Evaluation report, Barents HIV/AIDS programme

18.9 2011

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Intro

HIV-infections have spread rapidly in the Russian Federation (RF) since the first local outbreaks were reported i.e. in Kaliningrad (Leinikki 1997) and St. Petersburg (Smolskaya 1997). Globally, the spread of the epidemic has shown a stabilizing trend during the last ten years in many of the most affected areas (i.e. sub-Saharan Africa, the Latin Americas), at least in part due to internationally coordinated countermeasures. At the same time, in the RF, the spread of the infection has continued even at an accelerating speed. In fact, according to international analysts (UNAIDS, ECDC, 2010) this is currently the fastest growing epidemic in the world.

The driving force for the spread of the infection in the RF has been a concomitant "epidemic" in the use of illegal drugs, most notably heroin (Stellit, 2010). Using non-sterile injection equipment and sharing syringes and needles, the injecting drug users (IDU) transmit the virus to one another and later, via sexual transmissions, to their other partners and finally to the general population.

In North-Western Russia (NWR) the situation has been particularly bad in St. Petersburg, Leningrad, Kaliningrad and Murmansk regions. Whether there is a potential for rapidly spreading local epidemics in other cities and regions in NWR calls for careful surveillance.

The Barents HIV/AIDS Programme was developed by a group of public health experts from northwest Russia, Finland, Norway and Sweden, set up by the Joint Working Group on Health and Related Social Issues of the Barents Euro-Arctic Council (JWGHS of BEAC). It was launched in the beginning of 2005, and its implementation is planned to be continued also during the next Barents co-operation period 2012-2015.

The project "Controlling the spread of HIV/AIDS in the Barents and Northern Dimension Partnership Programme Regions" that was started in 2005 was intended to organize the work of the programme and at helping to get the spread of HIV/AIDS under control in the Barents and NDPHS regions and to minimize its damage due to social, health, economic and security consequences. It consists of three components: 1. coordination of the HIV/AIDS Programme, 2. development of low threshold services (for risk groups) in Murmansk and Kantalahti, and 3. technical assistance to the HIV/AIDS expert group of Northern Dimension Partnership in public health and social well-being (NDPHS).

The current evaluation is aimed at analyzing the situation and the role and impact of the Barents HIV/AIDS Programme phase II which has been operating from I/2008 to 12/2010. Its specific objectives are listed on p.5. The terms of reference (ToR) and the objectives of the evaluation as defined by the steering committee of the programme is enclosed as Annex 1.

Executive summary

The epidemic spread of HIV and its social consequences in the Russian Federation (RF) are very serious compared to almost any other European country. In the worst hit regions (some of which are located in the North-West Region (NWR) of RF the overall prevalence of infections approaches 1% of the population and the spread is among the fastest in the world. A striking feature is the role of injecting drug use with non-sterile needles and syringes as the dominant risk factor for transmission. There seems to be a rapidly spreading "epidemic" of drug addiction and illegal drug use making preventive and other interventions for HIV very challenging indeed.

The Barents HIV/AIDS Programme evolved from a long-standing network of collaboration between experts of governmental, regional and non-governmental (NGO) bodies from the Nordic countries and the Barents region, NWR. The initial planning process using LFA format and involving a great number of different organisations and institutions in all NWR regions concerned enabled to shape common objectives and find good action plans to achieve them. It has close links with the NDPHS activities mainly through its Expert groups on HIV/AIDS, (formally the Expert Group on HIV/AIDS and Associated Infections of the Northern Dimension Partnership in Public Health and Social Well-being (HIV/AIDS&AI EG of NDPHS)) and its Expert group on prison health, that was recently assimilated with the expert group on primary health care. The Barents Programme focuses mainly on activities within the NWR area while the NDPHS activities are expected to have a wider geographical coverage.

By the end of 2010, 21 projects have been completed, 13 are currently being implemented and 6 are being considered for financing. The projects share overall objectives and strategic priorities defined in common LFA seminars shared by all stakeholders. The steering committee (SC), where all regions and partners are represented, have met regularly and has had an important role in the overall guidance of activities. The resources for the meetings and for implementation of individual projects have come mostly from Russian, Finnish and Norwegian sources.

The evaluation is based on published written material and personal meetings with representatives from Arkhangelsk, Murmansk, St. Petersburg and Karelia. In addition answers to "evaluation questions" pre-defined by the SC, and a set of questions distributed by the evaluator before the personal meetings were used. The evaluation is not focused on individual projects but rather on an analysis of the current epidemic situation and of the "political environment" to make a judgement of the feasibility of the programme today and suggestions for further activities as mentioned in the ToR.

The most important outcome of the programme has been the support given to Russian counterparts in their efforts to build up prevention of the epidemic in their own regions. The programme has given Russian experts an opportunity to get an insight into the working methods and ideas behind them that are implemented in the Nordic countries. This has led to adaptation of new working formats that have been integrated into the regular work in health and social sectors. Another important field has been the support to develop inter-sectoral collaboration. Prevention of HIV and in particular the newly emerging threat of HIV/TB co-infections need good cooperation between sectors such as health, prison administration, drug control and tuberculosis control. Unfortunately, this has not been achieved in all regions. Various opportunities to obtain new, relevant information in various forms of training and exchange visits were appreciated by several interviewed experts. The role of SC in coordination and enhancing collaboration between different regions and stakeholders was also highly valued.

It is questionable whether the course of the epidemic can be effectively controlled during the next couple of years. In part this is due to the serious illegal drug use "epidemic" that continues to feed new infections to the population. At the same time, an increase in the incidence of sexual transmissions is on the rise and call for prompt enhancement of focused preventive actions. Nevertheless, there are signs of

stabilizing in some of the most affected areas (most notably in Murmansk, which has been a partner in a number of collaborative activities and where many pilot projects have been implemented successfully) which should indicate that while more efforts and more resources are needed, a significant impact is achievable and the course of the epidemic could be turned down. The long-term goal should be set so, that the epidemic could be brought under control in all of the most affected areas in the Barents region. Examples showing that this is feasible are available from elsewhere in Europe. The list of recommendations for the next stages of the programme include concrete proposals for the development of technical capacity, prevention and surveillance, anti-retroviral therapy (ART), human rights issues and coordination.

Methods used for evaluation

The results and conclusions given in the current report are based on a set of background documents (See ToR), site visits to Arkhangelsk, Murmansk, Karelia and St. Petersburg, written material from local experts in RF and comments from Norwegian, Swedish and Finnish members of the steering committee. A list of issues in a form of a questionnaire was used as the tool for collecting data and opinions. In addition, responses from various stakeholders to a list of "evaluation questions" defined by the SC were analysed.

Situation analysis

North-West Russia: Overall, the incidence (number of new cases reported per year) has become somewhat stabilized, but unfortunately at a high level, making the epidemic in the area one of the fastest growing epidemics in the world (Smolskaya 2011). However, what comes to the spread of the infection, the overall situation may be slightly better than what the figures show, in several regions a majority of newly detected cases are among older age groups than earlier (i.e. Bailuk 2010). The most probable explanation to this is that "hidden", previously undetected cases are now becoming "visible". Availability of potent drugs and lessened stigma are probably also contributing.

Infections linked with injecting drug use (IDU) still seem to be the driving force to the epidemic in NW Russia. Even if the share of other ways of transmission has increased, spread of HIV among drug users and their "constituency" (steady and occasional sex- and drug-use contacts) needs to be the focus of all preventive activities at least for the next five years. This group is very challenging in terms of preventive or treatment interventions. Often difficult to reach, with poor ability to adhere to any kind of treatment or rehabilitation schemes, experiencing discrimination by the society and by authorities, (medical, social and law enforcement), they are often not receiving the services usually available in health or social services for the general population. Their special needs have already been taken into account in some regions by establishing special service sites such as low-threshold service centres (LTSC) with easy access, free-of-charge and anonymous services and rapid testing, but such activities should rapidly be extended to achieve an epidemiologically significant impact in the region.

Anti-retroviral treatment (ART) has become widely available through federal funding but international and national experts still calculate that the coverage is not sufficient at the moment, mainly because the number of undetected HIV-cases is estimated to be quite big. This is unfortunate, since ART is useful not only for the infected individuals by alleviating symptomatic disease, but it also diminishes the risk of transmission in person-to person contacts thus having a potential for limiting the epidemic (Salminen, 2011). The coverage and ways of implementation will probably gradually improve over the

next years. This, along with effective prevention could reduce the costs of the epidemic to the society by preventing new infections but unfortunately – according to some analysts (presented in the Murmansk seminar in December 2010 and European AIDS conference in Tallinn 2011) – the number of patients who have proceeded into the AIDS stage has started to rise rapidly, putting additional and growing strain to the resources needed in health and social sectors.

At the same time new threats emerge: Prevalence of tuberculosis (TB), and in particular prevalence of multi-drug resistant tuberculosis (MDRTB), is quite high and is rapidly accumulating in the same risk groups as HIV. Concomitant infections are becoming more and more common and underlying deterioration of immune defence due to HIV increases the risk of transmission of TB to the general population. Surveillance of TB among HIV-infected individuals and HIV among TB patients is an important priority area for actions during the next couple of years.

Another concomitant disease with growing impact is hepatitis C (HCV), which has been spreading through needle and syringe sharing among drug users since the early 1990:s. The clinical disease may not become apparent until decades after transmission, but now the trend seems to be that HIV-patients are more and more suffering from the clinical manifestations such as acute forms of hepatitis and hepatic carcinoma (Nature New Biology, May 2011). Successful prevention of parenteral HIV transmissions prevents also the spread of HCV buth there is a need to enhance surveillance and implement proper treatment schemes for it.

Geographic variation in the extent of spread of HIV in NW-Russia is quite considerable. High prevalence areas such as St. Petersburg, Leningrad Oblast, Kaliningrad or Murmansk have up to ten times higher figures than some other areas, i.e. Arkhangelsk. The Republic of Karelia provides an example, where within a single region a few "hot spots" due to spread of infections among IDU:s dominate the overall figures while among the majority the epidemic is running a different course. For instance the role of IDU in shaping the spread may be different in different regions. Therefore common projects need to take into account the local circumstances and appreciate the local knowledge that has accumulated over the years.

Recent changes in the social environment have been rapid and have – and will in the near future – have a significant impact on the HIV epidemic in the future. Economic growth has improved the capacity of the health and social sector to meet the challenges. Involvement of NGO:s has enabled new types of approaches and probably also contributed to the improvement of general awareness and more "neutral" attitudes of the society to the problem. Also, increasing scientific interest has catalysed networking of local doctors and scientists with international collaborators thus stimulating the growth of professional skills and resources. In the Russian epidemic, several features of the disease can be studied that are not easily observable in other European countries that have lower incidence and prevalence, thus providing a fruitful basis for scientific collaboration.

There are some worrying observations and comments, that awareness among the general population and also among the young people about the public health aspects of HIV are deteriorating. A need to better integrate HIV and sex education to the school curricula is obvious.

The unstable situation and growing epidemic in the Russian Federation has caused concern in the neighbouring Nordic countries. Increasing traffic across the borders and the big difference in the prevalence of HIV infections and AIDS and the newly emerged threat due to MDRTB have all drawn the attention of politicians, experts and laymen. There seems to be a wide political willingness to

deepen the regional collaboration in issues related to HIV/AIDS. The Barents region has provided many excellent examples of collaborations with important new discoveries and sustainable improvements in preventive interventions and ways of treatment and care.

The legislative basis for anti-AIDS work in RF is based on laws developed in the mid-1990:s. In interviews, this was still seen as a completely adequate framework for proper counteractions or arranging treatment and care. The new (2010) legislation concerning the HIV testing policy is following recent international recommendations. At the same time, recent anti-drug legislation has gone through significant changes promoting social rehabilitation and seeing drug addiction rather a medical condition than a result of "bad habit". Unfortunately, some elements of harm reduction, proven effective in several carefully analysed international studies and recommended by WHO and other international organizations, and implemented for instance in many European countries, cannot be used in RF. This may risk the prospects for a positive development in the future in particular in regions with high incidence of HIV and high share of IDU:s among the risk population. A close follow-up of the situation is of paramount importance.

Finland, Norway, Sweden: The epidemic situation has stabilized in all these countries. The number of new cases is 4-6/100 000 inhabitants per year and the implementation and coverage of ART is good. The proportion of new infections linked with IDU is very low. Recently in Sweden new strategies have been adopted including needle and syringe exchange programmes. Most concern is now caused by the high prevalence and incidence of infections among men who have sex with men (MSM). Also, immigrants from high-endemic areas (Sub-Saharan Africa) contribute to a significant proportion of new cases in these countries.

Bilateral and multilateral collaboration in the region: Most of the projects linked with the Barents HIV/AIDS Programme have been implemented on a bilateral agreement between Finland and RF or Norway and RF. Often, the priorities and objectives of several projects coincide or even overlap. The programme has helped coordination and enabled the projects to adopt to special local circumstances. In wider networks, for instance those promoted by the public health funds of the European Union, this is often difficult, making them less suitable at least for the time being. Also, the specific "added value", so important for any regional collaborative efforts, is much easier to obtain in projects based on close cooperation with local implementing people and bodies rather than large, multicenter networks where the objectives and ways of implementation often have to be modified to meet a consensus.

Barents HIV/AIDS programme. Objectives, indicators and response

The Programme has six specific **overall objectives.** Here an overall evaluation of the impact of the programme is given:

A. Overall objectives:	**Impact of the programme:**
1. Existing legislation for effective national policies to control the HIV epidemic updated	The impact of the programme on this has been very limited
2. Technical, partner and response capacity for programme or project planning and implementation improved	This has been well achieved
3. Comprehensive and realistic prevention and surveillance activities are implemented	This has been well achieved

4. ARV treatment affordability and accessibility within the public health system correlate to individual needs	Impact of the programme has been moderate
5. Programmes ensuring respect towards human rights, including persons living with HIV/AIDS (PLWHA) are implemented	Impact of the programme has been moderate
6. Coordination between HIV/AIDS services and primary health care, educational, penitentiary and social services and sectors is established	Impact of the programme has been limited to moderate
B. The following groups have been identified for specific focus:	
1. Groups with high incidence and prevalence of HIV-infections: Intravenous Drug users, commercial sex workers, prisoners, and men who have sex with men	well achieved
2. The youth and adolescent	moderately achieved
3. People infected by HIV	moderately to well achieved

Evaluation indicators and responses:

For evaluation the following indicators/issues were listed in the ToR. Below, each component is briefly commented. (The comments are based on data collected during the site visits and from the available material):

1. **Changes in HIV situation and working context:**

- No significant change in the HIV situation during the last two years is evident, although the development has been more favourable than in several other regions in the RF (stabilizing incidence).
- Coverage and implementation of ARV have improved.
- A need for prompt and effective response to the emerging threats due to HIV/TB and HIV/HCV co-infections has been acknowledged, but coordination between various sectors still poor/non existent.
- Financial resourcing is still minimal compared to the needs and international benchmarks (see later in the text). Almost all of the money from federal funds are used for ARV and very little is available for preventive work.

1.1 HIV among pregnant women

- The incidence clearly demonstrates an increasing trend. For instance in Murmansk the number of newly detected infections has gone up from 53.4/ 100 000 in 2002 to 81 in 2010 (Bailuk 2011). This probably reflects the increase of HIV infections among women in general. At the same time there is a decrease in the number of pregnancies. In some statistics (i.e. Karelia 2011) the proportion of new infections among pregnant women contributes almost half of all new HIV cases detected among women. This may indicate less effective diagnostics among non-pregnant female population.

1.2 Mother-to-Child transmissions

- The frequency of vertical transmissions has reduced considerably during the early years of the 21st century but now seems to be stuck at a level (8-9%) that is higher than in most of the European countries (Smolskaya, 2010). At the same time the coverage of chemical prevention has increased considerably reaching almost 90% in 2010. A possible explanation is probably the increasing incidence of very recent infections among pregnant women. The diagnosis is missed because of the "window-period" when the first HIV test done during early pregnancy and the chance to start ARV in due time is lost.

1.3 HIV among injecting drug users (IDU)

- The figures have stabilized in Murmansk but are very high in St Petersburg according to studies (61.4% in 2009, Centre for Social Research and Prevention). At the same time injecting drug use (heroin) is becoming more and more prevalent at an alarming rate. However, the view of the experts in Murmansk is that "the situation would be much worse, if the proper actions like the LTCS and outreach work would not have been implemented".

1.4 HIV among commercial sex workers (CSW)

- Increase has been observed in Murmansk (Bailuk 2011). The explanation given is that more and more of the CSWs are drug addicted and exposed to parenteral transmissions. Their "bridging role" towards the other sectors of population needs further surveillance.

1.5 HIV among prisoners

- A steady increase (i.e. from 900 to 2900 per 100 000 tested prisoners in Murmansk in ten years) is seen everywhere in RF. The important impact of this increase to the rest of the society is generally acknowledged but collaboration between the health and social sector and the prison system is still insufficient leading to gaps in i.e. ARV treatment. Also the increase in HIV/TB among prisoners may pose a threat upon release. A good social rehabilitation would be important but needs considerable efforts and can benefit from further international collaboration.

1.6 People living with HIV and AIDS (PLWHA) and anti-retroviral treatment (ARV)

- Due to federal financing and efforts by the local AIDS centres both the implementation and coverage of ARV has become better. This has also created a more close relationship between PLWHA and AIDS centres leading, in turn, to better delivery of services. Unfortunately, in spite of achievements, there are still problems due to undiscovered cases and difficulties to access most-at-risk populations (MARPs).

1.7 Multi-sectoral collaboration

- In all regions some forms of collaboration have been established. However, the preventive work seems still to be quite vertically implemented due to the established working formats in the different branches. Improving collaboration especially with TB- and Prison systems and various actors working in health promotion and social rehabilitation (including NGO:s, schools and civil society) should still be in the focus of the programme.

1.8 Legislation changes

- The federal law covering HIV/AIDS (1995) is still valid and regarded as sufficient. New additions deal with testing policies ("sanitary rules", 2010) and drug control (new law 2011). The new law for drug control emphasizes the importance of treatment and rehabilitation but also puts some restrictions that may hinder successful anti-HIV work in the future.

2. Description of development in:

2.1 Existing legislation

- Federal laws regulate activities quite strictly. Implementation at regional levels seems to indicate that some freedom of choices is yet possible. New anti-drug legislation guides political thinking but previous activities can still be continued successfully. It should be stressed that main objectives of work among IDU:s is prevention of HIV and this has to be, and can be, successful even with most strict anti-drug legislation.

2.2 Technical, partner and response capacity for programme or project planning:

- Training in various forms has been successful and well received. It was regarded as the most important component of the program in several interviews and should be extended further.

2.3 Comprehensive and realistic prevention and surveillance activities are implemented:

- Important and successful work has been done by LTCs.
- The working principles in AIDS Centers have changed and are now more focused on MARPs, whose access to treatment and care has improved concomitantly.
- Increase in knowledge concerning risks and prevention has not been widely measured and some studies indicate clear problems here. Access to vulnerable groups has improved, no data is available from condom use.
- Secondary surveillance has been implemented in some areas.
- Role of NGOs has become bigger.

2.4 ARV treatment affordability and accessibility within the public health system:

- ARV is implemented by local AIDS Centres where the clinical expertise and accessibility are good and stigma less pronounced. In remote areas a “trusted doctor” works as the intermediate. Supporting laboratory facilities have improved significantly. With the current system, the delivery of treatment is relatively good, but gaps still remain in coverage (unidentified cases, non-complying customers) and implementation (interruptions, complexity of treatment schemes and follow-up). Adherence data is scanty.

2.5 Human rights issues

- Wide implementation of ARV has increased the contacts between PLWHA and health care personnel having a positive impact on the attitudes of both sides. Still problems in sectors where PLWHA are seen only occasionally. In interviews, all sectors were mentioned in a negative context, including the primary health care system. Employment of PLWHA is still uncommon. (There is no obligation to reveal one’s HIV status upon employment but in real life concealing the status can lead to further problems due for instance to need for regular check-ups and taking of drugs).

2.6 Coordination between AIDS centres and primary health care system and other sectors

- Exchange of information has increased but primary health care is still rather an outsider in the process. This may be good for the time being since the know-how and resources lie within the AIDS Centres. Also, within primary health care stigma and discrimination may still be encountered. However, in a longer perspective the role of primary health care in particular in identifying new cases of infections should and will become more pronounced.
- The AIDS Centres are collaborating with TB dispensaries, drug-control authorities, narcological centres, prison authorities and educational sectors. However, in some interviews considerable problems were reported. There seems to be a need for coordination by high-level political leadership, in order to bring all relevant stakeholders (health and social sectors, educational and law enforcing elements etc.) together to discuss the regional problems and common policies.

3. Views of the local implementation capacity (training)

- Training has been an integral part in almost all projects implemented through the programme. It was highly appreciated by all interviewed persons. Also new initiatives were hoped for. In particular the "new fields" such as HIV/TB and HCV would be welcome.

4. Sustainability issues

- Pilot projects in Murmansk (outreach work, LTSC) have led to sustained activities operated by local administration. Acceptance has been good particularly in Murmansk and Arkhangelsk. This was regarded as one of the important results of the program.

5. Local management

- Well established, although collaboration with other sectors such as TB and Prison health system could still be improved. Data exchange using modern technology would be welcome but resources to make necessary adjustments are not available.

6. Collaboration between international projects

- Excellent examples in Murmansk, Karelia and Arkhangelsk from Norwegian and Finnish funded projects exist. Outreach-, LTSC- and training activities are all well in balance with each other and with the priorities.

7. Relevance of Barents programme

- Main achievements are the permanent exchange of information in a well working network of experts and political decision makers, supporting priorities that reflect the regional needs. Impact on the epidemic situation cannot be definitely verified yet. "The situation would be much worse without it"/ "The situation has only gone worse" The important question is can the spread of HIV be stopped while the IDU situation is getting worse.
- Impact on the know-how and attitudes of local experts and decision makers is probably

significant, helping them to understand the contexts of various interventions and policies against observations and experiences from neighbouring countries. Overall, both the local stakeholders in NWR and the external evaluator regard the programme relevant and having a significant impact. There is a clear need to continue such activities.

Further observations and background for the recommendations:

1. In several regions in NWR, still a very high proportion of all HIV cases are due to injecting of illegal drugs using non-sterile needles and syringes (= sharing with others). There seems to be an alarming, almost epidemic spread of IDU. Heroin is the prevalent additive drug injected. The proportion of HIV-infected among all (registered) IDU:s has increased dramatically according to studies in St. Petersburg ("HIV epidemic among injecting drug users (IDU) in St. Petersburg, Russia: Process dynamics and the actual situation according to a review of relevant studies. Centre for Social Research and Prevention. Bulletin 2010/1"). The situation is bad also in Murmansk, less so in Arkhangelsk and Karelia.

Compared to the neighbouring western countries and most other European countries the difference is obvious, in these countries both the incidence and prevalence of HIV among IDU:s has decreased significantly and consequently the risk of an expanding HIV epidemic among the general population is much smaller. Within the Russian Barents region, same types of strategies as in these countries (outreach, free-of-charge services, and easy access sites for most at risk populations) have been implemented but seemingly with only limited success. The explanations could be

- rapidly increasing numbers of drug (heroin) addicts whose social exclusion makes successful prevention of HIV difficult or impossible, or,
- scale of efforts implemented so far is too modest.

Compared to a couple of "indicator countries" with established benchmarks the resources that are used in RF are still lagging considerably behind. Also, in RF the entire palette of countermeasures (full use of internationally recommended harm reduction measures) has not been used. It is possible that political leaders see here a contradiction with the necessary anti-drug policy.

Table

Estimate of national expenditures for HIV, a comparison:

	Portugal	**Russia**
Total budget (MEUR)	200*	500**
Population (Million)	10	130
Euro/Inhabitant	20	3.3
HIV prevalence%	0.7	0.8
No of HIV+ people	70 000	1 000 000
Euros/HIV+	2900	500

*Barros: Personal communication. European AIDS Conference, 2011, Tallinn, Estonia.

**Federal Budget for 2011: 19.7 billion Rub = 500 000 000 Euros. (Smolskaya, personal

communication 2011).

2. Co-infections with TB and HIV are emerging as serious problems in some areas of the region. In part, the increase is due to the fact that the same risk factors that lead to HIV-infection may also lead to TB. Furthermore, thanks to the successful implementation of ARV, the number of PLWHA is rapidly growing, and since they are more sensitive both to contract the infection and to activation of latent infection. All this means an increased risk of TB for the general population, aggravated by the high prevalence of drug-resistant TB strains. Considerable attention is already now focused on this problem in the RF but the necessary countermeasures may not be easy to get into action. The situation may call implementation of infection control measures long forgotten and experienced as unpleasant both among the individual patients and health and social care workers.

3. The economic burden due to HIV is rapidly growing pressing hard both social and health sectors. Comparisons with other European countries may help decision makers in RF and in the regions to optimize their strategies for dealing with this problem.

4. In spite of the availability of free anonymous testing for the population, there seems to be an obvious need for easy access to anonymous testing for the general population (Murmansk survey 2009, other observations). One suggestion put forward in international discussions is adoption of a "lighter" version of counselling in connection with the testing. In particular members of the risk groups may not be so anxious to hear the same "story" over and over again. Easiness could be a gate to a better access to people with risk behaviour and prevention among them. This could also be a good field for international collaboration.

5. The projects implemented under the Barents HIV/AIDS Programme have brought important information about the risk factors and their evolution among IDU:s (Egorova et al, 2010). This helps to focus the interventions in a feasible way. For instance the study showed that even if needles and syringes are available through pharmacists, wherever exchange programs have been implemented, the access has improved reducing the risk for HIV transmissions.

6. Cost effectiveness of preventive work is not duly studied or appreciated. One single case of prevented HIV infection saves not only in potential ARV treatment costs (approximately 4-8000 Euros/year for 10-20 years) but also other health expenditures (that are higher among PLWHA:s than in the general population due to various forms of co-morbidity). The costs resulting from social marginalization and exclusion due to HIV are more difficult to estimate but could be quite considerable. If, as an example, the 131 new cases that MAC detected through its LTSC-services between the years 2008-2010 could lead to a prevention of 50 new infections, the amount of money saved would probably exceed the total budget of MAC. Producing accurate data for instance by a research project and drawing political attention to the results would be of importance and a topic also for the Barents HIV/AIDS Programme.

7. The programme has had a role in the coordination of activities, which have been financed through other international financiers such as Nordic Council of Ministers and the EU Commission. This is an area where the programme has good potential also in the future by providing training, expertise and practical help to our Russian counterparts in their attempts to get financing and administering projects.

8. Sustainability is an important indicator of successful international work. This should not be interpreted so that only projects and activities that become sustainable are useful, often also pilot projects may bring important information about what is feasible and what not. The Barents HIV/AIDS Programme has implemented several projects that have led to sustainable developments and the long-term collaboration in the region has helped to further develop local activities and

provide models for adaptation in new regions.

9. Role of primary health care is somewhat controversial. Primary health care provides the natural contact point of individual citizens with the health care system and an optimal arena for detecting new, previously undiscovered cases. Its role in implementing the necessary care, if properly guided, would also help infected individuals to get an easy access to necessary help and support. However, a risk for encountering stigma and discrimination in the primary health care is currently thought to be bigger than in the AIDS Centres. Also, the confidentiality may be compromised, in particular in smaller communities.

Analysis:

Main achievements:

- Access to most at risk populations has been established in sites where low threshold centres and outreach work have been implemented, with an impact on the spread of the disease and the social and medical consequences.
- Civil society and NGOs have been involved.
- Training of experts has modified attitudes more favourable towards vulnerable populations and given tools to work with them.
- The need for coordinating activities has been met.
- Planning processes for programs and projects have been improved (LFA, training).

Main problems:

- More resources are necessary to overcome the spread of infection among injecting drug users.
- Coverage of and adherence to ART is still not sufficient.
- Burden due to concomitant infections by tuberculosis and hepatitis C is growing and inter-sectoral coordination needs improvement.
- Resources available for preventive work are currently not sufficient, in particular a lack of local money is mentioned in several occasions.

Obstacles:

- Long distances, poor connections, poverty in particular in the distant areas.
- Shortage of overall resources in health and social sectors.
- Dominant role of drug addiction in the HIV-epidemic
- High and growing prevalence of PLWHA

What could be done:

- Make a plan to stop the spread in major cities and “hot spots”. A realistic plan for each region

should be agreed upon to reach the “zero-target” set by UN (2011) within a reasonable time table.

- Demonstrate problems and analyze their reasons and ways how to fix them using modern research methods, and explain the results to the political decision makers and general public.
- Increase and maintain technical and professional support and exchange of views and experience.

Recommendations:

1. Development of technical capacity
    a. Platform for international collaboration should be maintained and developed further. Here, coordination and regular meetings of the steering committee are the most important tools. Also the link with the Northern Dimension Partnership should be maintained. Activities should include high level training in the forms of seminars, exchange visits and collaboration in working with media and involving NGO:s.
    b. Development of data exchange between sectors. This has been proven a difficult field in many countries including Russia. Technology is more advanced in Norway and Finland and this could be utilized in the collaboration.
    c. Projects supporting independent academic research and networking of academic institutions should be promoted.
    d. Dialogue concerning legal and economic issues should be continued and promoted. The topics could include data exchange of patient data between different sectors, financial issues concerning the potential savings and economic burden to various sectors, and reviewing the horizons and long-term goals of sufficiently comprehensive AIDS policy.
    e. Trainings on project and programme planning (e.g. by Logical Framework Approach) should be continued.

2. Prevention and surveillance
    a. Support to easy access low-threshold centres and outreach activities should be extended to meet the challenges that the widening epidemic will pose in the near future. Amount of LTSCs should be increased in the region. All approaches available should be utilized in their work. The importance of prevention of sexual transmissions in particular among IDU:s and their constituency should be emphasized and supported for instance by distributing free condoms to most-at-risk populations. The problems related to the prison population should also deserve special attention. The working principles of the low-threshold centres also offer the best platform for interventions among sex workers and other vulnerable groups.
    b. Support to peer training and voluntary work should be continued and promoted. Learning from NGO:s that have worked for a long time and achieved an established position in their countries to develop new approaches and strategies for the work in the region is important. Collaboration to achieve international funding for activities should

be continued and promoted.

c. Promotion of anonymous testing with easy access and quick results should be promoted. Linking such activities with research should be encouraged to find the optimal algorithms and best access to at-risk populations.

3. Anti-retroviral drug therapy (ART)

a. Currently, implementation of ART is guided and financed by Federal orders. Exchange visits and conferences for clinical experts could help Russian counterparts to improve professional skills but the programme should also support work to identify “gaps” and “hidden needs”. The high number of patients and the spectrum of clinical manifestations should provide an interesting field for international collaboration between clinicians in different countries in the region.

4. Human rights

a. Projects dealing with this issue should be promoted also in the future. In particular discrimination and stigma encountered in health and social sector and in connection with employment should be in the focus.

5. Coordination

a. Inter-sectoral coordination is becoming more and more important. Topics such as data exchange and management (see above) and joint efforts to improve social rehabilitation of drug users and ex-prisoners should be prioritized.

b. The Steering Committee of the Barents HIV/AIDS Programme has an important role in promoting inter-sectoral coordination and collaboration. This should be further emphasized in its work.

Annexes:

1. ToR for the current evaluation
2. Response and analysis of the predetermined surveillance questions.

List of references.

(Complete list available from the author)

Acknowledgements:

Experts from all sites visited devoted their valuable time for in-depth discussions and analysis and this is highly appreciated. My sincere thanks go also to the coordinator of the programme who not only organised all the practical details for the process but also gave valuable suggestions and observations during the visits and development of the final report.

Annex 1.

Terms of Reference
Programme evaluation expert

Within the framework of the project "Controlling the spread of HIV/AIDS in the Barents and Northern Dimension Regions (Phase III)", the expert will evaluate the Barents HIV/AIDS Programme during the period indicated in the contract between THL and the expert. The expert will report to the Programme Coordinator Outi Karvonen at THL.

The aim of the monitoring process is to provide

1) ***General description about the current HIV situation in North West Russia and, particularly, in the Barents Region***
2) ***A description of the progress of the Barents HIV/AIDS Programme in the Russian Barents region and***
3) ***Recommendations for the Programme period in 2012–2015.***

Main issues to be covered by the evaluation process

- Changes of the HIV situation and working context of the Barents HIV/AIDS Programme after autumn 2004 when the Programme was planned and its objectives defined, and mainly focusing on changes after the monitoring of the Programme in 2008. Special views shall be presented in the framework of the objectives defined in the Programme Document.
- Description of the development in the sphere of the following objectives:
    1. Existing legislation for effective national policies to control the HIV epidemic updated
    2. Technical, partner and response capacity for programme or project planning and implementation improved
    3. Comprehensive and realistic prevention and surveillance activities are implemented
    4. ARV treatment affordability and accessibility within the public health system correlate to individual needs
    5. Programmes ensuring respect towards human rights, including persons living with HIV/AIDS (PLWHA) are implemented
    6. Coordination between HIV/AIDS services and primary health care, educational, penitentiary and social services and sectors is established.

- Views about the local implementation capacity, with special attention to possible needs for further training
- Sustainability issues
    - acceptance of activities by relevant authorities, e.g. Health Committee, regional administration, police, drug control unit
    - local financing for activities
- Local management of the activities within the Programme framework
- Collaboration between different international projects
- Collaboration between international projects and local programmes, relevance of Barents HIV Programme when considering other programmes
- Management and organisation of the Programme (Steering Committee etc.)

The following regions and organizations are to be visited and interviewed:

1. **St. Petersburg**
   - Northwest District AIDS Centre (Tatiana Smolskaya)
   - NGO Stellit

2. **Petrozavodsk**
   - Republican AIDS Centre
   - Ministry of Health and Social Development of the Republic of Karelia

3. **Murmansk Region**
   - AIDS Centre, including Low Threshold Support Centre
   - Ministry of Health
   - Anti-Drug Commission

4. **Archangelsk Region**
   - AIDS Centre
   - Health Committee

In each region there may be additional organisations to be interviewed.

In addition, phone or e-mail interviews of the Norwegian, Swedish and Finnish Steering Committee members according to questions sent beforehand should be conducted.

The Evaluator is entitled to carry out any discussion relevant for the implementation of the evaluation. The Evaluator is not entitled to make any agreements on behalf of the Programme or THL. The development of detailed plans for all the visits will be done together with the Programme Coordinator, who will also assist in the necessary practical issues.

The relevant background documents are:

- Barents HIV/AIDS Programme. Barents Euro-Arctic Council, Working Group on Health and Related Social Issues. 24.3.2005
- Project proposal for 2011–2013 "Controlling the spread of HIV/AIDS in the Barents and Northern Dimension Regions. Phase III", 31.8.2010
- Final report for the project "Controlling the spread of HIV/AIDS in the Barents and Northern Dimension Partnership Programme Regions. Phase II "
- Barents HIV/AIDS Programme Steering Committee annual progress reports
- Murmansk evaluation report, compiled by professor Pauli Leinikki (2007)
- Barents HIV Programme monitoring report by Dr. Ali Arsalo (2008)
- Evaluation of Norwegian-Russian HIV projects in the Archangelsk Region, Prof. Pauli Leinikki (2009)
- Answers of the Steering Committee members to an evaluation questionnaire, November 2010.
- Evaluation report on collaboration between Finland and Russia in the social and health spheres during 2004-2009 (by Pauliina Aarva)
- UNGASS report of the Russian Federation

- The anti-drug strategy of RF (published in summer 2010)
- Latest relevant legislation of RF

Other useful documents:

- Minutes of the meetings of the Programme Steering Committee

Annex 2. Summary of responses to questions posed by the Steering Committee:

Name of Your Region/Country: Summary from Komi, Murmansk, Karelia and Archangelsk				
	Fully completed	**Somewhat completed**	**Not at all completed**	**Irrelevant**
1.1. Networks of low-threshold centres for hard-to-reach target groups strengthened.		**Komi**: Work with organization "Drugoi Vzglyad" (LGBT) + seminars for PLHA **Murmansk**: Centers exist only in Murmansk and Kandalaksha	**Archangelsk:** there are no low-threshold centers in A **Karelia:** Low-threshold centers not established	
1.2. Links between drug treatment, HIV counselling and testing programs and primary health care services established.	**Komi**: Links established **Murmansk**: Links have been established but consulting on HIV can be strengthened in PHC **Karelia**: Counselling on HIV introduced but not sufficiently conducted in PHC facilities **Archangelsk:** 18 screening labs and 54 medical facilities use express tests. All districts appointed doctors. AIDS centre is the coordinator and it provides medicines.			
1.3. Programs, towards increased knowledge, encouraging healthy attitudes, developing skills or changing behaviour among youth, instituted.	**Komi:** The curriculum includes classes on HIV prevention **Karelia:** HIV prevention and healthy life style programs are in operation, but they should be extended Archangelsk: 1. Seminars and lessons for youth and teachers 2. Project "Face the	**Murmansk**: Classes on sex education are not included into the curriculum. Young people get informed about healthy lifestyle and changing		

	problem" by financial help from Norway	behaviour		

1.4. Accessibility for young peoples to user-friendly STI services, voluntary counselling and testing (VCT), condoms and other resources for sexual health improved	**Komi**: Established **Murmansk**: Offices for young people are available in all cities of Murmansk Region **Karelia**: 4 centres "Youth-friendly Clinic" are working **Archangelsk**: 1. Youth clinic "Yuventus, dermatological clinic 2. Anonymous testing and counselling at the AIDS centre and medical facilities in the region			
1.5. Health care workers counselling skills development programs established	**Murmansk**: All medical personnel get counselling every year **Karelia**: Medical personnel get counselling and training **Archangelsk**: Seminars for medical personnel and methodical recommendations			
1.6. Monitoring of changes in the risk behaviour patterns that are associated with HIV, and monitoring of sexual behaviour, especially among the vulnerable groups is established	**Komi**: Prolonged sociological studies **Murmansk**: Monitoring of the studies of behaviour patterns among the youth and risk groups is done except for MSM **Karelia**: Selective questioning takes place among different groups of people	**Archangelsk**: Questioning before informing about the matter	**Murmansk:** No monitoring among MSM	

1.7. General awareness on current trends of care, prevention and infection safety, among health care workers indirectly involved with HIV/AIDS increased	**Komi**: Annual training of medical staff with attestation on HIV/AIDS issues **Murmansk**: In local hospitals of each city there are doctors appointed to deal with HIV/AIDS prevention and infection safety **Karelia**: Medical workers get trained on the issues of HIV infection prevention and treatment **Archangelsk:** Seminars and cycles of post-graduate training for medical faculty (jointly by AIDS centre and Northern State Medical University)			
1.8. Communication strategies to promote services, improve symptom awareness and STI treatment seeking behaviour are established and operational.	**Komi**: National information strategy is being implemented **Murmansk**: A long-term STI prevention and treatment program is under implementation in Murmansk region **Karelia**: Medical faculty "Republican Dermato-venereologic Dispensary" and "Youth-friendly Clinics" work for STI prevention **Archangelsk:** Planned activities at medical and training facilities on the whole territory of the region			
1.9. Mass-media participation in information dissemination on HIV/AIDS ensured	**Komi**: Ensured **Murmansk**: Mass media (TV, radio and newspapers) are actively involved in disseminating information about HIV/AIDS	**Karelia:** Mass media are involved in increasing awareness of HIV/AIDS on World AIDS Day **Archangelsk**: Different mass media are involved but		

		there is no clear strategy		
1.10. HIV prevention programs in prison settings established	**Komi**: HIV infection testing **Karelia**: Medical personnel and psychologists from the penitentiary system are trained on prevention methods and they work independently in penitentiary facilities **Archangelsk**: Project till 2009 (Norwegian church support project since 2010 "social partnership against HIV/AIDS. System for HIV infection testing developed	**Murmansk:** No special programs. There is a great need in programs implementa-tion		
1.11. MTCT prevention activities for pregnant women with drug dependence or placed in prisons are established and operational.	**Komi**: All pregnant women are tested for HIV **Murmansk**: All pregnant women are tested for HIV. There are problems with testing drug addicted pregnant women **Karelia**: All pregnant women are tested for HIV infection and in case of positive results they are registered at the AIDS centre and get chemical prevention treatment **Archangelsk:** All pregnant women are tested for HIV			

Summary. Part 2. Response to questions posed in Arsalo's and Leinikki's evaluations:

Is prevention still the field that would require most attention? (Contra treatment, diagnostics, legislation etc.)

Komi: Yes
Archangelsk: this field is equal to the others. However, prevention is not financed as well as treatment and diagnostics. Prevention requires more attention. Treatment is available for each resident of A. region, all patients get it.
Karelia: Since prevention makes a strong impact on the situation, this field remains urgent. Unfortunately it gets no financing from the regional budget
Murmansk: Prevention requires considerably more attention in the region. Today, treatment and diagnostics are available to all those who need them.

Do all regions have peer support groups for PLWHA?

Komi: Society established in 2010
Archangelsk: A group has just been formed in A region (up to 10 persons) thanks to "Patient School" project implemented together with Red Cross and AIDS centre in 2010, where peer consultants are working
Karelia: Despite the support from the republican AIDS centre and NGO Russian Red Cross, the support is not working at the moment. No initiative from PLWHA.
Murmansk: Peer support groups exist only in the City of Murmansk

Are NGOs well included into the preventive work and work with PLWHA?

Komi: Yes
Archangelsk: Yes, preventive work includes "Rassvet" Red Cross, Rakurs, PLWHA-Red Cross, Rassvet
Karelia: Yes, Russian Red Cross helps working with PLWHA
Murmansk: Yes, they are

Are there good contacts between AIDS and TB services to work with co-infections?

Komi: Yes, via an appointed TB doctor
Archangelsk: Yes. Planned and urgent examination of HIV infected cases, availability of a doctor-coordinator for co-infection for Archangelsk region at TB dispensary, TB chemical prevention in case of positive indications, organization and implementation of TB treatment in HIV infection cases, Dispensary monitoring, information exchange and continuity
Karelia: Republican AIDS centre and Republican TB dispensary work in close contact.
Murmansk: Yes, since 2009 a joint Russian-Finnish project "Cooperation in the area of TB+HIV co-infection" has been implemented.

Possible threats and your response:

Sharp reduction in domestic financing and external resources?

Komi: No
Archangelsk: The situation continues to deteriorate
Karelia: Reduction of financing for prevention programs can result in reducing awareness and growing incidence
Murmansk: There is such a threat. Preventive programs are going to be considerably cut in Murmansk region

A hidden epidemic emerging among risk groups?

Komi: Phase of concentrated epidemics among IDUs
Archangelsk: 1. Strengthening interactions with "Rakurs" organization (people with non-traditional sexual orientation), trips of the bus to the parties and meeting points with HIV express tests and counselling. During the whole period, 15 cases have been identified among homosexuals, including 4 (26, 7%) in 2010.
Karelia: When awareness decreases, behaviour risk increases, and as a result the incidence grows (also in risk groups)
Murmansk: In the course of 2010 HIV infection spread among drug users and their specific

weight made 61,2 % (72% among men and 44,7 among women). Compared to 2009, the total number of transmission via drug use reduced by 17,3 % and by 25,4% among men. The share of women among the total number of HIV infected cases increased to 40%. 83,4% out of them were diagnosed in sexually active age.

Cooperation between authorities deteriorates?

Komi: No
Archangelsk: Project Pertinax Group envisages coverage of the specialists of local authorities in all districts where activities are planned. In November those are Kotlas nad Koryazhma. Project "Social Partnership against the spread of HIV/AIDS in Northwest Russia" envisages expansion of the interaction.
Karelia: due to the lack of coordination by AIDS committee in the Republic of Karelia, there is low level of interaction, lack of coordinated activities by different ministers and agencies on HIV infection prevention
Murmansk: No such fear so far

Increase of TB among HIV-infected and XDR TB?

Komi: Yes
Archangelsk: At the end of 2009: in total 31 cases were registered (22 men and 9 women)
Karelia: There is an increase of TB cases in HIV infected and increase of TB MDR cases.
Murmansk: Increase of TB incidence among HIV cases and increase of TB with MDR is connected with the general trends in TB dynamics in Murmansk region as well as with better diagnostics of HIV+TB and HIV/MDR cases (improvements in the work of laboratories and registration of cases)

Recommendations/suggestions:

Increasing of collaboration with universities - e.g. in behavioural and epidemiological research

Komi: Further cooperation with higher and secondary education facilities is planned
Archangelsk: 1. Research project "Management of HIV/AIDS in NW Russia" The final conference will take place on Dec 2 2010 at Northern State Medical University in A. 2. NSMU together with AIDS centre- training programs for doctors and nurses on laboratory diagnosis of HIV infection
Karelia: We consider this are to be of great importance; however we have had no extensive experience of research cooperation with Petrozavodsk State University or Karelian Pedagogical Academy. In 2010 the department of Social and Political Sciences of Petrozavodsk State University, independent non-commercial organization "Sodeistviye" and Republican AIDS centre questioned school girl students from 9-11 grades and their parents about their knowledge of HIV/AIDS and behavioural risks within the project "Sodeistviye" "Prevention of HIV infection spread among girls of 15-19 years if age"
Murmansk: Murmansk AIDS Centre cooperates with higher education facilities in the City of Murmansk when disseminating questionnaires for studying behaviour patterns among the youth.

Support to training and empowering of primary care nurses and doctors in particular what comes to their possibilities to enhance promotion and early case finding

Komi: The AIDS Centre of the Republic of Komi has no opportunity to give additional power to PHC doctors and nurses
Archangelsk: 54 medical facilities of the region use express tests for urgent situations. Two nurses got trained at Olafia Clinic.
Karelia: PHC personnel get training on healthy lifestyle development, HIV infection prevention and clinical suspicion for early exposure of infectious diseases. However, this work should be extended to cover doctors also.
Murmansk: Primary health care doctors and nurses supervising training facilities and schools continuously work on developing health lifestyle

Youth education: Peer education and training visits should be promoted and supported

Komi: A group of PLHA was formed; peer-to-peer training is carried out among PLHWA and LGBT
Archangelsk: Project on peer-to-peer training (Pertinax group) – study trips to Kotlas and Koryazhma in November 2010
Karelia: Volunteers are trained for peer-to-peer work. Constant methodological support to such groups of specialists is required as well as experience exchange, including study tours.
Murmansk: Peer-to-peer training was launched and has continued in the region

Social support and rehabilitation to vulnerable people such as IDU:s, ex-prisoners, CSW:s

Komi: The republic has social security facilities (Centres for helping people in crisis situations, hot lines etc.)
Archangelsk: There are no rehabilitation centres
Karelia: On the whole, the programs of social rehabilitation of ex-prisoners, IDUs and CSW are not working. Regional programs have some sub-areas: anti-drug program has a block on ex-IDUs rehabilitation.
Murmansk: this is a hot issue. Such work is done within the project, and it has been planned to open a special centre for ex-prisoners under the governmental social service in Murmansk in 2011