

RESULTS

Background information of the participants

All participants were women and their average age was 36 (24–56) years. Eight had acquired higher education, one – basic. By profession: nurse – 1, social worker – 5, civil society representative – 1, specialist from the Correctional Inspection – 1. Eight of the participants worked directly with risk groups, one worked indirectly. One had less than one year of experience in working with drug users, four had 1–4 years, one 5–9 years and two had more than 10 years of experience.

Results of the focus group discussion

Participant knowledge about TB and HIV

- All the respondents agreed that TB is a serious disease in general and a grave problem in Lithuania in particular. The analysis of the current situation showed an increase in TB cases among IDUs, people who live in shelters or on the streets, or are dependent on alcohol.
- The discussion proved that specialists knew more about HIV than about TB.

Knowledge gaps

- All the participants agreed that they lacked specific information about TB and HIV:

- statistical data on TB (prevalence, incidence) and HIV (analysis of the existing situation);
 - transmission channels, risk factors;
 - TB/HIV treatment, resistant TB;
 - personal safety in the workplace and prevention measures (how can TB be prevented and treated), the safety regulations that have to be implemented;
 - how to inform clients/patients about TB/HIV, how to explain TB/HIV to them, how to motivate them to get diagnosed and treated;
 - how to calm down those clients/patients who are afraid of infections and are agitated that they are in the same institution as clients with symptoms of the diseases;
 - how to cope with the stigma and discrimination related to TB (patients with TB avoid disclosing their disease to others) and HIV and the possible conflicts.
- The lack of information increases fear and uncertainty about the safety of the working environment, affects service delivery, etc.

HIV and TB risk

- The respondents believed that they faced a very high risk of contracting TB and felt unsafe and concerned about their personal health.
- The problem-solving strategy adopted by the participants was to request patients with TB symptoms to undergo a test. If the client agrees to do so and has open TB, he/she is asked to cover his/her mouth.
- Rules on how to prevent TB in the workplace are not clear. Some believed that measures such as using quartz tubes, frequently washing one's hands, disinfecting and ensuring indoor ventilation, spending less time with TB patients etc. should be effective.
- According to their line of work, specialists undergo a medical examination every year or every three years.
- Compared to TB, the risk of contracting HIV is lower, but incorrect information causes irrational fear.

Access to TB testing

- All clients, either insured or uninsured by the state insurance fund, receive an X-ray scan in the Vilnius TB hospital when referred there by a health care institution. The service is of high quality and patient-friendly.
- The main problem is low patient motivation to get tested for TB or receive TB treatment, especially if they have faced discrimination and stigmatisation in other health care institutions. In this case it is very difficult to motivate patients to make a repeat visit to this institution.
- Problems are also faced by institutions that are required to have X-ray equipment (hostels and other accommodation establishments) but do not have medical personnel

who could refer clients to TB hospitals for an X-ray scan. In this case they can inform clients about the locations where they can go to receive an X-ray scan (a family doctor's office) or seek advice from the Vilnius Centre for Addictive Disorders.

Access to TB treatment

- The respondents agreed that getting access to TB screening for risk groups, including IDUs, was easy as long as the institution had a medical doctor (a referral is needed).
- Obtaining TB treatment is trickier compared to TB screening. The main reason is that the system is very complicated and difficult: patients have to visit several institutions to acquire different certificates.
- In some cases, doctors require more documents than they actually need (they are not aware of the required procedures and the client's type). It would be beneficial to implement mediation (mediators) or case management in difficult and unsuccessful cases.
- The main problems related to TB treatment are overcrowded hospital wards (four to six patients in one room); inappropriate patient behaviour (low motivation, alcohol dependency); access to second-line medication (only available in hospitals).
- The respondents agreed that in some cases treatment must be mandatory, e.g. when a person with a resistant or open form of TB refuses to seek treatment.

Access to HIV testing

- HIV testing for risk groups is not available free of charge. The reason that was mentioned most often was political – there is no responsible institution that could advocate for HIV testing for risk groups.
- Currently, only the NGO Demetra provides free HIV testing (thanks to an international supporter – the AIDS Healthcare Foundation). However, there is a good possibility that this problem will be solved.
- Free of charge HIV testing is only available for insured patients in case of a II level specialist (infectologist, dermatovenerologist, etc.) referral. In all other cases people are charged for the HIV test.

Access to HIV treatment

- ARV treatment is more readily available in comparison with HIV testing. There are of course some problems for IDUs, e.g. low motivation to start and continue treatment, uncertainty about who will pay for medical tests (CD4, virus load, etc.). In Klaipeda, for example, the delivery of ART drugs was interrupted for some time.

Main outcomes

- TB is a serious disease and a grave problem in Lithuania; the number of clients with TB is increasing.
- Specialists knew the main TB/HIV symptoms, but were unsure of the correctness of the information. They lacked official and clear information about the TB/HIV situation in Lithuania as well as the main symptoms of TB and HIV, the diagnostics and treatment thereof, and how to work with this risk group with its special needs.
- All the respondents mentioned that they have had patients with various diseases. Discrimination and stigmatisation among different client sub-groups is one of the main problems. The respondents felt that they needed to be provided with more knowledge and skills in order to solve these problems.
- Personal safety in the workplace is one of the main areas that the specialists are interested in.
- TB screening (if the institution has a medical doctor) in Lithuania is easier to access in comparison to TB treatment. The greatest problems are the patients' low motivation, the complexity of the system, the poor availability of second-line medication (only in hospitals), in some cases discrimination and stigmatisation in a health care institution.
- HIV testing is not available for free and access is more restricted compared to ARV treatment.
- Procedures or legal acts are in place/exist, but in real life, not everything functions without individual case management for service coordination.
- Case management can be a very useful problem-solving tool for patients with TB and HIV.
- The respondents agreed that HIV and TB trainings would be very useful. They proposed dividing trainings into two parts: the first to present general information about TB/HIV/IDUs and the second to concentrate on prevention, prophylaxis and the options of receiving support – both for the members of the vulnerable group as well as society as a whole.
- Informational leaflets for patients, family members, specialists and the general public could be very valuable.

ROMANIA

I Report on the injecting drug user focus group discussion

METHODS

Time: April 27, 2012, 1 h 40 min

Organised by: Romanian Angel Appeal Foundation (RAA)

Venue: Titan Centre for Integrated Services (Bucharest)

Conducted by: Fidelie Kalambayi, RAA, co-moderator: Nicoleta Manescu, RAA

Procedure of the focus group discussion (methodology)

The participants were selected by the Romanian Anti-AIDS Association (ARAS) according to the following selection criteria established by the RAA:

- The IDUs are clients using the services ARAS (harm reduction and/or OST);
- The IDUs are sober and able to answer questions for about 1.5 h;
- Four or five IDUs with a history of injecting drugs, including ethnobotanical substances (also known as “legal drugs”, “ethnobotanicals” or “light drugs”) – psychoactive substances that are smoked, inhaled or injected and that contain herbs and/or chemical (synthesis) compounds;
- One or two IDUs with regular jobs;
- One or two female IDUs;
- Two or three IDUs who are younger than 24;
- Three or four IDUs with imprisonment experiences;
- Two or three IDUs living in poor conditions (i.e. on the streets, in a squat, in overcrowded rooms etc.).

The criteria and their weight were established based on the socio-demographic profile of the IDUs living in Bucharest. The profile was determined on the basis of the latest bio-behavioural survey (2011) conducted by the National Antidrug Administration, UNODC and RAA.

Eight respondents (two women and six men) were recruited pursuant to the criteria and agreed to participate in the discussion.

RESULTS

Background information of the participants

The participants included:

- 1) Laura (32), graduated from the 6th grade, unemployed; faces the risk of becoming homeless (has lived on the streets for a few days; is going to live temporarily with one of her children at the house of a relative, also an IDU). Never used ethnobotanicals. Used heroin for 14 years and enrolled in the OST programme in January 2011.
- 2) Nae (34), graduated from the 8th grade of a special school (however, claimed to have graduated from upper secondary school), unemployed, with a history of psychiatric treatment and imprisonment; living in overcrowded homes. Used heroin for eight years and for the last two years has also injected “legal drugs”. In December 2010 enrolled in the OST programme at the Titan Centre. Has a history of methadone substitution therapy (in 2007). Has experienced serious neuropsychological problems due to the use of “legal drugs”.
- 3) Iulian (22), graduated from the 10th grade, unemployed. Used heroin for seven years and enrolled in the OST programme one year ago. Occasional user of “legal drugs” (for the last two years).
- 4) Alin (30), upper secondary school graduate (from the 12th grade), taxi driver. Never used ethnobotanicals. Used heroin for ten years and enrolled in the OST programme in June 2011. Diagnosed with TB two years ago. Completed six months of TB treatment. Currently undergoing regular examinations (every six months).
- 5) Gicu (23), graduated from the 4th grade, unemployed, with a history of imprisonment; living in an overcrowded house. Used “legal drugs” for about 1.5 years. Following the advice of his friends began injecting heroin in order to overcome his dependence on ethnobotanicals. Currently enrolled in the OST programme (has been a participant for about one year).
- 6) Narcisa (24), graduated from the 10th grade, unemployed. Used heroin for 11 years and enrolled in the OST programme in January 2012. Has also used “legal drugs” during the last four years.
- 7) Bogdan (25), graduated from the 2nd grade, unemployed. Has never used ethnobotanicals. Used heroin for five years and enrolled in the OST programme in July 2011.
- 8) Aurel (24), currently studying in the 10th grade, attended vocational training to become a professional driver and chef. Used heroin for eight years and enrolled in the OST programme in January 2011. States that he has been injecting “legal drugs” occasionally over the last two years.

Results of the focus group discussion

Participant knowledge about TB and HIV

- The first time for most participants to hear about HIV was when they accessed the harm reduction services provided by ARAS. Hepatitis C (HCV) was however more notorious, since HCV is significantly more prevalent among the IDUs living in Bucharest.
- All the participants were able to name the main HIV transmission channels (sexual contact and sharing syringes) and they believed they had sufficient HIV-related knowledge to protect themselves.
- At the same time, almost half of the participants proved that they did not truly take in the health-related information they received at the centre. The participants started discussing the sources of various diseases (such as HIV, HCV and even TB), revealing that on the streets, their peers (i.e. the opinion leaders of the IDU community) believe that “everyone is born with all the diseases, but not all diseases are triggered in all individuals” (B., male, 25).
- When enquired by the moderator about the factors that trigger diseases, the participants who believed in the idea pointed out lifestyle choices:

Moderator: “How did you get HCV?”

“I did not eat properly, I did not sleep enough, I took drugs and my liver suffered.”

(A., male, 24)

- Four participants also stated that according to their experiences and the information they have acquired, heroin use contributes to suppressing and/or reducing the symptoms of various illnesses:

“I fell ill [with TB] one month after I quit heroin and enrolled in the methadone substitution treatment.”(A., male, 30)

“The drugs [heroin] keep the virus from developing. When you quit drugs you fall ill, because your body gets weak.” (B., male, 25)

“When I had a fever I would inject [heroin] and then I was as good as new. I didn’t feel the fever or the pain anymore” (I., male, 22)

- Except for one participant who was diagnosed with and treated for TB two years ago, only four other respondents reportedly knew some facts about TB. They mentioned “saliva”, “air” and “close, face-to-face contact” as transmission channels. They identified “violent cough”, “coughing up blood”, “weight loss” and “heavy perspiration” as symptoms of TB. One respondent also mentioned that “TB treatment lasts for six months” and another said that TB could not be transmitted through “sexual contact, sharing a meal or a drink with someone who is infected”.
- According to the assessments of the participants, (except one with TB history) TB-related knowledge was too poor/insufficient to help them to protect themselves.

Disclosing a HIV/HCV/TB diagnosis in the community

- All the participants agreed that should an IDU be infected with HIV or HCV, he/she should inform other IDUs or the doctor of his/her condition: “I tell my injecting buddies that I have HCV and they shouldn’t use my syringe.” (A., male, 24)
- None of the participants personally knew an HIV patient, but all of them had heard about the spread of HIV among the users of ethnobotanical drugs.
- Two participants (except one with TB history) mentioned that their family members have been diagnosed with TB: the sister of one, also an IDU, stopped getting her TB treatment and died because of health complications; the father of another, diagnosed with TB during the respondent’s childhood, completed his course of treatment. Nevertheless, neither of the two participants (L., female, 32, and B., male, 25) was able to explain how their relatives became infected with TB.
- The participant with TB history was the only one aware of the stigma surrounding TB patients and understood the importance of challenging it: “Years ago you could die from TB. Many people are afraid, they don’t admit they have the disease and instead claim to have pneumonia. They are ashamed of their illness. But [TB] is treatable; you don’t have to be ashamed. TB is dangerous because of the shame [attached to it]: you can catch it from people who don’t come clean about their illness.” (A., male, 30)

Access to HIV prevention, diagnosis and treatment services

- The participants knew that they could get free rapid tests for HIV, HBV and HCV at the centre. All the participants had been tested at the centre, some even more than once: “When I was using [heroin] I was regularly tested for HIV at the centre.” (N., male, 34)
- When their IDU friends ask them about syringe exchange programmes, methadone substitution therapy or HIV/HBV/HCV testing, the respondents refer them to the centre.
- Although they did not personally know anyone living with HIV/AIDS, the participants assumed that HIV treatment could be obtained at the infectious disease hospital, but it would be very expensive.¹ Only two respondents knew that ARV treatment is free of charge.
- When asked about HIV treatment, the respondents said the following: “it prolongs your life” (I., male, 22), “it kills the microbes” (L., female, 32), “it keeps the virus at a certain level” (B., male, 25), “it boosts your immunity” (N., female, 24).

Access to TB diagnostics and treatment services

The participant with TB history (A., male, 30) was the only one who had ever sought out TB diagnostics and treatment services. According to his experiences:

¹ According to national guidelines, ARV treatment is administered to all HIV patients who are eligible according to a set of medical/immunological criteria.

- The services are free of charge and available in every city. TB treatment is administered as follows: the first three weeks in a hospital, and then up to six months at home.
- The first three weeks in hospital are compulsory. The respondent reported to have heard that the TB patients who quit treatment during the first three weeks were brought back to the hospital by police force.²
- The participant also knew that after treatment, the TB unit staff makes home visits to check if the former patients are well and live in appropriate conditions.
- After three days since initiating TB treatment, the patient is not infectious anymore – he/she can stay in the same hospital room as other (non-TB) patients.³
- The infection returns if the treatment is discontinued.
- About TB treatment: “The Koch’s bacillus is very strong. The treatment does not kill the bacillus, just puts it to sleep. [The Koch’s bacilli] are like little worms in a sack.”

All the participants assumed that if they ever wanted to access TB diagnosis services they would contact the harm reduction services for IDUs or go directly to an infectious disease hospital – if nothing more, the staff there would know where to refer them.

Assessing the risk of becoming infected with HIV or TB

- All the participants agreed that they could get TB from anyone (friends, family, co-workers etc.): “I believe I caught it from a customer. [...] All the members of my family were tested for TB after I was diagnosed and none of them had the disease.” (A., male, 30, working as a taxi driver)
- However, the participants did not believe that they have been exposed to TB while injecting drugs, despite the fact that most drug injecting activities are performed indoors, usually in a room with several other persons.
- Only one of the participants admitted to have been exposed to the risk of contracting HIV while injecting ethnobotanical drugs in a group of IDUs, one of whom, as he later learned, was HIV positive. He also believed that the proportion of HIV infections would soon become comparable to the number of HCV infections, especially among IDUs who inject “legal drugs”.

² The respondent is probably referring to the application of article No. 352 of the Penal Code, according to which, acts that prevent or impede measures designed to fight the transmission of infectious diseases (including TB) are punished with a prison sentence ranging from six months to two years or with a fine. If intent is not proven, the punishment shall be a fine or imprisonment from one month to six months. However, we have no reports of this law having been enforced recently. Nevertheless, this method of ensuring compliance with TB treatment was widely employed in the country during the communist period.

³ TB patients usually become non-infectious after 2–3 weeks since starting treatment.

Assessing the gravity of infections

- All the participants agreed that HIV was the most serious infection that an IDU could contract; even if it is manageable (with treatment), those infected will eventually die from it.
- Hepatitis C and TB are equally serious, but less so than HIV. According to the participants, “the body recovers with the help of interferon” (referring to hepatitis C) and with TB treatment, totally eliminates the disease from the body.

Use of “legal drugs”

- Five of the eight respondents also had a history of injecting “legal drugs” for periods ranging from three months to four years.
- Four of the participants (three males and one female) had experienced mild to severe neuropsychological and psychiatric problems while injecting ethnobotanicals (paranoia, psychosis, sometimes leading to being committed into a psychiatric ward).

II Report on the service provider focus group discussion

METHODS

Time: March 15, 2012, 1 h 37 min

Organised by: Romanian Angel Appeal Foundation (RAA)

Venue: Romanian Angel Appeal Foundation (Bucharest)

Conducted by: Fidelie Kalambayi, RAA, co-moderator: Cristina Enache, RAA

Procedure of the focus group discussion (methodology)

Invitations were sent to the main organisations (non-governmental and governmental) working in the field of HIV prevention among IDUs. All these organisations are based in Bucharest, but some of them also work in other cities. Six people responded to the invitation. Three others, who were initially unable to attend the group, eventually did participate (one psychologist working in one of the prevention centres of the National Antidrug Administration, one medical doctor working in an OST centre run by the Prof. Dr. Matei Bals National Institute for Infectious Diseases in Bucharest and ARAS, and one medical doctor from the National Administration of Penitentiaries).

RESULTS

Background information of the participants

The participants included:

- 1) C.M. (33), a medical doctor at Samu Social. Samu Social is an NGO providing emergency social and medical services for adults living on the streets of Bucharest (i.e. food, clothing, washing opportunities at the day centre, basic medical care, vocational counselling, referral to other services). Within the organisation, C.M. provides emergency medical services to the homeless who also use drugs (but no TB diagnosis or treatment). Work experience: ca. ten years in HIV outreach services targeting IDUs, sex workers (SW) and street children. Experience in referring IDUs to TB services (upon their request/due to violent coughing).
- 2) D.P. (30), a social worker, outreach coordinator at the Romanian Anti-AIDS Association (ARAS). ARAS is the oldest Romanian NGO working in HIV/AIDS prevention and the most important provider of harm reduction services for IDUs. Work experience: ca. ten years in HIV outreach services targeting IDUs, SWs and street children. Experience in referring IDUs to TB services (upon their request/due to violent coughing).
- 3) A.D. (33), a counsellor, Executive Manager at the Sens Pozitiv Association – an association of people living with HIV. The organisation mainly provides HIV-related information and post-test counselling services to people newly diagnosed with HIV (including IDUs). Work experience: ca. five years of experience in providing services to people living with AIDS.
- 4) A.V., a legal counsellor at the Sens Pozitiv Association. Work experience: less than one year in HIV-related psychosocial support services. Personal experience in accessing TB diagnosis/treatment services.
- 5) C.C., a psychologist at the HIV/AIDS department within the Prof. Dr. Matei Bals National Institute for Infectious Diseases in Bucharest. Work experience: ca. five years of experience in providing services to people living with AIDS. The participant has had/has clients with a HIV/TB co-infection.
- 6) V.C (32), a psychologist, coordinator of an OST centre (administered by ARAS). Work experience: ca. ten years of experience in HIV prevention services targeting IDUs, SWs and street children. Experience in referring IDUs to TB services (upon their request/due to violent coughing).

Results of the focus group discussion

Participant knowledge about TB and HIV

- All the participants had extensive experience in HIV prevention/diagnosis/treatment services targeting IDUs: HIV-related information, education and communication, HIV counselling and testing, syringe exchange programmes, condom distribution, HBV and HAV vaccination, psychosocial counselling for IDUs with or without HIV, opiate substitution therapy.
- Over their careers, all the participants had received extensive training (formal and informal) about the prevention of various types of HIV and intervention activities targeting IDUs (i.e. post-diagnostic counselling, HIV counselling and testing, syringe exchange programmes etc.)
- The participants with experience in outreach services believed that the risk of contracting TB was lower when/if: they mostly worked outdoors (on the streets) and kept contacts with IDUs short (less than 30 minutes).
- They also engage in what they believe to be risk-reducing strategies: keeping a safe distance from every client during conversation, making sure that the client is not breathing or coughing in their face.
- All the participants showed keen interest in the existence of any rapid TB diagnosis/screening test that could be used in outreach.

Work experience related to TB services

- All the participants had encountered clients who had been diagnosed with TB or were TB suspects. Although their organisations do not offer TB diagnostics services, they knew that they could refer IDUs diagnosed with TB or TB suspects to the Marius Nasta National Pneumophthisiology Institute (for diagnosis or treatment).

Training experience related to TB diagnosis/prevention/treatment

- The participants with experience in outreach services for IDUs had received in-service training on protecting themselves from a potential TB infection and on places where they could refer clients diagnosed with TB/potential TB suspects. This was an informal training provided by one of the outreach team members with a medical background.
- The participants had never received specific training regarding the prevention/diagnosis/treatment of TB among IDUs, but expressed keen interest in undergoing such training – especially about TB prevention and TB screening and referral to non-medical professionals working in outreach services and low-threshold clinics.

Assessment on the prevalence of TB among the IDUs in Bucharest and the risk of TB transmission

- The participants believed that there was a significantly high number of IDUs with TB (due to their poor living conditions and weak immunity caused by chronic drug use and co-infections).⁴
- Participant No. 2 shared the following anecdotic example: in 2011 their outreach team started working with a new group of IDUs and only after four months of providing them with outreach services (syringe exchange, condom distribution etc.) was the team informed (by one of the clients) that four or five of them had actually been diagnosed as MDR TB cases but refused further treatment.

The access of IDUs to HIV prevention and OST services

- The participants believed IDUs to have fairly good access to most existing HIV prevention/diagnosis/treatment services.
- However, harm reduction services provided in outreach or low-threshold clinics have been running almost entirely on international funding. After the end of the GFATM Round 6 programme in 2010 and the UNODC programme in December 2011, these services have been affected by a lack of funding and as a result, decreased their coverage.
- IDUs can access free HIV counselling and testing (only rapid testing) or fee-charging testing services (rapid testing or ELISA testing).
- Access to HIV treatment is equal to everyone in Romania and is only provided through infectious disease hospitals.
- Access to HIV treatment is complicated due to adherence problems, treatment interaction issues (e.g. interaction of the OST treatment with HCV treatment and HIV treatment) and the lack of functional integration with OST services.
- The access of IDUs to OST services is limited due to the insufficient number of available places⁵ and the IDUs' lack of identity documents (and consequently, health insurance).

The access of IDUs to TB services

- Outreach workers (as well as the employees of low-threshold clinics) refer IDUs to TB diagnosis/treatment services if they have been coughing for weeks (or report coughing up blood), are breathing heavily, are underweight or report persistent sweating.

⁴ According to the latest bio-behavioural survey among the IDUs living in Bucharest (2011), the sample surveyed (N=385) registered a 88% HCV prevalence, as well as a 3% prevalence of HBV.

⁵ According to the latest report of the National Antidrug Administration (2011), OST services, public and private, are able to accommodate ca. 400 people. The estimated number of IDUs living in Bucharest alone was, as of 2010, 18,316 (95% confidence interval) (source: National Antidrug Administration, National Report Regarding the Drug Situation, 2011).

However, this type of screening and referral is provided *ad hoc* – these services are not officially a part of the harm reduction package offered by most NGOs.

- The participants nevertheless believed that they were not properly equipped to actually make valid decisions on TB symptoms among IDUs (i.e. some of them are underweight because of their chronic drug use, others cough violently because of their excessive smoking etc.).
- All the participants were interested in knowing whether there was a rapid TB diagnosis/screening test that could be used in outreach. They strongly believed that conventional TB diagnostics services did not match the social and behavioural profile of most IDUs. The access of IDUs to TB diagnosis (and treatment) can be limited by the following:
 - Lack of identity documents (and consequently, health insurance). The participants reported that they knew of cases in which IDUs without any documents were refused diagnosis and treatment because all the costs associated with a TB case have to be accounted for and connected to a personal identification number (according to Romanian law).
 - Most of the time, the clients are not sober or motivated enough to get tested after being referred to testing by an outreach or low-threshold clinic employee.
 - Users of “legal drugs”⁶ develop serious neurocognitive problems, which affect the quality of their contact with the surrounding environment.
 - IDUs do not take advantage of the appropriate personal/social/professional support offered to go through the process of testing, diagnostics and treatment.
- All IDUs who test positive for HIV are also tested for TB and other infections at the infectious disease unit.
- TB treatment schemes are not coordinated with HIV and/or OST treatment schemes. As a result, IDUs tend to discontinue one of the treatments (most often the TB treatment). The situation is even more difficult when the IDU is also pregnant or injects “legal drugs”.

The relevance of TB infection among the IDUs in Romania

- The participants acknowledged that among EU countries, Romania has the highest prevalence of TB among the general population; they also agreed that it is possible that TB affects a significant number of IDUs.
- The participants believed the detection of TB and disclosing a TB diagnosis to be the most important measures regarding IDUs. However, they were reluctant about the possibility of including TB services in the HIV prevention/treatment package currently offered by service providers targeting IDUs. In their opinion, the efforts currently made

⁶ Synthetic psychoactive substances that are not intended for human consumption – i.e. bath salts, sprays, solvents, pesticides etc. According to the latest behavioural serosurveillance survey (UNODC, NAA and RAA, 2011), 76% of the IDUs living in Bucharest had also been using “legal drugs” during the last 30 days preceding the survey.

should focus more on consolidating and expanding the existing HIV prevention/treatment services for IDUs and less on diversifying the services (i.e. adding TB services for IDUs).

- The respondents believed that until TB treatment services are adjusted to the specific needs of IDUs (i.e. outreach DOTS or low-threshold TB treatment centres), there is an increased risk of MDR development in the IDU community. The reason being that IDUs find it difficult to comply with the strict TB treatment; their adherence is challenged even further if they are also enrolled in OST or any other treatment (HIV, HCV, other STIs).

Recommendations on improving the level of knowledge and access to health care in the field of HIV and TB

- Develop an administrative procedure that would facilitate access to OST and TB services even for the IDUs who do not have identity documents and health insurance.
- Design services for IDUs who also use “legal drugs”.
- Develop/consolidate accompaniment and referral services at the level of municipalities and/or NGOs currently working with IDUs.

Trainings for specialists, i.e. outreach workers (social workers, psychologists), TB diagnosis and treatment unit staff, employees from HIV treatment units working with IDUs:

- TB screening and referral by non-medical staff (in an outreach or low-threshold clinic for IDUs);
- TB diagnosis disclosure;
- Adherence counselling (for TB treatment or combined treatment – HIV, TB, HBV and other STIs).

