

ITPCru's 2013 Annual Report

The main focus of ITPCru in the region of Eastern Europe and Central Asia (EECA) and Russia in 2013:

1. Increasing awareness of the general public, communities and experts about issues related to treatment access and shaping opinion towards those issues through communication channels of ITPCru;
2. Improving access of regional communities to information, skills, and structures to lead and advocate for improved treatment access (aligned with ITPCru priorities);
3. Advocating reduction of prices for ART and Hep C drugs on the regional level through negotiations with pharmaceutical companies and advocacy campaigns.

The Russia-specific component was focused on advocacy of systematic changes in drug supply system, from applicable legislation to implementation of specific procurement procedures, namely ART and HCV price reduction through research, engagement of the mass media and patient organizations and communities, improvement of regulatory framework in the field of HIV treatment, and work with brand and generic pharmaceutical companies.

Increasing awareness of the general public, communities and experts about issues related to treatment access and shaping opinions towards those issues through communication channels of ITPCru.

In 2013, ITPCru focused on strengthening the traditional communication channels of ITPCru and developing new ones. The number of subscribers has reached 1106 members (as of December 31, 2013). In total, more than 2 000 messages were sent to the ITPCru mailing list in 2013. ITPCru

continues to be the largest information and opinion-shaping channel for HIV and hepatitis C in the EECA region.

ITPCru developed, translated into Russian and reposted essential materials in the field of HIV and hepatitis C treatment access.

The main documents included:

1. Manual on antiretroviral drugs and patents developed by I-MAK (http://itpcru.org/news/post_448.html); the data from the manual were used at EECA CAB, a joint initiative with the Eastern Europe and Central Asia Union of PLHIV (ECUO) meetings in the preparations for negotiations with pharmaceutical companies.
2. Training Manual on Hepatitis C for Treatment Activists developed by TAG (http://itpcru.org/files/files_498.html); the translation of the manual has already been used by several organizations and has been reprinted in the “Shagi” (Steps) magazine (the leading magazine about HIV for NGOs in Russia);
3. Unofficial translation of the WHO guidelines summary (http://itpcru.org/news/post_432.html) published before the launch of the official version to increase awareness and to start discussion about the new recommendations;
4. Summary of the UNAIDS Global Report (http://itpcru.org/news/post_466.html);
5. Presentation on new hepatitis C drugs developed by ITPCru (http://itpcru.org/files/files_490.html); the presentation will be updated on a regular basis as new drugs appear in the pipeline and get registered. The materials from the presentation are used at EECA CAB meeting to prepare for negotiations with pharmaceutical companies.
6. The reposted materials included, among others, the Russian hepatitis C and HIV treatment guidelines and the WHO TB and HIV treatment guidelines. All the documents can be found on the website of ITPCru. The documents to be translated/prepared/reposted were chosen based on the strategic priorities of ITPCru (pricing, procurement, patents, and treatment guidelines).

Using the ITPCru listserv, the staff of ITPCru collected recommendations for the WHO meeting about the new treatment guidelines in Istanbul. The consolidated recommendations were presented during the meeting; the report about the outcomes of the meeting was published in the listserv (both in Russian and in English). It can be found online at http://itpcru.org/news/post_511.html.

ITPCru also published news related to treatment access issues both in the region and globally on the website, on facebook and in the mailing list. In total, over 100 materials were published in 2013, ranging from stock-outs of

antiretroviral drugs in Russia to registration of new hepatitis-C and HIV drugs in the US and EU.

In 2013, ITPCru produced 13 videos related to various aspects of HIV and hepatitis C treatment access:

1. “I’ve been told I have HIV” about diagnosis acceptance featuring Andrey Skvortsov and Dr. Damir Bikmukhametov – 3 335 views;
2. Street action beside the Ministry of Health before the World AIDS Day;
3. Street action beside the Ministry of Health on the World Hepatitis Day;
4. Lecture on the history of AIDS denialism by Dr. Plavinskiy, head expert on evidence-based medicine in Russia – 446 views;
5. “Don’t be a fool – HIV exists” – viral video with some famous Russian musicians starring (Billy’s Band, Olaya Oli) – 5 919 views;
6. «Condom is a safety belt of your health” promoting the use of condoms as an effective method of HIV prevention – 3 671 views;
7. A 30-minute presentation on how to cover HIV in the mass media by Denis Godlevskiy – 683 views;
8. Press-conference about the consequences of decentralized procurement;
9. International AIDS Day on TV-RAIN (the most popular Internet TV channel) – 4 interviews, including Denis Godlevskiy and Alexandr Ezdakov (current communication officer);
10. 25-minute video on the importance of taking ART – 711 views.

All the videos are published on the youtube channel of ITPCru (<http://www.youtube.com/user/ITPCruTV>) As of December 31, 2013, the channel has 83 subscribers and 77 000 views in total. The video materials about street actions were used and reposted by different media (grani.ru, “Moskovskiy Komsomolets”). The videos about treatment adherence were shown in several AIDS centres. In 2014, ITPCru will continue to develop this area.

In 2013, ITPCru produced 10 podcasts, with approximately 100 listeners per each podcast. Podcasts are traditionally used for mobilizing activists from all over the region and discussing the hottest issues related to treatment access in the region and globally.

Together with FOCUS-MEDIA, ITPCru produced a poster on the benefits of ART treatment initiation. Overall, 200 copies have been printed so far, 50 of them have been distributed at various events (Suzdal conference in December, round-table meetings about ART procurement in oblasts – see below for more detail). Several organizations, both Russia-based and regional, have expressed their interest in the poster; in 2014, ITPCru will continue disseminating the poster in AIDS clinics and at high-level events

(such as the EECA Conference on AIDS in May). The poster can be found online at: http://itpcru.org/files/files_512.html

Improve access of regional communities to information, skills, and structures to lead and advocate for improved treatment access in such fields as treatment guidelines, national procurement programmes, patent law and pricing.

In 2013, three meetings of the Eastern European and Central Asian Community Advisory Board (EECA CAB) were held, uniting the leading treatment access activists from 14 EECA countries. All EECA CAB meetings have a training component with a focus on the strategic priorities of ITPCru.

1. Kyiv, February – a training session on patents and registration was organized prior to the meeting with ViiV Healthcare.
2. St. Petersburg, May – a half-day training on generics and clinical trials by Dr. Plavinskiy.
3. Kyiv, October – a training session on patents at the meeting with the Medicines Patent Pool.

Every EECA CAB meeting has a special session at which representatives of national CABs present their experience (UCAB, Mold-CAB, TatCAB etc) and exchange ideas with the other CAB members.

Prior to the meetings, the participants receive background materials prepared specially for each meeting (with information on companies and issues that are going to be discussed, links to important treatment access materials etc). The background materials are developed by the staff members of ITPCru with the help of external experts. Those are not publicly available (only for CAB members) but can be provided upon request.

In spring 2013, the website of EECA CAB was launched (<http://eeccab.org/en/>). On the website, one can find the detailed minutes of the meetings with pharmaceutical companies, news about treatment access, information on the drugs already available and in development, position papers of EECA CAB regarding policies of certain pharmaceutical companies etc. The minutes of the EECA CAB have on several occasions been used by decision-makers and communities in EECA countries in their negotiations with pharmaceutical companies (Latvia, Moldova). The website is updated on a regular basis.

In March 2013, one of the staff members of ITPCru provided technical support during the first meeting of the Georgian CAB; the technical support included presentations on the experience of EECA CAB, ECAB, TB-CAB, an

overall presentation about global advocacy efforts in the field of access to treatment, and a presentation on new hepatitis-C drugs.

During the World Hepatitis C Campaign, ITPCru provided technical support to several national organizations (Armenia, Moldova), mostly with formulating open letters and developing messages for street actions.

Advocating reduction of prices for ARVT and hepatitis C drugs on the regional level through negotiations with pharmaceutical companies and advocacy campaigns

In 2013, EECA CAB held negotiations with the following pharmaceutical companies:

1. ViiV Healthcare (Kyiv, February).

Minutes of the meeting: http://eeca-cab.org/media/2013/05/26/eeca_cab_meeting_viiv_eng_f.pdf

Position of EECA CAB: <http://eeca-cab.org/en/2010/05/06/viiv-healthcare/>

Outcomes of the meeting:

- One follow-up meeting on the situation in Russia in Moscow;
- Improved communication with the company (regular information exchange, list of country representatives published on the website of eeca-cab, enabling the regional community to exert further pressure on the company);
- The company has been informed about exorbitantly high prices for maraviroc in one of the regions; the company representatives have assured the CAB members they will not be working with this particular distributor anymore.

2. Janssen Pharmaceuticals (St. Petersburg, May)

Minutes of the meeting: http://eeca-cab.org/media/2013/08/08/eeca_cab_janssen_en_31_may_2013.pdf

Position of EECA CAB: <http://eeca-cab.org/en/2010/05/06/janssen-johnsonjohnson/>

Outcomes of the meeting:

- The company was informed of all the cases of disrupted tenders for darunavir; actions were taken and some tenders were re-announced;

- Discussion about the prices for telaprevir and darunavir in the region was initiated.

3. Gilead Sciences (St. Petersburg, May, Kyiv, October)

Minutes of the meeting:

http://eeca-cab.org/media/2013/08/07/eeca_cab_gilead_en_30_may_2013.pdf

http://eeca-cab.org/media/2013/12/12/eeca_cab_meeting_gilead_oct2013_en.pdf

Position of EECA CAB: <http://eeca-cab.org/en/2010/05/06/gilead/>

Some outcomes of the meetings:

- At the second meeting, the company announced its plan to register Atripla in Russia, although at the first meeting the company indicated quite clearly that they were not going to do so;
- After the meeting in May, the company filed an application to include tenofovir in the Russian Essential Drug List, although the initial plan was to file an application for “Truvada” only (see the minutes);
- Discussion about the prices for tenofovir-containing drugs was initiated.

4. Pharmasyntez

(Russian generic manufacturer of ARVs and second-line TB drugs)

Minutes of the meeting: http://eeca-cab.org/media/2013/08/07/eeca_cab_pharmasyntez_en_29_may_2013.pdf

Position of EECA CAB: <http://eeca-cab.org/en/2013/06/01/Pharmasyntez/>

Some outcomes:

- EECA CAB received the clinical trial protocol for Perchlozone for evaluation; three members of EECA CAB evaluated the protocol and submitted their comments to the researcher.
- Discussions about the price for generic lopinavir initiated.

A separate meeting with Roche, following a sign-on campaign, with 83 organizations from all over the region signing the letter with the demand to reduce prices for pegylated interferons (both to Roche and Merck), was held in St. Petersburg in December. It was not a meeting of EECA CAB. The sign-on campaign was initiated by Patients in Control within the framework of the World Hepatitis Day campaign and supported by ITPCru.

The minutes of the meeting are available at: http://eeca-cab.org/media/2014/01/13/meeting_minutes_eeca_cab_roche_101213_eng_final.pdf

Next year, ITPCru and partners will follow up on the outcomes of the meeting and will continue pressure on both Roche and Merck.

Widen access to quality uninterrupted treatment in Russia through price reduction and establishment of an effective system of treatment provision for PLHIV and PLHIV/HCV in the Russian Federation.

The activities used to achieve this goal can be divided into several categories. The first one is establishing a system of monitoring and collecting the data about drug procurement and provision, which can then be used as a basis for advocacy efforts.

In 2013, the procurement of antiretroviral medicines and drugs for treating hepatitis C was decentralized; instead of 38 federal tenders, there were around 3 000 tenders in 83 regions. To effectively monitor these tenders, ITPCru trained a team of monitors chosen from activists in several regions (mostly with traditionally strong community-based organizations, such as Kaliningrad, Yekaterinburg etc).

In total, on different stages of the project there were from 15 to 20 people monitoring tenders and carrying out advocacy activities. Two trainings were organized, both in St. Petersburg. The first one in March was focused on the monitoring component and was led by the ITPCru staff members and an external public procurement expert. The second one was more oriented towards advocacy and was led by Denis Godlevskiy and Dmitro Sherembey. After the March training, the team of monitors worked under the supervision of one of the ITPCru staff members (Alexey Mikhailov), who was in charge of coordinating the project and collecting and presenting the data to the other staff members responsible for advocacy activities.

In 2013, the staff of ITPCru attended 5 round-table meetings with officials on the provincial level in Khakassia, Perm, Samara, Krasnodar, and Kaliningrad. These round-table meetings were dedicated to the problems with decentralized procurement of antiretroviral drugs. One notable example of a successful local advocacy campaign against stock-outs of drugs

was Khakassia, where 450 signatures were collected under the letter to the Government of Khakassia to increase funding for HIV; the issue was discussed on the national channels. As a result, the activists received an official promise through the media that the funding will be allocated. 30 patients who were not prescribed therapy due to lack of drugs (all with the CD4 count of less than 300) received the medicines.

Based on the interim results of the monitoring, a report on the outcomes of decentralization was prepared and disseminated widely among different stakeholders at different events, including the annual conference of Rospotrebnadzor in Suzdal in December, the St. Petersburg HIV Scientific Congress named after prof. Vinogradova, the meeting of the Ombudsman in St. Petersburg, the meeting on HIV in the Public Chamber etc. The conclusions and recommendations from the report were used widely in the media, including several TV channels. The final version of the report is to be produced within a month. ITPCru also prepared and published a separate report on the procurement of hepatitis-C medicines in Russia. Recommendations were presented at various high-level events, disseminated in the media and submitted to key decision-makers in the field.

On the eve of the World AIDS Day, the issue of stock-outs and problems with the provision of HIV drugs was for the first time over a long period brought to national channels (NTV 1 and Vesti-24 2). The specialized magazine about pharmaceutical industry Vadamec devoted a whole issue to the problem of decentralized procurement of HIV and hepatitis-C drugs.

The results of the ongoing monitoring were used as a background for street actions. In 2013, ITPCru provided technical support for three street actions organized by activists of Patients in Control. Two of them were a continuation of the “Pharma Greed Kills” campaign launched in 2012. April, 29, a street action was organized in front of the office of R-Pharm – the leading ARV distributor in Russia. The second one was held on the World Hepatitis Day and was focused on exorbitantly high prices for hepatitis-C treatment in Russia. The third one was focused on the crisis of the HIV response in Russia and was held in front of the President’s Administration. All the three actions received very wide coverage in the mass media³. To increase media coverage, the actions were accompanied by press-conferences (an example can be found here). The main messages were the rising epidemic and the lack of actions by the authorities, as well as specific problems identified by the monitors, including high prices, low ART

¹ <http://www.ntv.ru/peredacha/segodnya/m23700/o201956> (minute 15:00)

² http://www.vesti.ru/only_video.html?vid=557996

³ See, for example, <http://www.mk.ru/social/article/2013/10/23/935194-otdayte-vich-v-mchs.html>, <http://vadamec.ru/news/detail4408.html>, <http://medportal.ru/mednovosti/news/2013/07/26/224price/>, <http://ria-ami.ru/news/91652>.

coverage, stock-outs etc. One of the speakers at the press conference on the World Hepatitis Day was a representative of the Russian WHO office; the regional UNAIDS office attended the press-conference in the observer status. On the World AIDS DAY, ITPCru organized a high-level press-conference together with ESVERO and FOCUS-MEDIA, with Dr. Pokrovskiy from the Federal AIDS Centre as the headliner; the conference dealt with the current problems with the HIV response in Russia and received wide media coverage.

Based on the results of the monitoring, a campaign in the press was organized in summer of 2013 to speed up tender announcement.

Based on the results of the monitoring, in 2013 ITPCru, in collaboration with partners, organized several sign-on campaigns with coverage in the mass media. The most significant ones concerned tenofovir (24 organizations signing the petition to include tenofovir in the list of Essential Drugs), and the use of fixed-dose combinations (several regions refused to purchase fixed-dose combinations; the letter was addressed to the Government and to the Federal Anti-Monopoly Service). Also, on the eve of the World AIDS Day, an open letter to the President of Russia regarding the crisis of the HIV response in Russia was published, with signatures of 10 major Russian NGOs working in the field of HIV. The tenofovir campaign was conducted in two stages: in June, when applications for the Essential Drug List were submitted, and in November-December, when the MoH Commission on EDL was having negotiations. The tenofovir campaign received very wide coverage in the media⁴. As a result, tenofovir was included in the draft of the revised EDL which will be approved as soon as the relevant Decree on Essential Drug Lists comes out (See Evaluation for more detail).

The results of the monitoring were also used for the negotiations with pharmaceutical companies regarding the situation in Russia. One notable example is the hepatitis C tender in St. Petersburg, where, following the pressure on the AIDS Clinic and on the companies, the price for a 48-week treatment course went down to 9,000 USD.

Next steps

The experience of 2013 with regard to decentralized procurement of medicines and activism on the local level showed that community-based advocacy on the local level often brings short-term results (Ivanovo, Khakassia, Pskov). ITPCru plans to expand its network of monitors by involving completely new members and develop the procurement monitoring system.

⁴ See for example, <http://www.kommersant.ru/doc/2366762>, <http://medportal.ru/mednovosti/news/2013/06/19/469tenofovir/>

Regionally, ITPCru will continue consolidating the efforts of the civil society in the region around treatment access issues through the EECA CAB project. Ideally, EECA CAB will become a pool of leading activists with very high expertise on pricing, procurement, guidelines, registration, clinical trials, who will be capable of engaging into high-level discussions on treatment access issues with decision-makers on the national level.

Also, ITPCru will continue supporting treatment advocacy initiatives in the region through the grant programme and technical support programme.

As countries of the EECA region gradually initiate government treatment programmes, ITPCru will support the procurement and price monitoring projects in the region, both with technical expertise, and, if possible, through the grant programme.

In Russia, ITPCru will concentrate on launching the National Hepatitis C strategy and treatment programme for Russia.

ITPCru will continue the projects around raising treatment literacy through information channels.