HIV/AIDS treatment and care in Estonia

Evaluation report June 2014













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Contents

1.	Ex	ecutive Summary	1
2.	Int	troduction	3
2	.1	Country epidemic: latest trends	3
2	.2	Investments in the national HIV/AIDS response	4
2	.3	General health care	4
2	.4	People who inject Drugs	5
3.	Pu	rpose and objectives	5
4.	Me	ethods	6
5.	Fir	ndings — strengths and achievements	6
5	.1	Comprehensive national HIV/AIDS strategy	6
5	.2	Treatment guidelines	7
5	.3	Testing guidelines	7
5	.4	OST and NGO support	7
6.	Fir	ndings — weaknesses and challenges	8
Prio	rity	y area 1: Surveillance	9
Prio	rity	y area 2: Optimizing HIV testing1	2
Prio	rity	y area 3: Adapt service delivery1	7
Prio	rity	y area 4: Optimize drug regimens and reduce costs	24
7.	Cro	oss-cutting issues	!6
7	.1	Sustainability and access to services	26
7	.2	Human rights	27
8.	Re	commendations	!8
8	.1	Main recommendations 2	28
8	.1	Specific Recommendations	30
9.	Re	ferences	32
Ann	ex ˈ	1- Simple calculation of undiagnosed population	;4
Ann	ex ź	2 — Terms of References	6
Ann	ex (3 – Review team and informants	9

List of abbreviations

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapy
ARV	antiretroviral
CBT	cognitive behavioural therapy
CD4	cluster of differentiation 4
DOT	directly observed treatment
EHIF	Estonian Health Insurance Fund
EU	European Union
EEA	European Economic Area
GDP	gross domestic product
GP	general practitioner
HCV	hepatitis C virus
HIV	human immunodeficiency virus
HTC	HIV testing and counselling
ID	infectious disease
MoSA	Ministry of Social Affairs
NGO	nongovernmental organization
NIHD	National Institute of Health Development
NNRTI	non-nucleoside reverse-transcriptase inhibitors
NSP	needle and syringe exchange programme
OD	overdose
OST	opioid substitution therapy
PI	penitentiary institute
PI/rtv	protease inhibitor/ritonavir
PLHIV	people living with HIV
PWID	people who inject drugs
STI	sexually transmitted infection
ТВ	tuberculosis
UNAIDS	the Joint United Nations Programme on HIV/AIDS
UNODC	The United Nations Office on Drugs and Crime
VCT	voluntary counselling and testing
WHO	World Health Organization

1. Executive Summary

This WHO country mission was performed in May 2014 to assess the achievements, strengths and shortcomings in the implementation of the Estonian national programme on HIV/AIDS treatment and care, and to generate strategic recommendations for improving key outcomes and impacts. The mission focused specifically on providing recommendations on the response of the health system to the many new HIV infections, on organization of procurement and provision of ART, and on improvement of prevention interventions.

The mission found that HIV will remain a public health problem in the coming years in Estonia. This was echoed by all involved national stakeholders in the field. The epidemic is concentrated among people who inject drugs (PWID), but there are signs that it is increasingly affecting the general population. A worrying observation is the tendency that people with HIV are diagnosed late, that a large share starts treatment late; and there are many examples of non-adherence to treatment or long-term treatment interruptions. The problem of linkage and retention in care, particularly for the PWID population, needs urgent attention. The current health care system is not functioning to an extent that provides the PWID community with adequate treatment options and support. This needs to be addressed as high a priority in order to halt the HIV epidemic.

The treatment cascade presented in Fig. 1 (p. 11) shows two major challenges in the care continuum: firstly that the number of people diagnosed is considerably higher than indicated in the figure; secondly, that among those diagnosed, only about 1 in 4 are retained in care. This means that the majority of those infected – the reservoir of further transmission – are still outside the treatment and care system, which explains the continued relatively high onward transmission. Furthermore, for those already diagnosed, it means that they start treatment very late, straining the hospital system, as they have already developed life-threatening AIDS related diseases.

Estonia's national HIV/AIDS strategy 2006-2015 is comprehensive. Over the years substantial progress has been made to fulfil its strategic objectives and subobjectives. Health care and social affairs are coordinated by the Ministry of Social Affairs (MoSA), which has formed a high-level multisectoral advisory body, the Governmental HIV and AIDS Committee, as a forum for developing and monitoring the country's response to HIV/AIDS treatment and care.

Main findings

The HIV epidemic in Estonia is mainly concentrated among specific most-at-risk subpopulations, mainly people who inject drugs (PWIDs), sexual partners of PWIDs, commercial sex workers and men who have sex with men. Such risk groups are hard-to-reach under normal circumstances, but given the levels of social inequality and stigma that seem to exist, it remains very challenging to gather data on these subpopulations in order to understand the extent of the size and characteristics of the epidemic. Attempts to estimate the size of the infected population using back-calculation-based methods would currently be difficult given the lack of data on immunological status at HIV diagnosis. By using the "London method 1" the report gives a crude estimate for the total number of people living with undiagnosed HIV in Estonia to be 5 477, which

implies that the total number of PLHIV in the country is 13 500 instead of the UNAIDS' based estimations on 7 200-11 000 for 2012.

In 2012 more than 58 000 HIV tests and in 2013 more than 69 000 were performed on people based on clinical indication or risk group. However, there is no detailed registry with information on the reasons for testing. The percentage of new HIV cases belonging to the category of late diagnosis is an important indicator for the efficiency of the actual testing procedures and policies. Around 30-40% of new HIV diagnoses are considered to be late presenters (with CD4 cell counts below 350), although data on CD4 count at diagnosis is not yet collected systematically. Better targeting of HIV testing towards most-at-risk groups as well as more frequent use of rapid tests is thus highly recommended.

Most-at-risk populations face multiple challenges in accessing health services. In Estonia the largest most-at-risk group are people who inject drugs; part of this population can be reached through needle and syringe programmes and opioid substitution therapy sites, and offered HIV testing and counselling. It is important to improve the quality of information, counselling and referral services, including informing about OST as beneficial evidence-based treatment. All OST sites and most NSP sites provide social counselling, but there is a great need for additional social assistance to navigate through the existing municipal social support system, as people who inject drugs often have social problems, are unemployed, and often do not speak Estonian.

Estonia's public procurement system, forecasting and supply management seem to be working properly, with no reports of stock-outs. It seems that the procurement plan/selection of ART drugs can be simplified according to WHO guidelines with less first-line drug options. The use of PI/rtv as part of the first-line regimen should be decreased, guidelines and regimens simplified; and the use of single-tablet fixed-dose combination increased for better retention in care and adherence.

The mission found a rather negative attitude among many health care providers as well as among clients to PWIDs and the effect of OST. Acknowledging the evidence of the effectiveness of OST programmes to increase adherence to ARV, it is surprising to see this attitude. There is an urgent need to consider how to tackle this situation; and leadership from both clinical society as well as political leadership is needed to change the situation. It is highly recommended to duplicate the experience from the West-Tallinn Central Hospital's OST programme providing directly supervised ARV dispensing to other regions of the country.

Main recommendations

- Strengthen the surveillance of the HIV epidemic in the country, which lacks important indicators, and ensure that available data is adequately analysed and used to inform policy decisions on priorities within the national HIV programme.
- Scale-up HIV testing targeting key most-at-risk populations.
- Ensure that health care providers involved in the care of PWID embrace OST as an indispensable means to achieve appropriate care of this population group.
- It is highly recommended that the experience from the West-Tallinn Central Hospital's OST programme providing directly supervised ARV dispensing is duplicated to other regions of the country.
- Introduce strategies to address the insufficient enrolment and retention in HIV care and ART, including shared care programmes, integrated services, including collaboration between HIV clinics and NGOs, TB hospitals and substance use disorder care units as well as scaling up harm reduction programmes and OST coverage.
- Simplify and optimize ARV drug regimens for a cost-effective public health approach to treatment of HIV in the country.

2. Introduction

2.1 Country epidemic: latest trends

Estonia has a population of approximately 1.3 million as of May 2014. The estimated HIV incidence in the general population is 23.5 per 100 000 populations, which places it among the five EU/EEA countries with the highest rates of HIV infection.

The annual number of new HIV cases in Estonia peaked in 2001 with 1 474 new cases, and has since then been decreasing to 325 new cases in 2013. By the end of 2013, Estonia had reported a cumulative total of 8 702 HIV cases (5 866 men and 2 836 women) (17).

The percentage of new HIV cases detected among youth (15-24 years old) has decreased from 78% in 2001 to 15% in 2013, and the average age of newly diagnosed HIV cases increased (17). From 2000-2010, almost 70% of all new HIV cases were diagnosed among men, but in recent years the percentage of infected women has risen to 40% (1). Data on transmission routes are not complete, but a 2012 study found that 35% of new infections were due to injecting drug use, 62% due to heterosexual contact and 2% due to mother-to-child transmission (10).

There are important local variations in the country epidemic. The most affected regions are the capital Tallinn and Ida-Viru County in North Eastern Estonia, which both have high prevalence of people who inject drugs. Here the numbers of new HIV infections are 46 and 81 HIV cases per 100 000 population, respectively, as compared to 2 per 100 000 in the rest of Estonia (17).

Around 30-40% of new HIV diagnoses are considered to be late presenters (with CD4 cell counts below 350), although data on CD4 count at diagnosis are not collected systematically (2).

2.2 Investments in the national HIV/AIDS response

In Estonia, health care and social affairs are coordinated by the Ministry of Social Affairs (MoSA), including Estonia's response to HIV. Since 2007, the country's HIV response is funded mainly through governmental contributions, co-funding from municipalities (e.g. to run counselling sites), and through limited international contributions (EU, WHO).

Estonia has a GDP per capita of 13 172 euros and 3.6% of total GDP is spent on human health and social work activities (2012).

The Ministry of Social Affairs has formed a high-level multisectoral advisory body, the Governmental HIV and AIDS Committee, as a forum to develop and monitor the country's response to HIV/AIDS treatment and care. The committee members are representatives of all relevant ministries, municipalities and counties, Parliament, the office of the Prime Minister, the four thematic working groups, PLHIV and youth organizations' union (1). The committee meets twice a year and the Ministry of Social Affairs works as secretariat to the committee. The committee has four thematic working groups (prevention, harm reduction, treatment and care, monitoring and evaluation), which are open to specialists and both governmental and nongovernmental organizations working in the field of HIV/AIDS. The working groups focus on reviewing current plans, as well as developing new proposals to be presented to the committee.

In addition, the Ministry of Social Affairs has established a special committee, which approves annual ARV and TB medicine procurement plans (volume, prices, schedule, forecasting of needs) and conducts market research to purchase the drugs. Procurement is regulated by legislation and done by open tender. The drugs, which are delivered to a central warehouse by the wholesalers, have to be registered in more than one EU country or pre-registered with WHO (2).

2.3 General health care

Health care is financed through the national mandatory health insurance system, Estonian Health Insurance Fund (EHIF), which is the core purchaser of health care services. In addition, the Ministry of Justice coordinates and manages health care in prisons and the Ministry of Social Affairs' budget covers emergency health care costs, which every person in the territory of the Republic of Estonia is entitled to according to the Health Services Organization Act (17). The EHIF accounts for around 70% of the health budget and is largely financed by salary-based payments from employers (2).

Around 94% of the population is covered by the EHIF. The 6% uninsured are mostly working-age population (20-60 years) who are economically inactive or unemployed (3). Due to the economic crisis in 2008, EHIF experienced some budget cuts, which they dealt with by applying a coefficient to its payments (2). A modest user fee is charged for consultations and for long-term services, which may act as a barrier for people with limited resources to access adequate health care.

It is fair to say that many of the 6% without health insurance belong to the group of PWIDs, who are not all necessarily available to the labour market. A disability pension is available for PLHIV with CD4 count is <200, but this would be removed when the CD4 count rises as a result of starting treatment. This is very counterproductive if you wish PLHIV to be retained on ARV.

2.4 People who inject Drugs

Current estimations, based on expert opinion, suggest that there are 9 000 PWID in Estonia, including 6 000 opioid injectors (35).¹ Opioids (including Fentanyl and heroin) remain the predominant injected substances, but mixed use of drugs, including amphetamines, are increasingly common (28). One study found that 71% of PWID injected amphetamines, though not necessarily on daily basis (12).

Studies using respondent-driven sampling (RDS) and carried out in Narva in 2010 and in Kohtla-Jarve in 2012 suggest that the number of new injectors has significantly decreased. Apparently PWID has become a population group around 30 years of age, predominantly Russian speaking, socially disadvantaged males, with a history of injecting for 10 or more years on average (12,15).

Among PWID in Narva 20% shared syringes or needles and 24% shared other equipment (filters, cotton pads, and mixing dishes) during the past four weeks. The most common reason given by PWID was that not having a clean syringe at the time of the injection. 15% of HIV positive PWID shared their syringe with others during the last six months. 89% of Narva PWID injected drugs in prison and three quarters of them shared injecting equipment (on average used by four different people). (12). The Kohtla-Jarve PWID study found a 62% HIV prevalence, 75% were HCV-antibody positive and 1.5% reported having had TB (15).

3. Purpose and objectives

The purpose of this evaluation of HIV/AIDS treatment and care was to assess the achievements, strengths and shortcomings in the implementation of the Estonian national programme on HIV/AIDS treatment and care; and to generate strategic recommendations for improving key outcomes and impacts.

A specific objective was to provide recommendations on how the medical system can respond to a situation with many new infections; how the procurement and provision of ART can be organized, and how prevention work can be improved.

¹ Kristi Ruutel, personal communication, mission meeting May 16, 2014.

4. Methods

The evaluation builds on a desk review and a country mission which took place from 12-16 May 2014 in Tallinn, Narva and Kohtla-Järve, Estonia.

Readily available information on the country epidemic and HIV/AIDS treatment and care has been drawn from secondary sources including journal articles, national publications, WHO reports etc.

During the country mission, the WHO experts met with advisors of the Ministry of Social Affairs, the National Institute for Health Development, health professionals at Narva hospital, Ida-Viru Central hospital and West Tallinn Central Hospital, Estonian Health Insurance Fund, the National Health Board, Society of Family Doctors, and representatives from the civil society organizations Estonian Network of PLHIV, "Sind ei jäeta üksi" and "Me aitame sind" (see complete list in Annex 3).

5. Findings – strengths and achievements

5.1 Comprehensive national HIV/AIDS strategy

Estonia's national HIV/AIDS strategy 2006-2015 is comprehensive and, over the years, substantial progress has been made to fulfill its strategic objectives and subobjectives.

National HIV/AIDS Strategy				
By 2015 new HIV cases per 100 000 people	The country has experienced an important			
is down to 20	decrease in new HIV cases from the 2004 baseline			
	indicator of 55 to around 25 in recent years.			
By 2015 the share of pregnant women	This target was almost reached in 2012 where the			
infected with HIV among all pregnant	percentage was 1%			
women is <1%				
Permanent decrease in the number of new	This objective was reached in 2013 with 96 new HIV			
HIV cases per 100 000 15-29 year olds from	cases registered among 15-29 year olds, but it is			
200 in 2004 to 100 by 2015	not yet confirmed that it is a permanent decrease			
A stabilization of the spread of HIV among	2013 data from a survey among PWIDs in Tallinn			
injecting drug users in 2009 and 2015 at the	found a 58% HIV prevalence, which suggests a			
estimated 2004 level of 62%	slight decrease.			
Number of injecting drug users undergoing	From the baseline indicator of 400 in 2005, the			
opioid agonist substitution maintenance	country has experienced an increase in the number			
therapy	to 1 157 in 2012 – thus surpassing the set target of			
	900 by 2015			
100% of PLHIV in need of treatment are on	In 2013, 2 691 PLHIV were on ART compared to			
ART	estimations of 4 400 in need of treatment			

The national HIV/AIDS strategy 2006-2015 is slowly being replaced by the National Health Plan for 2009-2020 (NHP), which assembles and integrates several of the previously independently existing thematic development plans and strategies.

With regards to surveillance and data collection, doctors and laboratories carrying out HIV tests have since 2009 been required to submit data on new HIV cases through the NAKIS online reporting system (21).

5.2 Treatment guidelines

European and WHO guidelines are being followed with regards to Adult ART guidelines, Prevention of Mother-to-Child Transmission and Pediatric ART guidelines (22), and specific national guidelines exist for provider initiated testing and counselling and for prevention of perinatal transmission (14,11).

There is a national commitment to provide ART to all PLHIV who need it and considerable progress has been made to reach this target (2). Hospitals and clinics provide ART, and by February 2014 2 691 adults and children were receiving antiretroviral therapy (ART).

5.3 Testing guidelines

HIV testing is mandatory for blood and organ donors (and in some cases for individuals serving in the armed forces) and recommended for pregnant women, prisoners, people with TB, STIs, hepatitis, a history of PWID or engaged in risky sexual behaviours (1). In 2013, more than 212 000 HIV tests were conducted on 150 000 people (of which 100 000 were pregnant women and blood donors) – including 4-5 000 people in prison (13). In years 2004-07, approx. 100 000 people (not pregnant women and blood donors) were tested annually; this number declined dramatically in 2008 to the current 50 000 annual tests (1).

Testing is conducted in health facilities by medical personnel. People with health insurance get free HIV tests at the general practitioners or specialists, whereas people without insurance or who chose to get tested anonymously can go to other free testing options (counselling centres, etc.) (17). There is a network of AIDS counselling centres (ACCs) across the country – 11 in total – that provide free, anonymous HIV testing, as well as hepatitis B and C counselling and testing (17). Blood samples are tested at 33 laboratory facilities across the country, and results are normally available within three working days.

5.4 OST and NGO support

Civil society and NGOs provide a range of services, in particular to marginalized groups such as PWID, sex workers, HIV testing and counselling (HTC) programmes, and work in advocacy and reduction of stigma and discrimination (7). In 2011, approx. 11% of the national budget for the HIV response and 50% of the harm reduction budget were spent on activities implemented by civil society – both as direct support and as contracts awarded through tenders, e.g. for running needle and syringe exchange programs (7). Several civil society organizations are involved in counselling

and support to PLHIV and other most at-risk groups. One example is the Estonian Association of Sexual Health, which coordinates youth counselling centres where STI and HIV testing, counselling and treatment is provided free of charge for people up to 24 years of age (17). However, NGOs targeting sex workers or managing needle and syringe exchange programs do not routinely offer HIV testing, but refer people to anonymous VCT sites (17).

6. Findings – weaknesses and challenges

The treatment cascade below shows some of the challenges of HIV/AIDS treatment and care in Estonia, which will be dealt with stepwise in this chapter. As can be seen in the cascade, there are two major challenges in the care continuum, firstly that the number of people diagnosed is considerably higher than indicated in the figure; secondly, that among those diagnosed, only about 1 in 4 are retained in care. This means that the majority of those infected – the reservoir of further transmission – are still outside the treatment and care system, which explains the continued relatively high onward transmission. Furthermore, for those already diagnosed, it means that they start treatment very late, straining the hospital system, as they have already developed life-threatening AIDS related diseases.



Fig. 1: Estimated treatment cascade in Estonia, 2013 (13, annex 1)

There is a national commitment to provide ART to all PLHIV needing it. As seen in the table below a comparison of modelled need for first –line ART estimates and the actual number of patients receiving ART shows a treatment gap of 1 000-1 500 people in need of treatment but not on ART (1).

Year	PLHIV on ART (1)	ART estimated need (1)	Gap
2012	2647	4000+	1400 +
2013	2691	4400	1700
2014	3600	4500+	900 +
2015	4000+	4750	750

The number of PLHIV on ART is thought to be increasing in the coming years, however the above assumptions does not take into account the large number of undiagnosed people, many of whom will also be in need of treatment if diagnosed. As long as the people infected remain undiagnosed, the gap between those on ART and those in need of ART will not decrease.

Priority area 1: Surveillance

The HIV epidemic in Estonia is mainly concentrated among specific at-risk subpopulations, mainly PWID, sexual partners of PWID, commercial sex workers and men who have sex with men. Such risk groups are generally hard-to-reach under normal circumstances, and given the levels of social inequality and stigma that seem to be present, gathering data on these subpopulations in order to understand the extent of the size and characteristics of the epidemic remains very challenging.

The mission concluded that estimations of the total size of the HIV-infected population have been made by using only one method: Workbook & Spectrum (developed by UNAIDS). In brief, Workbook is a method to estimate adult HIV prevalence in the whole population. It is based on data from prevalence surveys and therefore requires information on the size of risk groups (risk groups with concentrated epidemics, as well as the background population with a low-level epidemic) and the prevalence of HIV amongst these risk groups. These estimates are then fed into Spectrum, alongside other demographic and epidemiological information to estimate the size of the infected population and those needing ART.

The main concern regarding the UNAIDS-based estimates for Estonia is the lack of accurate data on the size of the PWID population. Current estimations of the size of this risk group varies from 6 000 (28) to 9 000 (35), whereas the EMCDDA estimate was 10 000 to 30 000. Given that the prevalence of HIV among PWIDs is estimated to be 50- 70% (24), these numbers combined provide a huge range in the estimated number of HIV-positive PWIDs in Estonia. Further, national estimates of the size of the PWID population have suggested that in 2005, 2008 and 2009, the numbers were 15 675, 11 493 and 5 362 respectively (28). An actual decline in injecting drug use may of course have happened, but a two third decline seems fairly unlikely even accounting for emigration or deaths among PWID. Although the proportion of new HIV cases diagnosed among PWIDs seems to have fallen dramatically over time (now down to 20% in 2013), PWID still bear a disproportionate number of HIV infections. Therefore risk group size estimates are still key in producing accurate estimates using the UNAIDS-based method.

Attempts to estimate the size of the infected population using back-calculation-based methods would currently be difficult given the lack of data on immunological status at HIV diagnosis. Further, as anonymous HIV case reports were included in the total number until 2009, there is a risk of double-reporting of HIV cases, among the 8 702 cases diagnosed in total in Estonia by end of 2013 (from 2000-2008 approximately 30% of new cases were diagnosed anonymously (1)). Another concern is the underascertainment of deaths among people with HIV. From 1996-2013 the registered number of AIDS related deaths is 472, and from 2000-2013 the number of direct drug-related deaths is 1 401, which could be PLHIV related in approximately 50% of the cases.² There is also a group of people about whom not much is known; 6% of the population are not covered by the EHIF, the majority of whom are not in employment and who may be more likely to have HIV acquisition risk factors. There is the potential that such individuals could be a large part of the driving force behind the non-decreasing number of new HIV cases, due to lack of interaction with medical institutions, the inability to pay for clinic visits, low motivation or interest in health care, or perhaps reliance on disability benefits which they will only be eligible for if they have low CD4 count.

Data on use of antiretroviral drugs seem to be one of the most concrete sources of information, as the drugs are all stored and distributed by a single central system under the Estonian Health Board. The extent to which these drugs are actually taken by patients is, however, unknown. Approximately 11 to 14% of ART-experienced people interrupted or were lost to follow-up during the last year, in addition to anecdotal evidence that some ARV drugs are sold on the black market.

In order to inform trends in rates of HIV diagnosis, i.e. probability of being diagnosed with HIV, given that said person is HIV-positive, data on the uptake of HIV tests is important. Rapid HIV tests are mainly used at anonymous VCT/STI sites, youth counselling centres and by some NGOs in collaboration with health care organizations (*31*). Data on rapid testing included in the report for the National Health Plan show that in 2013 some 7 200 rapid tests were made at VCTs and another 7 200 at other locations.³ However, the details from these tests are not included within national statistics. Some data are available on the reasons for HIV testing (e.g. from VCT sites, (*31*)), although a clean-up of the number of options for this variable in 2009 has made this somewhat harder to interpret. Although the number of HIV tests conducted are higher than in most other EU countries (52 tests per 1 000 population if blood donors and pregnant are excluded, (*31*)), the fact that all pregnant women, regardless of risk, are recommended to get HIV tests doubted is different from the number of people tested. Additional funding for extra HIV tests to be conducted seems to be limited, although cost–effectiveness analyses could be conducted to evaluate the impact of further HIV tests on disability-adjusted life years (DALYS), averted, mortality and incidence.

 $^{^2}$ Data provided by Public Health Department Ministry of Social Affairs, 22. June 2014.

³ Data provided by Public Health Department Ministry of Social Affairs, 22. June 2014.

Continued efforts to record CD4 count at diagnosis are crucial and should be regarded as a high priority to improve the quality of surveillance data. Currently, data are available on CD4 count at first presentation to care, but this is limited to the people actually linked to care (in 2012-13, 92% of those diagnosed were linked to care within 90 days). Although linkage to care seems to be improving with time, in 2012-13 the median CD4 count at presentation was 305 cells/mm³ and 27% had CD4 count ≤200 cells/mm³. Only 39% had CD4 count >350 cells/mm³ at presentation.

Annex 1 shows a simple, illustrative calculation of the undiagnosed population, using the "London method 1". Applying this method, one crude estimate for the upper limit of the total number of people living with undiagnosed HIV in Estonia is 5 500, which would raise the total number of PLHIV alive in the country to 13 500 instead of the now estimated 9 000-10 000. However, this estimate requires future refinement when data are available on counts of new diagnoses restricted to those presenting with HIV symptoms.

In conclusion, the total number of undiagnosed PLHIV seems underestimated, the number possibly being considerably higher than reported.

Recommendations

- Available data should be thoroughly analysed and it is recommended to prioritize measures that ensure a comprehensive and extensive understanding of the problem.
- To improve the quality of surveillance data continued efforts to record CD4 count at diagnosis are crucial and should be regarded as high priority. Currently, data are available on CD4 count at first presentation to care, but this is limited to the people actually linked to care
- The national communicable disease registry (NAKIS) should be expanded to include the following data:
 - CD4 at diagnosis
 - o Viral load
- NAKIS includes transmission mode, but it is currently underreported, and efforts to collect better data on this are crucial across the health care system.
- The EHIF database contains data on the number of HIV tests and where they are conducted, but the detailed recording of whom is tested and the particular reasons for testing remains underreported. Data on this need to be improved.
- It should be mandatory to report all relevant surveillance data and made them available for NIHD/MoSA.

Priority area 2: Optimizing HIV testing

According to the national testing guidelines (2012), HIV tests may be ordered by health physicians or other medical personnel, and it is recommended that a test for HIV infection is offered to:

- all pregnant women
- all neonates of HIV-positive woman
- all people visiting a doctor on suspicion of a sexually transmitted infection
- al people visiting a pulmonologist on the suspicion of TB
- all incarcerated people
- all patients in rehabilitation programmes and undergoing addiction treatment
- donor blood and blood products
- all patients with indicator disease
- all patients from groups at risk
- in Harju County and Ida-Virumaa, the test should be done for all 16-49 year old outpatients (14).

In Estonia approximately 150 000 people were tested for HIV in 2013 and the total number of tests was more than 212 000 (17,22). Of these some 100 000 tests were on two routinely screened groups, blood donors (approx. 64 000 people) and pregnant women (approx. 18 500 people). The latter group is normally tested for HIV twice during pregnancy. Of the total yearly HIV tests, 50 000 are performed based on clinical indication or risk behaviour; however there is no detailed registry with information on the reasons or motivations for testing in spite this being mandatory to report for new cases. Due to the underreporting, the Health Board has only limited information on the reasons for testing, e.g. data are only available for 240 cases in 2013 (see table below).

This limitation makes it very difficult to follow trends in the epidemic and in the testing of risk groups. One explanation for the underreporting is that people may be reluctant to state their possible mode of transmission, but data on provider reasons for testing could still be collected more consistently.

Reason	Number of cases	
Suspicion of HIV infection	100	
Contact with HIV infected person (incl. mother)	41	
Prisoners	28	
Occupational risk of infection	0	
Patients with STI	4	
Patient with Hep B	0	
patient with Hep C	2	
PWID	24	
Homosexual contact	4	
Sexual intercourse for money or drugs	2	
Pregnancy, abortion	18	
Blood/organ donors	1	
Other	30	

Table 2: Reasons for testing 2013 (n=240, may be more than one reason for one person)

Source: Data from CD Registry, Estonia

The preferred mode of testing is the automated or semi-automated investigation of venous blood (ELISA testing), whereas the use of rapid tests is less widespread. 2013 data from 11 HIV counselling and testing offices with a total of 7 110 clients, show that the ELISA testing method was used in 71.2% of the cases, and that rapid testing was used predominantly in West Tallinn Central Hospital, which runs the country's biggest counselling office (*31*). There are examples of rapid HIV testing used outside clinics and counselling offices to reach most-at-risk populations. For example, in 2013, the NIHD and the Estonian Network of People living with HIV (EHPV) joined forces to organize events of rapid HIV testing in gay oriented bars and clubs (*17*). Initial (positive) results of anonymous ELISAQ tests or rapid tests are not reported to the Health Board nor included in the number of new HV cases identified (*31*).

One important indicator for the efficiency of the actual testing procedures and policies is the percentage of new HIV cases classified as late diagnosis. Around 30-40% of new HIV diagnoses are considered to be late presenters (with CD4 cell counts below 350), although data on CD4 count at diagnosis are not collected systematically (2). A better targeting of the HIV testing towards most-at-risk groups is recommended as a way to identify people with HIV infection earlier.

One of the largest most at-risk groups in Estonia for acquiring HIV infection is the PWID population. As mentioned, the exact size of this population in unknown and expert estimations ranges from 6 000 to 10-15 000 people. The majority of PWIDs are male, and their mainly female partners constitute another most at-risk population, which may act as a "bridge group" spreading the epidemic to the general population (1,33). The rate of HIV testing among PWID has increased in recent years (17). Data from the National Drug Information Centre show that two thirds of NSP clients with an injecting history of 3 years or more had been tested for HIV during the last 12 months (28). Recent bio-behavioural studies among PWID found that the percentage of PWID tested at least once in their lifetime was 90% in Kohtla-Järve (sample size 600) and 72% in Narva (sample size 350) (15,12). However, only around 50% of PWID had HTC during the last 12 months in Kohtla-Järve.

Compared to other countries a large share of Estonia's opioids dependants are HIV positive (33). The figure below shows the prevalence of HIV according to different studies and according to the statements of the respondents. Over time the gap between actual prevalence and self-reported prevalence has been decreasing (28).





Source: REITOX 2013 National Report (28)

There is no HTC on a regular basis on the premises of needle and syringe exchange programmes (NSP), which are usually driven by NGOs. NGOs are not allowed to conduct HIV testing as obtaining blood samples is legally a medical procedure. However, NSPs are encouraged to remind their clients to undergo testing at least once per year, as stipulated by the national guidelines on HIV testing. The NSP staff often passively refer their clients to anonymous VCT/STI sites, usually at county hospitals or other health care institutions. However, lack of motivation from the side of PWID, geographical remoteness and stigmatization of HIV and PWID at health care institutions, may actually be barriers for PWIDs' adequate access to HTC on a yearly basis. In Tallinn, one project offered NSP clients a 5-euro bonus for presenting at anonymous VCT/STI sites. Nevertheless, this HTC project failed because this bonus did not increase PWIDs' motivation to undergo HIV testing.⁴

The Estonian Network of PLHIV (further – Network) offers flexible community based HTC with rapid HIV tests. The rapid tests are funded by the US charity American AIDS Foundation and the nurses' services are remunerated from the NIHD. In order to perform HTC, NGOs need to be in agreement with a licensed health care institution, and tests should be performed by the licensed nurse. Community-based testing is targeted at specific risk groups, including PWID. Thus, HTC for PWID can be performed at NSP premises or during outreach activities. If tested positive by rapid tests, PWID are actively referred for further confirmation of diagnosis at anonymous VCT/STI sites by the Network. Representatives of the Network indicated that, in 2013, more than 10 000 rapid tests were done. Around 60% of the overall HTC clients at anonymous VCT sites were referred by the Network.⁵ The efficiency and cost effectiveness of targeted testing in risk groups is apparent from the numbers. According to the Linda Clinic in Narva, the number of rapid tests performed in July-December 2013 was 1 176, from which 113 PLHIV were identified (35 identified for the first time) giving an HIV prevalence of 3%. In 2013 for the total of non-VCT settings 7 272 rapid tests were conducted, and 69 PLHIV identified for the first time, which imply a prevalence of 0.9%.⁶

The national guidelines on HIV testing recommend that HIV screening is routine for all outpatients between 16 and 49 years of age in health care facilities in Harju County and Ida-Virumaa. This attempt to normalize HIV testing is very important. However, the mission identified a number of barriers to this approach at both client and provider-level. Patients do not always feel comfortable in these settings and health care personnel experience challenges in implementing it due to lack of training, support and financial resources.

⁴ Personal communication by Kai Zilmer at the meeting in West Tallinn Central Hospital, May 15, 2014

⁵ Personal communication at the meeting with the Estonian Network of PLWH, May 16, 2014

⁶ Data provided by Public Health Department Ministry of Social Affairs, 22. June 2014

Mainstreaming HIV testing in Health care Facilities

An example of "good practice" is the Narva hospital where the recommendations to mainstream HIV testing are currently being implemented. The involved health care staff had written articles about the importance of HIV testing in the hospital newsletter, conducted training, participated in heads of department meetings, and made regular analyses of the number of HIV tests offered, which were shared with the clinicians. Also, an attempt had been made to analyse medical records of all newly diagnosed PLHIV to identify any previous visits that could constitute a missed opportunity for HIV testing. The results were presented to the responsible clinicians, who were made aware of possible signs for earlier diagnosis.

Testing programmes/activities should have clear linkage to care pathways in order to ensure that people testing positive for HIV are in fact linked to care. This was identified as not adequately secured in the country, i.e. in one project only 30% of people with a positive HIV test were known to have taken a confirmatory test and accessed care.

As mentioned above, most pregnant women are offered HIV tests twice during pregnancy. The number of newly diagnosed HIV cases among pregnant women was 41 in 2008 and 2009 and down to 30 in 2010 (1). The overall prevalence rate of HIV among pregnant women is below 1% in most regions, except the north-east where it is around 2% (1). The effectiveness and cost effectiveness of testing most pregnant women twice requires further analysis as this practice is not recommended by WHO and cost savings seem possible. It would be relevant to compare the HIV prevalence in pregnant women when the first and the second test is taken in order to assess whether the second HIV test is in fact justified or could be removed. If the second test of pregnant women is removed, the costs saved could be diverted into expanding testing of PWID, which is urgently needed. In general, testing programmes should have a clear aim; is the aim surveillance of the epidemic or is it to identify as many HIV positive as possible? Moreover, the collected and reported surveillance data should be put to use for strategic planning of the interventions.

Recommendations

- Strengthen data collection on reasons for testing in order to evaluate coverage of risk groups and changes over time
- Scale-up HIV testing among most-at-risk populations, allow non-medical personnel to offer HIV testing at centres that see risk groups, introduce more rapid tests
- Technical and financial support of testing in health care facilities (GPs, hospital departments, emergency departments); training, support materials and financial resources to cover the cost of the test is needed
- Strengthen active linkage to care in all centres offering HIV testing
- Remove the offer of a second test during pregnancy, which is not cost-effective nor recommended by WHO

Priority area 3: Adapt service delivery

As described above, for the vast majority of PLHIV the HIV infection related to injecting drug use. Even though important measures have been taken in terms of harm reduction, there are still fundamental challenges to the retention in HIV care and treatment for this most-at-risk population group. The mission has observed that low coverage and quality of harm reduction programmes, lack of integrated services and lack of trust in the effect of OST programmes have major consequences for this group's access to and retention in HIV care and ART – and thus for controlling the HIV epidemic in the country.

The WHO consolidated guidelines, recommends the following for most-at-risk populations:

Most-at-risk populations (including sex workers, men who have sex with men, transgender people and people who inject drugs)

In several settings, most-at-risk populations face multiple challenges to accessing health services. Service delivery approaches to improve longitudinal care and maintain adherence for most-at-risk populations remains a critical gap in many settings. Experience indicates encouraging results with peer-based interventions that include strong social support such as outreach teams, peer educators and health workers providing multidisciplinary, non-judgemental and respectful care (WHO consolidated guidelines: 178)

Specifically with regards to the importance of opioid dependency treatment, vast literature shows that OST enhances PWID adherence to HIV treatment.⁷ Broadly, ART outcomes are reported as better among drug users receiving OST compared to drug users not receiving OST. Opioid substitution therapy was independently associated with HIV-1 RNA suppression in several studies, and in one study an increase in CD4 cell count was also associated with OST. The positive effects of OST on ART adherence may be explained by a stabilization of the patient's social situation, regular access to care and referral, being accustomed to taking medication on a daily basis, as well as an improved social support network.

⁷ See Fiellin et al (2011). Drug treatment outcomes among HIV-infected opioid-dependent patients receiving buprenorphine/naloxone. *J.Acquir.Immune.Defic.Syndr., 56 Suppl 1*, S33-S38. Gowing et al (2008) Substitution treatment of injecting opioid users for prevention of HIV infection. Cochrane.Database.Syst.Rev., CD004145. Gowing et al. (2011). Oral substitution treatment of injecting opioid users for prevention of HIV infection. Cochrane.Database.Syst.Rev.,CD004145. Lloyd-Smith et al (2006). Impact of HAART and injection drug use on life expectancy of two HIV-positive cohorts in British Columbia. *AIDS, 20,* 445-450. Malta et al (2010). Adherence to antiretroviral therapy among HIV-infected drug users: a meta-analysis. *AIDS Behav., 14,* 731-747. Malta et al (2008). Adherence to antiretroviral therapy for human immunodeficiency virus/acquired immune deficiency syndrome among drug users: a systematic review. *Addiction, 103,* 1242-1257. Spire et al. (2007). Adherence to HIV treatment among IDUs and the role of opioid substitution treatment (OST). *Int.J.Drug Policy, 18,* 262-270. Stotts et al. (2009). Opioid dependence treatment: options in pharmacotherapy. *Expert.Opin.Pharmacother., 10,* 1727-1740. Sullivan & Fiellin (2005). Buprenorphine: its role in preventing HIV transmission and improving the care of HIV-infected patients with opioid dependence. *Clin.Infect.Dis., 41,* 891-896. World Health Organization (2005). *Effectiveness of drug dependence treatment in preventing HIV among injecting drug users* World Health Organization, Geneva, Switzerland.

For the Estonian response to PWID the consulted literature points out that while the quantity of OST and NSP services are monitored, little data is available on the quality of services, and it is unclear which institution is responsible for quality assurance of drug prevention and drug treatment services (2). It should be mentioned that the NIHD performed an audit of all methadone substitution therapy services in 2013 to determine the quality of services and potential for improvements (34).

Needle and Syringe Programmes (NSP) and their integration with HIV/TB care

The first needle and syringe programme opened in Estonia in 1997, and since then the coverage has increased. By May 2014 there were 37 stationery and outreach NSP sites located in or near the capital (Tallinn, Maardu), in Central Estonia (Tapa, Paide) and in North-East Estonia, and operated by 10 NGOs.⁸ The NGOs operating the NSP sites receive sustainable and sufficient funding from the National Institute for Health Development (NIHD). A syringe exchange database was established in 2007 as a tool for service providers, and it serves routine monitoring purposes at NIHD. In addition to the online system, data are currently still exchanged between service providers and the National Institute by email. The aim is to transform the database into a web-based data collection system and to use web-based questionnaires by 2015.⁹

In 2012, a total of 2.2 million syringes were distributed to 1 319 new clients and 6 643 follow-up clients (the total number was around 8 000), which translates into 164 syringes distributed per client per year. Client data collected show that 80% were male, 85% were Russian speaking and the average age was 28 years (range 15–60). The main substance injected is Fentanyl, but amphetamines play an increasing role. The number of visits to the NSP has dropped from a peak of 180 000 in 2010 to around 150 000 in 2012, and it is a challenge to keep these services attractive to the target population. One study conducted in 2012 (as part of the TUBIDU project¹⁰), showed that 78% of surveyed PWID obtained their sterile syringes from NSPs and 13% from pharmacies. Most pharmacies in Estonia sell syringes to PWID, but pharmacists do not legally belong to the medical profession nor do they provide counselling. In some areas, the stationery NSP are supplemented by outreach services provided by street workers or mobile units.

⁸ Personal communication, meeting at National Health Development Institute, May, 12, 2014

⁹ 2013 National Report (2012 data) to the EMCDDA by the Reitox National Drug Information Centre: Estonia: New developments, trends and in-depth information on selected issues.

¹⁰ TUBIDU is an acronym for the project 'Empowering the public health system and civil society to fight the tuberculosis epidemic among vulnerable groups'. The project is co-funded by the Executive Agency for Health and Consumers (EAHC) and its activities include: drawing up an overview of the situation and scope of the problem in selected countries; capacity building among public health, health care and civil society professionals; and the development of quality guidelines and models for community based organisations working with vulnerable groups, including PWID. The project ends in 2014 (www.tai.ee/tubidu).

The number of syringes (164) distributed per 1 NSP client in 2012 was satisfactory according to WHO/UNODC/UNAIDS criteria (low < 100 > medium < 200 > high).¹¹ However, some informants indicated that NSP should not only concentrate on the "mechanical" increase of syringe distribution, including delivery of syringes to unrecorded PWID for a secondary exchange, but also on providing higher quality of information, counselling and referral services, especially to female PWID. This point is underlined by some studies, which indicate that in spite of the important improvements in harm reduction services; this may not necessarily translate into a major decrease in risk behaviour among PWID (1). In addition, specifically designed strategies are needed to reach PWID, who do not regularly attend NSP.¹²

The NIHD identified a need for continuous training to increase the professionalism of some NSP staff and outreach workers, who were themselves PWID, either active or receiving OST. This has led NIHD to fund a system of on-going training for NSP staff through quarterly, specifically designed participatory sessions.¹³ These efforts should be continued to increase the quality of information, counselling and referral services, including information about OST as beneficial evidence-based treatment.

PWID who are tested positive for HIV infection at NSP sites are referred for infectious disease (ID) specialist consultation, but there is generally no active follow-up on whether they actually see an ID specialist. In Tallinn, Narva, and Kohtla-Järve hospitals, the waiting time for a specialist consultation varies from one to four weeks. A 5 euro specialist fee is another important factor, which may reduce PWIDs' motivation to consult an ID specialist.

Due to a very high number of opioid (fentanyl) overdoses – 170 in 2012 - NIHD has since September 2013 funded an opioid overdose prevention programme including distribution of naloxone by NSP staff in cooperation with health care organizations and provision of short training for PWID (28). This OD prevention programme was pioneered in the Baltic region. By January 2014 it involved four organizations and 10% of NSP clients had participated in naloxone OD prevention programmes.¹⁴ Another important strategy to decrease lethal OD would be to significantly increase the coverage of OST amongst people who inject opioids.

Opioid Substitution Therapy (OST) and its integration with ARV therapy, TB and HCV care

Based on WHO Guidelines NIHD developed the national OST clinical protocol in 2013 (available in Estonian). In 2013, NIHD performed an audit of all methadone substitution therapy services to determine the quality of services and potential for improvements *(34)*. The audit indicated that PWID with HIV infection constitute 60-80% of OST patients. Moreover, OST patients tend to have a longer history of injecting and more frequent co-morbidities, including TB.¹⁵

¹¹ Technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users, 2012 revision. WHO, UNODC, UNAIDS, 2013.

http://www.who.int/hiv/pub/idu/targets_universal_access/en/index.html

 ¹² Personal communication, meeting at National Health Development Institute, May, 12, 2014
¹³ Intervision Guidelines. UNODC Project Office for the Baltic States, 2010.

http://www.unodc.org/documents/balticstates/Library/PharmacologicalTreatment/IntervisionGuidelines/IntervisionG uidelines.pdf

¹⁴ Personal communication, meeting at National Health Development Institute (May, 12, 2014)

¹⁵ Personal communication, meeting at National Health Development Institute (May, 12, 2014)

The national Drug Treatment Database collects data from 14 treatment centres. The 2013 report shows that during 2011 532 patients entered treatment; in 2012 the number was 546 (34). With those already in treatment, 687 patients were on OST with methadone by the end of 2012 (1 123 patients in total in 2012). As mentioned, the exact number of PWID injecting opioids in Estonia is unknown, but one expert estimation sets it to 6 000 (28). Thus the OST coverage (around 12%) of injecting opioid population according WHO/UNODC/UNAIDS criteria is low (low < 20% > medium < 40% > high).¹⁶ Other sources estimate the numbers of PWID to be 10 000-15 000, thus implying that 5-6% of all PWID were on OST in 2010. It should be noted that among PWID injection of amphetamine is widespread, and this group would need another kind of treatment and rehabilitation aimed specifically at amphetamine addicts (12,34).

NIHD provided 1 037 504 euros for OST services in 2013, including some 125 677 euros for methadone and testing kits¹⁷, which was considerably less than the annual costs of ARV medications (11.5 million euros per year). Nevertheless, funding for OST has been slowly but steadily increasing. NIHD has also recently contracted Narva's OST programme to meet specific needs of female OST patients and their children. In Narva female PWID constitute 25% of overall PWID population, which is the highest female population among PWID in the country. 55% of PWID in Narva had biological children and 11% lived in the same household as a child (2010). To respond to this situation NIHD funded an additional social worker and socio-pedagogue to meet the needs of around 60 female OST patients (40% from the total number of OST patients) and 80 children of OST patients. This is a good example of patient-centred services and a flexible response to specific and individual needs of OST patients.

At different OST centres, the mean daily methadone dose varied in 2012 from 47 to 66 mg (28), which is slightly below WHO's recommended average methadone dose of >60 mg. For different reasons patients tend to stay on low methadone doses (in Narva the average is 45-50 mg)¹⁸, including the presumed easier termination of OST. During the mission we were told that some OST patients and NSP clients tend to have a negative image of OST. It is a prevailing misconception that "methadone" is just another replacement of an illegal drug, which is even worse than Fentanyl or heroin; therefore some patients preferred staying on the lowest dose for the shortest time possible. Perhaps due to the negative image of OST among PWID, in May 2014 there were no people on waiting lists for OST in Narva and Kohtla-Järve counties. A recent clinical audit of methadone substitution therapy services found that the service provided, e.g. use of specialized personnel, laboratory facilities and psychosocial work, vary between therapy centres to the extent that comparisons are impossible (*34*).

¹⁶ Technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users, 2012 revision. WHO, UNODC, UNAIDS, 2013.

¹⁷ Data provided by Public Health Department Ministry of Social Affairs, 22. June 2014

¹⁸ Meeting at the NGO "Me aitame sind" in Narva, May 13, 2014.

During the mission several national institutions, including NIHD, indicated that there is a lack of psychiatrists willing to work in OST programmes (see also 34). Management of drug dependence and integration of drug dependence treatment with HIV, HCV and TB care are not included in university post-graduate curriculum of residentially trained psychiatrists.¹⁹ On the other hand, as only psychiatrists are allowed to diagnose substance dependence disorders and initiate OST, which constitutes an additional barrier to expanding OST coverage in the country. In West-Tallinn Central Hospital (due to the long-term unavailability of psychiatrists), ID specialists were able to continue OST, including changing the dose of methadone according to clinical indications. Further involvement of family physicians in the provision of OST in cooperation with psychiatrists, especially in geographically remote areas, was discussed with the Society of Family Physicians during the mission as a potential way to decentralize and increase access to OST. However, this would require specific training and financial reimbursements.²⁰

An additional factor alienating OST from routine medical practices and preventing OST integration into mainstream health care is the praxis that medical records on OST patients, in contrast to routine medical record management, are not consistently included in overall electronic medical data bases.²¹ One explanation is that some OST providers have not developed sufficient IT support to join overall electronic bases and continue collecting patient information in separate folders or monitoring sheets (*34*). Developing more unified reporting and enabling electronic documentation should be a national priority area. One solution could be the Electronic Health Recoding's portal for doctors (eHealth) which is inexpensive and feasible to use for smaller service providers, but currently not suitable for psychiatrists (*34*).

The mission encountered that attitudes towards OST are rather negative among many OST providers and infectious disease specialists. The specialists claimed "*PWID do not listen to our advice, their psychology is distorted, and OST is not helpful*".²² OST is considered to have limited effectiveness as a treatment approach, especially from the abstinence-oriented treatment concept. In Narva and Kohtla-Järve, ID specialists were not considering integrating ARV therapy with OST programme as they consider OST to have very limited positive impact on patients' behaviour. There were no intentions to provide directly observed one-site dispensing of methadone and ARV for the most unstable patients.

As mentioned, in addition to stigmatization of PWID by specialists, the current waiting time for an infectious disease specialist consultation (one to four weeks) and the 5 euro consultation fee are other substantial barriers making HIV care less accessible to PWID. The urgency of addressing these impasses is reflected in the fact that 50% of PWID appear at specialist consultation with a CD4 count < 200.²³

¹⁹ Personal communication, meeting at National Health Development Institute, May, 12, 2014

²⁰ Meeting with Society of Family Physicians, May 16, 2014.

²¹ Personal communication, meeting at National Health Development Institute, May, 12, 2014

²² Personal communication, meeting at Kohtla-Järve Hospital, May 14, 2014

²³ Personal communication, meeting at Kohtla-Järve Hospital, May 14, 2014

OST-ARV integrated service

West-Tallinn Central Hospital's OST programme provides directly supervised ARV dispensing. This model has increased adherence for the most problematic patients and was highly appreciated by leading ID specialists in Tallinn. Unfortunately, this particular OST site has currently a waiting list of 10 patients, which can be enrolled only if someone leaves the OST programme.

NIHD funds quarterly training of OST staff through participatory sessions focused on helping staff manage difficulties at work. However, it was indicated to the mission by NIHD that this is not sufficient to improve the quality of OST.²⁴

Though OST programmes have social workers, there seems to be room for improving the individual, patient cantered approaches, including for example individual needs assessment, specific treatment plans, and professional coordination of services. The conclusion from the mission's meetings with ID specialists in the North-Eastern part of Estonia is that patients are not actively referred by case managers to HIV and HCV care and treatment or to their family doctors. It was also indicated that OST patients need continuous social assistance to navigate through the existing municipal social support system, because most PWID suffer from social problems, lack of employment and social skills, and many do not know the Estonian.²⁵ OST patients are for example not actively referred to municipal labour exchange offices, which could potentially contribute to vocational training and employment opportunities, and where national health insurance is also available.

Access to detoxification for opioid and non-opioid users is difficult for PWID from the North-Eastern part of Estonia. The country's only in-patient unit for detoxification of OST patients with poly-drug use (alcohol or amphetamine) is located in Tallinn at the Wismari Hospital. In 2012, Wismari Hospital received 102 785 euros from NIHD for detoxification services. Only 48 522 euros were spent due the early termination of detoxification by patients (28).

With regard to co-infections, all TB hospital units in Estonia have OST (methadone) available for inand out-patient treatment.²⁶ HCV infection treatment is available free of charge for patients with national health insurance, therefore rarely accessed by PWID. No data was obtained about how often OST patients are referred to HCV care and treatment.

All penitentiary institutions of the Ministry of Justice offer OST (methadone), and by May 2014 56 people were receiving OST in prisons.²⁷ It is possible for people on OST treatment to continue OST both in police custody and penitentiary institutions, i.e. before and after court sentences. Inside the penitentiary institutions small units for psychosocial treatment of drug dependence are functioning, and PWID can start OST, if so determined by the penitentiary institutions psychiatrists.

²⁴ Personal communication, meeting at National Health Development Institute, May, 12, 2014

²⁵ Personal communication at the meeting with Narva NGO, May 13, 2014

²⁶ Personal communication, meeting at National Health Development Institute, May, 12, 2014

²⁷ Meeting with the representative of Penitentiary Department of the Ministry of Justice, May, 14, 2014.

Currently four centres offer psychosocial treatment (rehabilitation), including two state-funded psychosocial treatment centres in Viljandi Hospital for men and women and in NEMC and for people with dual diagnosis of both genders, where primarily CBT (cognitive-behavioural therapy) was used. Governmental funding was provided also to an in-patient rehabilitation centre at Sillamäe (CBT and self-help approaches) for adults and LLC Corrigo center for minors (28). By 2014, there were in total 47 beds (10 for females). As the duration of psychosocial treatment was 6-12 months, the number of patients who received psychosocial treatment in 2012 was relatively low and could not have an impact on managing HIV infections. In 2012, all 4 psychosocial treatment centres enrolled 155 patients in total to treatment and roughly one half (66) successfully completed the therapeutic programmes.

One survey from Narva indicated that only 22% of PWID, whose average age was around 30, had ever received some form of treatment for dependence in the past. The study concluded that this is related to the shortage of accessible spectrum of different treatment programs for PWID (12).

To conclude, an extensive focus on handling the PWID is needed, otherwise Estonia risks experiencing an escalation of the HIV epidemic, which will be much more costly to tackle than today.

Recommendations

- Responsibility for treatment of PLHIV patients should remain with the ID specialists, but distribution of medicine should be where the patients are coming, be that OST centres or other sites (learn from good practice from West Tallinn Central Hospital)
- Equally for methadone, the supervision of treatment should be conducted by psychiatrists but medications can be given by others in the care system
- It is recommended that ART and OST is managed by the same specialist (or two specialists in close collaboration) to ensure that OST doses are adequately adjusted in the case of drug-drug interactions with some ARVs
- Not only concentrating on the "mechanical" increase of syringe distribution but also provide higher quality of information, counselling and referral services, especially to female PWID
- In addition to needle and syringe exchange, harm reduction services would need to be expanded with provision of other injecting equipment, sterile water, etc.
- OST programmes to upgrade individual, patient-centred approach, including individual needs assessment, specific treatment plans, and professional coordination of services.
- Treatment and rehabilitation facilities should be created for amphetamine drug users
- Actively referred by case managers to HIV and HCV care and treatment, and to their family doctors, for Labour exchange offices, which could potentially contribute to vocational training and employment opportunities.

- Crucial to deal with the negative attitude towards OST, etc. observed among both health care personnel and clients, who expressed:
 - o Lack of wish to know HIV status
 - Lack of wish to start ARV treatment
 - o Lack of wish to start OST
- It is highly recommended that the experience from the West-Tallinn Central Hospital's OST programme providing directly supervised ARV dispensing is duplicated to other regions of the country.

Priority area 4: Optimize drug regimens and reduce costs

Currently, ARV is provided at 5 ID clinics at hospitals in the larger cities in Estonia, as well as in prisons for incarcerated patients. Currently, there is limited experience and confidence in providing ART for example at OST treatment centres; however, a well-functioning service is established at the West-Tallinn Central Hospital.

In Estonia ARV medicine is solely financed by the state budget, and the overall budget for treatment has gone up every year to 12 million euros in 2013. The country has a system of public ARV procurement and supply management managed by the MoSA and the National Health Board. Overall the public procurement system seems to be working properly, with no reports of stock-outs. Moreover, it allows to purchase ARV at a relative low price compared to other countries in the region, and should be maintained according to the involved stakeholders.

Forecasting is, as mentioned previously, done by an expert commission under the Ministry of Social Affairs led by infectious disease specialists and bases its estimates on the previous year's consumption. The mission has not found any indications of problems with inadequate stocks and supplies, neither centrally or at the ID units. However, the fact that the system depends on expert opinion rather than a formalized methodology for forecasting and defined instructions for operating procedures, makes it vulnerable and unsustainable.

ART drug regimens

The ART drug regimens used follow decisions by the HIV treatment consilium and the European EACS guidelines, although with some local preferences. For example single-tablet fixed dose combinations such as Atripla are unavailable due to costs, despite being recommended as first-line treatment in WHO guidelines.

In Estonia the preferred first-line ART regimen in pregnancy and in fertile women is rtv-boosted PI and Combivir. The preferred first-line ART regimen in IV drug-users is rtv-boosted PI with Kivexa or Truvada, and there is also a tendency towards preferring PI/rtv (rather than NNRTI based regimen) in patients with low CD4-counts.

Overall, among all patients currently receiving ART, the following drugs are used (by drug class): The NRTI: the majority receive Kivexa (Abacavir+Lamivudine) (n=1 326), followed by Truvada (Tenofovir+Emtricitabine) (n=711) and Combivir (n=588). Among PI/rtv: The majority receive LPV/rtv (n=841); followed by Fosamprenavir (n=344), and Darunavir (n=283). Atazanavir is only prescribed in case of drug resistance to other PIs (n= 43). Other ARVs used in case of virological failure and resistance are: Raltegravir (n=79) and Maraviroc (n=3). The 'ARV procurement plan 2014' show planned share of NNRTI in drug-naïve 55% and 45% for rtv-boosted PI. It is recommended that the PI share is less than 20% and that ATZ is used as first line priority. Duranavir or Lopinavir can be used in patients with PI resistance.

Overall, the available data and programmatic experience continues to provide reassurance that exposure to Efavirenz in early pregnancy has not resulted in increased occurrence of congenital anomalies or other significant toxicity (supplementary section to the 2013 WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, Chapter 7 – Antiretroviral therapy). The cost of Efavirenz has decreased considerably; it is available as part of the daily fixed-dose combinations and continues to be the WHO preferred drug option in first line treatment for adults and adolescents as well as among pregnant women and women of reproductive age.

There is no evidence that Efavirenz cannot be used in patients who inject drugs. This is being used across Europe, shown in large European population cohort studies, like the EuroSIDA study (37,38,39).

RNA monitoring

Investments in HIV RNA monitoring has been prioritized and Estonia follow WHO guidance on routine monitoring. It is however not recommended to perform HIV RNA monitoring routinely while the patient has a high CD4 count and treatment has not been initiated. In such cases, focus should be on CD4 measurements. Cost savings on HIV RNA can be obtained by following this guidance without compromising the quality of care.

Viral suppression

Suppression rates are low among those in treatment which needs to be addressed. This becomes extremely important as the majority of PLHIV are still not on treatment and it is likely that this group will be particularly more difficult to handle. Those already on treatment are those who can adapt to this regularity in their life, which might be more challenging for those not yet on treatment (or one could assume they would already be on treatment).

Reducing costs

ARV accounts for a large part of the overall HIV/AIDS budget. By following WHO guidelines and procurement and streamlining drug regimens, possibilities for cost containments are present. It is evident that with the level of GNP and investment in health, it is difficult to maintain the same level of care as in other EU countries.

Recommendations

- The procurement plan/selection of ART drugs can be simplified according to WHO guidelines with less first-line drug options. The use of PI/rtv as first-line regimen should be decreased (target 10-20%). This will imply considerable cost savings.
- It is not recommended to perform HIV RNA monitoring routinely while the patient has a high CD4 count and treatment has not been initiated.
- With regards to the use of Efavirenz in drug users, there may be concerns for the development of NNRTI drug resistance (in case of poor adherence) and of drug-drug interactions with methadone. These issues are best addressed by focusing on measures to improve adherence (incl. shared care, DOT, etc.), and drug-drug interactions may require augmentation of methadone dose. However there is no evidence that efavirenz cannot be used in PWID.
- The procurement system can be more robust with the introduction of a formalized methodology for forecasting.

7. Cross-cutting issues

7.1 Sustainability and access to services

The involvement of general practitioners in the HIV response was evaluated during the mission. In order to ensure the normalization of HIV testing in the health care system, it is considered crucial to implement testing guidelines in primary care. This should be the GPs role in the HIV epidemic, without forgetting linkage to care measures are in place from GPs.

A number of obstacles to this were identified, including a lack of support from both GPs and IDs to this change because of limited financial resources for diagnostic tools in primary care practices and little trust in GPs from the community of risk groups, which questions whether the introduction of HIV screening in primary care will lead to a better capture of PWID living with HIV.

It is evident that the implementation of the testing guidelines in primary practice will require training, materials and financial support to the general practitioners.

At the moment it does not seem to be a good solution to involve GPs in the provision of ARVs unless supervised by ID physicians/psychiatrists, or if GP practices constitute venues that are more accessible to people in certain regions.

Urgent attention is needed to make the discipline of infectious diseases and narcology more attractive and to tackle the issue of migration for clinicians trained in the field. A need for supervision and training was also identified during the mission.

7.2 Human rights

ARVs and ID services are in principle available to everyone in need of treatment irrespective of the health insurance coverage. The 6% without insurance can be entitled to a disability pension that entitles them health insurance. However, the rule has been that you would only receive this pension when very sick, i.e. with very low CD4 count. This has had the consequence that some individuals may stop taking their medicine in order to keep the disability pension, which for some would be their only income. Linking a patient's entitlement to disability pension to a low CD4 count is counterproductive to retention and adherence to treatment. PLHIV should be navigated to have opportunities of the existing social support options, reinsertion to labour market in order to survive and sustain their children, instead of choosing this counter-productive option.

8. Recommendations

8.1 Main recommendations

Surveillance of the HIV epidemic in the country lacks important indicators, and available data are not adequately analysed and used to inform policy decisions on priorities within the national HIV programme

Recommendations

- To improve the quality of surveillance data continued efforts to record CD4 count at diagnosis are crucial and should be regarded as a high priority.
- The national HIV registry should include the following data:
 - CD4 at diagnosis
 - o viral load
- Improved efforts are needed to collect detailed information on reasons for conducting HIV testing, as well as on possible transmission routes for new HIV cases.
- Reporting of surveillance data should be mandatory and they be made available to NIHD/MoSA.
- To prioritize measures to ensure a comprehensive and extensive understanding of the problem.
- Post graduate training of the experts involved in surveillance and public health interventions to ensure appropriate analysis of data.

HIV testing does not target key most-at-risk populations

Recommendations

- Strengthen data collection on reasons for testing in order to evaluate coverage of most-atrisk groups and changes over time.
- Scale-up HIV testing among risk populations; allow non-medical personnel to offer HIV testing at centres seeing risk groups; introduce more rapid tests.
- Technical and financial support to testing in health care facilities (GPs, hospital departments, emergency departments); training, support materials and financial resources to cover testing costs is needed.
- All centres offering HIV testing to strengthen active linkages to care.
- Removal of the second test during pregnancy, which is neither cost-effective nor recommended by WHO.

Insufficient enrolment and retention in HIV care and ART

Recommendations

- Improve measures to support retention in care and compliance with ARV, e.g. directly observed therapy supplied at OST services.
- Support immediate counselling and active referral.
- Reduce stigma in health care settings through targeted campaigns and education, and by securing an empathetic and proactive attitude from management and lead ID physicians.
- Support shared care and more widespread services with one-stop for methadone and antiretroviral treatment (and Hepatitis or TB treatment for co-infected patients).
- Stronger attention to underlying conditions, e.g. support to patients with drug and alcohol dependence.

Lack of harm reduction programmes and low OST coverage

Recommendations

- Increase PWID's access to HIV testing and counselling at NSP, outreach sites and through community based HTC with expanded use of rapid tests and active referral to further HIV care.
- Increase attractiveness and quality of NSP services by improving information, counselling and referral to OST, and by ensuring a professional level of social services and training of the staff.
- Make OST more attractive to PWID by increasing the quality of OST services. This could include promoting patient-centred approaches recognizing the individual patient's needs and expectations, developing adequate treatment plans, coordinating with social and medical services, and integrating better with the existing system of vocational training and job placement offered by labour exchange offices. This could increase assistance to OST patients in navigating through available social and medical services, but requires a significant increase in funding for OST.
- Promote integration of OST services into the mainstream health care system through developing "best practice" and innovative models of integrated or shared care. Current efforts to integrate OST into existing medical services should be continued, including shared medical records, diversified models of funding for OST patients with health insurance, decentralization of OST provision to family physicians' practices and hospitals, especially infectious disease or TB units.
- Increase PWID's access to diversified drug treatment services, including in-patient detoxification services in psychiatric or specialized units and out- and in-patient psychosocial treatment, which could be integrated with HIV, HCV and TB care.
- Ensure that health care providers involved in the care of PWID embrace OST as an indispensable means to achieve appropriate care of this population group.
- It is highly recommended to duplicate the experience from the West-Tallinn Central Hospital's OST programme providing directly supervised ARV dispensing to other region of the country.

Lack of integrated services, including collaboration between HIV clinics and NGOs, TB hospitals and narcologists

Recommendations

- A shared care principle with involvement of community clinics in both HIV and OST response where the treatments go hand in hand should be prioritized.
- ID specialists should keep the responsibility for treatment of patients, but the actual distribution of medicine should take place where patients come regularly, e.g. at methadone treatment centres. The treatment should be supervised by psychiatrists, but the actual distribution of methadone can be handled by others in the care system with contact to the patients.

Simplify and optimise ARV drug regimens

Recommendations

- The procurement plan/selection of ART drugs can be simplified according to WHO guidelines with less first-line drug options. The use of PI/rtv as first-line regimen should be decreased (target 10-20%). This will imply considerable cost savings.
- It is not recommended to perform HIV RNA monitoring routinely as long as the patient has a high CD4 count and treatment has not been initiated.
- With regard to the use of Efavirenz in drug users, there may be concerns for the development of NNRTI drug resistance (in case of poor adherence) and of drug-drug interactions with methadone. These issues are best addressed by focusing on measures to improve adherence (incl. shared care, DOT, etc.); drug-drug interactions may require augmentation of methadone dose. However there is no evidence that Efavirenz cannot be used in PWID.
- The procurement system can be more robust with the introduction of a formalized methodology for forecasting.

8.1 Specific Recommendations

- Pay urgent attention to making the discipline of infectious diseases and psychiatry of substance use disorders more attractive and to tackling the issue of immigration of clinicians trained in the field. A need for supervision and training was also identified among clinicians during the mission.
- Review regulations of administration of disability pensions for PLHIV and make other options of social support accessible.
- PWID harm reduction interventions should not only concentrate on the "mechanical" increase of syringe distribution, including delivery of syringes to unrecorded PWID for a secondary exchange. Focus should be on providing a higher quality of information, counselling and referral services, especially to female PWID, and on developing strategies to reach PWID, who do not attend NSP regularly.

- In addition to needle and syringe exchange, harm reduction services should be expanded to provide other injecting equipment, sterile water, pads, etc. and to develop treatment and rehabilitation facilities for amphetamine drug users.
- OST programmes should improve and upgrade individual, patient-centred approaches, including individual needs assessment, specific treatment plans, and professional coordination of services. Patients should be actively referred by case managers to HIV and HCV care and treatment, their family doctors, and to labour exchange offices. This could potentially contribute to vocational training and employment opportunities.
- It is crucial to deal with the negative attitude towards OST, etc. observed among both health care personnel and clients, who expressed:
 - o lack of wish to start treatment
 - lack of wish to know status
 - lack of wish to start OST

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Annex 1- Simple calculation of undiagnosed population

To calculate a very crude estimate of the undiagnosed fraction, we have used the 'London method 1' (Working Group on Estimation of HIV Prevalence in Europe, 2011, AIDS). This is presented to illustrate a method that could be used in future with relatively minor data collection improvements. The following assumptions have to be made in order to apply London method 1 to readily available Estonian data:

- 1. CD4 count at presentation = CD4 count at diagnosis
- 2. All diagnoses were made as a result of the person having developed HIV-related symptoms.

Using assumption 1, of the 315 new HIV cases diagnosed in 2012, 85 (27% of 315) of those would have had CD4 \leq 200 cells/mm³ at diagnosis. Now let us also assume that:

- The 85 people who presented with CD4 ≤200 cells/mm³ had a uniformly distributed CD4 count distribution (with access to data on the exact CD4 count at presentation [which they should have?] this assumption would not need to be made)
- 4. Incidence of AIDS per person-year for those with CD4 count >200 cells/mm³ is 0.045 (for higher CD4 counts, it is likely to be even lower) (again, rates of AIDS at different CD4 count levels are known but to incorporate them would require knowledge of the exact CD4 count distribution at presentation)

CD4 count	Incidence of		Crude	e calculation
cells/mm ³	AIDS*		Number of observed	Estimated number of
	per person-year		diagnoses in a year	person years with
				undiagnosed HIV
0-19	2.015		10	10/2.015 = 5
20-49	0.721	\rightarrow	11	11/0.721 =15
50-99	0.436		21	21/0.436 = 48
100-149	0.220		21	21/0.220 = 95
150-199	0.108		22	22/0.108 = 203
>200	0.045		230	230/0.045=5111

Then the estimated number of people living with undiagnosed HIV is as follows:

* The incidence of AIDS used in our calculation were derived from the CASCADE cohort collaboration (CASCADE collaboration, 2004, AIDS; Porter K, 2011, personal communication). The rate of AIDS for higher CD4 counts could be even lower for CD4 counts significantly greater than 200 cells/mm³.

Therefore, given the many assumptions about the data as presented above (which were necessary because of the data availability), one crude estimate for the total number of people living with undiagnosed HIV in Estonia is 5477 (total of last column). However, this should be interpreted with caution. It may well be an *upper limit of the estimate* for the following reasons:

• The estimate for the number of undiagnosed people with CD4 count > 200 cells/mm³ particularly needs to be interpreted with caution because AIDS rates are much lower in in the higher CD4 count ranges and can thus lead to somewhat unstable estimates

• The estimate of the size of the undiagnosed population is an upper estimate because of assumption 2 above. That is, London method 1 relies on the assumption that new diagnoses are identified because AIDS develops and that leads to presentation, because the person is actually sick so they seek care. So proper application of the method requries restricting to new diagnoses in which symptoms are pesent.

Data on symptoms at HIV diagnosis are, to the knowledge of the mission team, not available in Estonia. If there is data on simultaneous HIV/AIDS diagnoses (defined as an AIDS diagnosis within 3 months of HIV diagnosis), then the estimate for the undiagnosed proportion can be refined further. This method requires only a short period of accurately collected data on the number of simultaneous HIV/AIDS diagnoses (or preferably the number of HIV diagnoses in the presence of HIV-related symptoms or AIDS) and the CD4 count at HIV diagnosis. It is therefore encouraged that this method be undertaken again as part of the Estonian surveillance programme, to provide an additional estimate of the size of the undiagnosed population to better inform screening programs and subsequent entry into HIV care.

Annex 2 – Terms of References

WORLD HEALTH ORGANIZATION **REGIONAL OFFICE FOR EUROPE**

WELTGESUNDHEITSORGANISATION

REGIONALBÜRO FÜR EUROPA



ORGANISATIONI MONDIALE DE LA SANTÉ BUREAU RÉGIONAL DE L'EUROPE

ВСЕМИРНАЯ ОРГАНИЗАЦИЯ ЗДРАВООХРАНЕНИЯ ЕВРОПЕЙСКОЕ РЕГИОНАЛЬНОЕ БЮРО

Evaluation of the National Programme on HIV/AIDS Treatment and Care in Estonia

12-16 May 2014

1. Background

Estonia is among five EU/EEA countries with highest rates of HIV- 23.5 per 100,000 populations in 2012. By the end of 2012, Estonia had reported a cumulative total of 8 377 HIV cases, 390 AIDS cases and 104 deaths among AIDS cases to the WHO Regional Office for Europe and the European Centre for Disease Prevention and Control (ECDC). For the year 2012, the country reported 315 new HIV cases, 36 AIDS cases and 5 deaths among AIDS cases.

Of the newly diagnosed infections with information about transmission mode in 2012 (204 – 64,76% of cases), 35.2% infections were due to injecting drug use, 62.2% to heterosexual contact and 1.9% to mother-to-child transmission. In 2012 one case of HIV infection among MSM was reported.

Data on CD4 count by the time of HIV diagnosis is not reported.

HIV treatment and care is provided by the governmental as well as nongovernmental institutions and there is a concern on access to ART for all who need, issues related to procurement and price for medications.

The deputy secretary general of the Ministry of Health has expressed an interest for the WHO external evaluation and emphasized issues of particular interest as follows:

- The model for ARV medications procurement considering increasing need in ART (centralized or decentralized, etc.)
- Retention in HIV treatment and care: how to address low level adherence to treatment)
- Enrolment in HIV care and timely initiation of ART: what are the barriers in health s System for late initiation of ART
- Significant increase of sexually transmitted infections rate and its link to HIV transmission.

2. Objectives of the mission

The WHO country mission will help to identify gaps and reveal challenges for scaling up and increasing effectiveness of treatment programme. The following technical areas along the cascade of HIV treatment and care services will be evaluated:

- HIV testing policy and practice and linkage to HIV treatment and care services
- Enrolment and retention in HIV care, including general HIV care, management of co-infections and co-morbidities, including integration of HIV/TB/services for PWID, CD4 count at diagnosis
- ART treatment: ART need and coverage, time and criteria for ART initiation, ART regimens, adherence to ART, ARV procurement and prices
- Monitoring of ART response: CD4 and Viral load, monitoring ARV toxicity

In addition to the mainstream of the HIV treatment and care services, country mission will focus on:

- Epidemiological data collected and analysed, including significant increase in STIs, use of epidemiological data for programmatic and managerial decisions
- Procurement and supply of ARV drugs, including prices and modes of procurement/delivery

The mission will assess the achievements, strengths and shortcomings in implementation of the National programme on HIV/AIDS treatment and care and generate strategic recommendations for improving key outcomes and impacts;

3. Participants

2 experts from WHO Collaborating Centre on HIV and Viral Hepatitis, Copenhagen, Denmark

- 1 expert on ARV procurement and supply
- 1 expert from the WHO CC on HIV Surveillance
- 1 expert from the WHO CC on Harm Reduction and OST

4. Methodology

Readily available information will be withdrawn from the secondary sources (publications, reports, etc.) during preparation stage for desk review and analysis.

During the country mission WHO experts will visit relevant institutions and facilities and interview key informants: policy-makers, health care providers and beneficiaries, NGOs, other national and international partners where appropriate.

Logistics support will be provided by the WHO Country Office in Tallinn and national health authorities.

5. Time, duration and geographical sites of the mission

Mission is planned for May 12-16, and 2 cities will be visited: Tallinn and Narva.

6. Deliverables

As a result of the mission a report which will include main findings and recommendations for increasing effectiveness of the national HIV response to Treatment of HIV/AIDS programme will be developed and posted on the WHO Regional Office for Europe website.

Annex 3 – Review team and informants

Review team members

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