



Barents HIV/TB Programme 2020 - 2023

The Barents Euro-Arctic Council, BEAC

Joint Working Group in Health and Related Social Issues, JWGHS

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1. Abbreviations and acronyms

AIDS – acquired immune deficiency syndrome

HIV – human immunodeficiency virus

JWGHS – Joint Working Group on Health and Related Social Issues

MDR-TB – multidrug-resistant tuberculosis

TB – tuberculosis

UN – United Nations

UNAIDS – Joint United Nations Programme on HIV/AIDS

WHO – World Health Organization

XDR-TB – extensively drug-resistant tuberculosis

2. Executive summary

The situation with HIV and tuberculosis in the Barents Region is diverse. While in the Nordic part of the Barents Region the rates are consistently low, in the Russian part the epidemiological landscape is complicated and characterized by decrease in TB (tuberculosis) incidence, but HIV incidence persists to grow. The other aggravating factors are high proportions of HIV/TB co-infection and patients with drug-resistant forms of TB.

The Barents HIV/Tuberculosis Programme, a merger of the preceding Barents HIV/AIDS and Barents Tuberculosis Programmes, is operational for four years, from 2020 till 2023. While keeping in the radar the goals defined by the WHO and United Nations, the Programme seeks to pursue the challenges common for the Nordic and Russian parts of the Barents Region and aims to scale up HIV-infection and TB response in the Barents Region through international cooperation. The intensification is envisaged through three core priorities – development and implementation of patient-centric approaches in management of HIV-infection and tuberculosis; improving competences of staff working with HIV-infection and tuberculosis; and ensuring consistent information and knowledge sharing.

It is expected that the Programme will elevate the role of the Steering Committee of the Barents HIV/Tuberculosis Programme as the regional expertise hub in HIV- and tuberculosis-related questions.

3. Introduction

3.1. *Notes on epidemiological situation*

Globally, the disease burden caused by HIV-infection and tuberculosis is steadily going down. Pursuant to WHO and UNAIDS estimates, in 2017, there were 1,800,000 new HIV cases (2,800,000 cases in 2000) and 10,000,000 new tuberculosis (TB) cases (slightly above 10 million new cases in 2000). There were as many as 940,000 HIV-related deaths (1,500,000 cases in 2000) and 1,300,000 deaths from TB (including 300,000 deaths among people living with HIV) (app. 1,700,000 TB deaths in 2000, of whom 500,000 among people living with HIV).

In the Barents Region, the epidemiological situation is characterized by the following features and factors:

Firstly, the HIV and tuberculosis situations differ between the Nordic areas and Russian areas of the Barents Region. The rates of the infections in the Nordic areas are lower than in the Russian areas.

Secondly, the key transmission routes for HIV-infection in the Nordic countries are sexual contacts, and primarily sex between men. In the Barents Russian regions the dominant modes are sexual contacts, where the share of the infection transmission through heterosexual sex overwhelms. Besides, the role of intravenous drug use is rather high and in some territories the drug use as a mode of HIV transmission may prevail.

Thirdly, in the Barents Nordic regions, many of the newly diagnosed cases of HIV-infection and tuberculosis have foreign origin. In the Barents Russian regions the proportion of migrants or infection brought from abroad in the epidemic picture is quite subtle.

The HIV-infection and tuberculosis rates in the Nordic countries have been on decline or at least stable in the last decade. The epidemic processes for HIV-infection and tuberculosis on the territory of Russia move in opposite directions. While the TB epidemiology has gone steadily downwards in the last decade, the HIV situation is characterized by aggravating fluctuations. Overall, the tendencies observed in the Russian Barents region follow the national tendencies. Yet, the HIV and TB epidemiological situation in the Northwest Russia, where the Russian Barents regions belong, is better than in most Russian regions.

In Russia, the HIV incidence exceeds the TB incidence starting from 2014, the HIV prevalence started to dominate over the TB prevalence since 2008, and HIV-related death rate has been higher than the death rate caused by TB since 2015.

With regard to HIV-infection and tuberculosis situation in Russia, two more current trends are worth mentioning:

- Increasingly more resistant forms of tuberculosis are being diagnosed in Russia, including Northwest Russia
- The co-infection of HIV and tuberculosis is diagnosed more frequently.

The HIV/tuberculosis co-infection places a heavy burden on health care systems and poses particular diagnostic and therapeutic challenges. Infection with HIV is the most powerful known risk factor is predisposing for *Mycobacterium tuberculosis* infection and progression to active disease, and it increases the risk of latent TB reactivation 20-fold. Tuberculosis is also the most common cause of death among people living with HIV. The flare-up of HIV/tuberculosis co-infections together with persistently high rates of drug-resistant tuberculosis seriously threaten successful achievement of the long-term targets formulated in the WHO End TB Strategy and the Action plan for the health sector response to HIV in the WHO European Region.

Despite the differences in the epidemiological patterns on the Russian and Nordic side of the Barents Region, there are features that are true to a bigger or smaller extent for all the territories of the Barents Region.

1. Although tangible, the progress is yet not fast enough. The rates are falling at about 2% per year while it should be at least 4-5% to be able to reach the health targets set forth in the UN Sustainable Development Goals. If the decline remains sluggish, the epidemic processes risk to revert and sweep away all gains achieved in the last decade.
2. Still quite many patients remain undiagnosed.
3. HIV-infection and tuberculosis are often diagnosed late, when the infections progress to advanced stages. This exposes patients to the risk of ill health, comorbidities and HIV/TB co-infection, death and further spread of the infections. All countries of the Barents Region should be encouraged to improve their screening programmes.
4. Reaching out to and working with key populations (people who inject drugs, migrants, undocumented and homeless people, prison inmates, youth) has space for improvements. The problem of adherence to therapy and follow-up, and success of treatment depend much on the coverage of the key populations with diagnostic and therapeutic services, linkage to care, and necessary patient-centered support and counselling.
5. HIV-infection poses a serious threat for curbing and elimination of tuberculosis, and this is particularly relevant to Russia, where the HIV/TB co-infection has demonstrated continued rise in the recent years. Tuberculosis is often confirmed as the cause of death among people with HIV diagnosis.
6. Stigma still represents a barrier for easy access to services. People feel reluctant to undergo testing, fear social isolation and disruption of their families, social networks, careers. Even health workers' attitudes towards patients may be stereotype-fueled.
7. Non-adherence to treatment leads to less effective outcomes and creates risks of permanent resistance to certain medicines. As a result, the cost of treatment may rise and therapeutic options get narrow.

3.2. *Merger of Barents HIV and Barents Tuberculosis Programmes*

Cooperation on infectious disease control in the Barents Region started in 2005 when a Barents HIV/AIDS Cooperation Programme was put into effect. The cooperation on infectious disease control expanded in 2013 with adoption of the Barents Tuberculosis Programme.

This Barents HIV/Tuberculosis Cooperation Programme follows the previous Barents HIV/AIDS Cooperation Programme and Barents Tuberculosis Programme, which both completed in the end of 2019. The duration of the Barents HIV/Tuberculosis Programme is four years – from 2020 till the end of 2023, and the geographic scope of the Programme embraces four regions in the Northwest Russia – Republic of Karelia, Murmansk Region, Arkhangelsk Region, and Republic of Komi – and the northern provinces of Finland, Sweden and Norway. This Programme capitalizes on the experiences of the previous Barents HIV/AIDS and Tuberculosis Programmes, captures the changing epidemiological situation in the Barents Region, and responds to the current needs and expectations of the infectious disease control and cooperation in the Barents Euro-Arctic Region. The Barents HIV/Tuberculosis Cooperation Programme is one of the sub-programmes of the Cooperation Programme on Health and Related Social Issues in the Barents Euro-Arctic Region.

In spring 2018, having examined the progress of the Barents HIV/AIDS and Barents Tuberculosis Programmes, their achievements and shortfalls, and the current demands of cooperation in the infectious control, the Joint Working Group on Health and Related Social Issues (JWHGS) put forward an idea about merging the both programmes.

The underlying causes for the possible merger, according to the JWHGS, were:

- The need to rationalize and optimize the use of resources;
- The possibility to revitalize HIV collaboration in the Barents Region;
- The attempt to support integration of HIV and TB services;
- The attempt to increase impact of the Barents cooperation;
- Last but not least, to possibly address the increasingly growing problem of the HIV/TB co-infection in Russia.

In September 2018, the Steering Committees of the Barents HIV/AIDS Programme and Tuberculosis Programme gathered in Syktyvkar (Komi Republic/Russia) to discuss the JWHGS' suggestion and possible priorities of action for the future. The Steering Committees unanimously agreed that cooperation on HIV and tuberculosis control and prevention in the Barents Region should continue and develop, welcomed the merger idea and formulated the following priorities, which could lay the basis for the forthcoming Barents HIV/Tuberculosis Cooperation Programme:

- Patient-oriented approaches both in the HIV and TB sectors aimed at ensuring adherence to therapy;

Both Nordic and Russian experts underscore the need to work closer with the patient and to focus more on the patient's needs. Many HIV and TB patients belong to socially deprived or marginalized groups and therefore require a holistic approach where medical services are piled up with social support and care, psychological counseling, peer support, and legal aid to the patient and patient's family. Much depends on building trustful communication between the patient and healthcare or social workers; the patient wants to deal with a prejudice-free and helpful professional from whom the patient seeks not just medicine but also advice and support. Adherence to follow-up and treatment requires huge effort from the patient, and assistance from professionals and peers is absolutely crucial, especially in the beginning. Majority of patients are scared that information about their diagnosis may leak, e.g. to the employers, and the issue of confidentiality comes forth. Patients should be offered, wherever possible, out-patient or home-based treatment and follow-up to decrease their loss to therapy and follow-up. The friendlier the approaches are to the patient, the stronger the adherence will be to the treatment and follow-up. As a result, this will reduce development of drug resistant forms of the infections and limit the spread of HIV and tuberculosis. In its turn, the reduction of drug-resistant infections and assured control of HIV-infection and tuberculosis will contribute to the achievement of UN Sustainable Development Goal No3.

- Competence building and education for healthcare workers on topics related to diagnosis, treatment and care of HIV infection and tuberculosis;

For years now education and training have been one of the key components in international cooperation activity. Training is one of the factors critical for the high-quality care and effective prevention. The target groups include health workers working in the HIV and TB sectors and community, with particular emphasis on rural areas, where deficit in up-to-date knowledge and skills is biggest. The aspects of training and education vary from new evidence-based treatment and care pathways to communication and counselling skills. Occurrence of co-infections requires knowledge about a range of infections and their prevention and care. Besides, new approaches and interventions in managing HIV-infection and tuberculosis develop all the time, and it is important for professionals to possess up-to-date knowledge and research findings, and see what could be adapted to improve performance. Training and education can be delivered in various ways, from face-to-face training modules and workshops to refresher courses and to online trainings.

- Monitoring of state of affairs - updating on epidemiological situations, discussing and analyzing best practices, and new approaches in the HIV and TB sectors.

Exchange of information about the epidemiological situation, updates in national legislative frameworks, innovative approaches and new practices in prevention and management of diseases has always been one of the central components of international cooperation in infection control and prevention. Exchange of updated information and discussions about current achievements and challenges provide basis for possible future cooperative scientific and development initiatives and projects, and most importantly, for tight people-to-people contacts beyond programmes or projects. Last but not least, exchange of latest

information about epidemiology and novel interventions is an effective tool for dialogue engagement, ensuring transparency and building of mutual trust.

In April 2019, the Steering Committees of the both Programmes discussed and agreed on the goal and objectives of the new Barents HIV/Tuberculosis Programme (see below in chapter 2).

Besides, the meeting addressed and decided on the Terms of Reference for the Steering Committee of the Barents HIV/Tuberculosis Programme. The document is attached as annex.

4. Goal and objectives of the Barents HIV/Tuberculosis Programme

Keeping in mind the current epidemiological trends and infectious disease control needs in the Barents Region and available resources, building on lessons learnt from previous programmes, aligning with the United Nations 2030 Agenda for Sustainable Development, and adapting the guiding principles of relevant policies – WHO End TB Strategy, Tuberculosis action plan for WHO European Region 2016-2020, and the Global health sector strategy on HIV 2016-2021, the members of the Steering Committees of the Barents HIV and Barents Tuberculosis Programme formulated the goal and objectives of the Barents HIV/Tuberculosis Programme for the period from 2020 to 2023.

The **goal** of the Barents HIV/Tuberculosis Programme is intensification of measures taken against HIV, tuberculosis, and associated infections in the Barents region on the basis of international cooperation.

The **objectives** of the Barents HIV/Tuberculosis Programme are:

1. To implement patient-oriented approaches aimed at ensuring adherence to therapy;
2. To promote competence building and education for healthcare and social workers on topics related to prevention, diagnosis, treatment and care;
3. To ensure a forum for discussions of best practices and new approaches in the HIV and TB sectors.

5. Approach

The Barents HIV/Tuberculosis Programme replaces the Barents HIV/AIDS and Barents Tuberculosis Programmes. The Barents HIV/Tuberculosis Programme has a Steering Committee with representatives from all Barents regions. The Steering Committee selects a Chair of the Programme, who takes the lead in the implementation of the Programme for at least 2 years. The Chair is assisted by a Coordinator. The Steering Committee meets regularly to monitor the progress of the Programme, discuss and make adjustments, if necessary. Otherwise the communication is done by electronic mail or tele/videoconferences.

The Joint Working Group on Health and Related Social Issues oversees the implementation of the Programme.

A programme approach presumes participatory development of a coherent set of goals, objectives and activities. A programme encourages synchronization of different stakeholders' aims and actions, both local and

international, within a common framework. It is therefore crucial that the stakeholders of the Barents HIV/Tuberculosis Programme renew their commitment, share the jointly established goals and strive to achieve the agreed objectives through their local or international actions.

A programme approach enables streamlining efforts along concerted directions of work, which, in the long run, lead to accomplishment of a common goal. By implementing a programme approach a wide circle of stakeholders is kept informed and engaged, and also the impact is more extensive and sustainable.

There are other programmes, structures and donors operating in the Barents Region or adjacent territories, and partnership links with them will create opportunities for synergetic actions, stronger and more viable outcomes, and to reinforce efforts in the field of communicable diseases, the Barents HIV/Tuberculosis Programme shall cooperate and coordinate its activities with the Northern Dimension Partnership in Health and Social Wellbeing (NDPHS) and its Expert Group on HIV, TB and Associated Infections, WHO, the Nordic Council of Ministers and European Centre for Disease Prevention and Control (ECDC), and the national agencies in the respective countries.

6. Expected results and indicators

It is expected that the Barents HIV/Tuberculosis Programme will facilitate the scale-up of international cooperation in prevention and control of HIV-infection, tuberculosis and associated infections in the Barents Region.

The most feasible and measurable indicator for the ultimate goal of the Barents HIV/Tuberculosis Programme will be the number of initiatives and events of international nature initiated or supported by the Barents HIV/Tuberculosis Programme. In this context, the initiatives and events of international nature mean project applications, projects, conferences, seminars, workshops or consultations with participation of experts from at least two countries of the Barents Region.

At the level of the Programme's objectives the following results are expected:

Objective 1. To implement patient-oriented approaches aimed at ensuring adherence to therapy

Expected results:

1.1. To have patient-oriented approaches and interventions implemented in the Barents Region mapped out and disseminated.

1.2. To have new evidence-informed patient-friendly approaches from outside the Barents Region consistently followed and presented.

1.3. To have events (conferences, seminars) and project ideas for testing and implementation of new patient-friendly mechanisms and practices initiated, formulated and submitted.

Objective 2. To promote competence building and education for healthcare and social workers on topics related to prevention, diagnosis, treatment and care

2.1. To have the core training and education needs documented.

2.2. To have training programmes designed and realized.

2.3. To have seminars and workshops together with other actors operating in the Barents Region initiated or contributed to.

Objective 3. To ensure a forum for discussions of best practices and new approaches in the HIV and TB sectors.

3.1. To foster and elevate the role of the Steering Committee of the Barents HIV/Tuberculosis Programme as the core of the regional expertise sharing platform in HIV- and tuberculosis-related questions.

3.2. To leverage the knowledge and ideas of external experts and networks.

3.3. To create space for discussion of themes relevant to HIV and tuberculosis prevention and control (epidemiology, regulatory frames, achievements and challenges, new solutions, etc.)

7. Financial resources and assumptions

7.1. Resources

The Barents HIV/Tuberculosis Programme is a framework programme of regional cooperation. The Barents partners allocate experts to the Steering Committee of the Programme and take care of the reimbursement of their work time and possible travel costs. The primary possible source of funding for activities aimed at the achievement of the Programme's goal and objectives are grants and funds available through calls for project proposals or donors.

7.2. Assumptions

Successful implementation of the Barents HIV/Tuberculosis Programme requires realization of certain circumstances. Such critical assumptions are:

- In the first place, renewed and consistent commitment from the Barents partners
- The members of the Steering Committee of the Programme and otherwise engaged experts work together as partners for the consensual goals and objectives – ownership of the Programme by the Barents partners is secured
- All those involved possess vigour, motivation and interest to do the work, and their knowledge and skills correlate with the Programme's needs

- There are funding opportunities to support initiatives and project proposals targeted at the achievement of the Programme's goals and objectives

8. Monitoring

The Steering Committee of the Barents HIV/Tuberculosis Programme is the key body to monitor the progress of the Programme and make necessary adjustments. The monitoring is done primarily in connection with the regular meetings of the Steering Committee. The Steering Committee will have at least one meeting per year, or more if deemed necessary. The Chair of the Steering Committee decides about the time and place of a meeting, and the Coordinator informs the members of the Steering Committee and sends invitations.

Information about the progress, achievements and challenges of the Programme is regularly delivered to the Joint Working Group on Health and Related Social Issues, which oversees the implementation of the Programme.