



**Hepatitis C and Drug Use in the New EU Member States and Neighborhood:
Consultation Report**



August 2006

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About the publication

The publication summarizes content, as well as organizational issues of the consultation *Hepatitis C and Drug Use in the New EU Member States and Neighborhood*, which took place on March 10-11, 2006 in Vilnius, Lithuania. The consultation's content summary covers situation, recommended and current policies and services and is structured around five issues: (1) spread of hepatitis C; (2) commitment, policy and rights; (3) prevention and testing; (4) access to and delivery of HCV treatment (including co-infection with HIV) and comprehensive care; and (5) role of drug users' community and liver patient organizations with the goal to provide a comprehensive overview of issues discussed, situation in the region and how interventions and services should be organized to effectively address HCV.

Annexes to the report: agenda; list of participant; feedback from participants; meeting budget. The publication is available in English and Russian.

Key words: Hepatitis C, drug users, injecting drug users, prevention, testing, treatment, harm reduction, European Union, Central and Eastern Europe

Organization information

The Central and Eastern European Harm Reduction Network (CEEHRN) is a regional network with a mission to support, develop, and advocate for harm reduction approaches in the field of drugs, HIV/AIDS, public health, and social exclusion by following the principles of humanism, tolerance, partnership, and respect for human rights and freedoms.

Founded in 1997, CEEHRN today unites more than 260 individuals and organizations from 25 countries of in Central and Eastern Europe and Central Asia. The network's members come from both the public and private sector and include government agencies, drug treatment and HIV specialists, harm reduction organizations, researchers, community groups and activists (notably, organizations of people living with HIV and drug users), as well as supporters and experts from outside the region. CEEHRN is governed by its members and through their elected representatives on the Steering Committee. The executive work is carried out by a Secretariat based in Vilnius, Lithuania.

The main activities of the network include advocacy for better policies on HIV/AIDS and drugs, informational support and exchange, and capacity building of members and other organizations involved in the field of reduction of drug-related harm in Central and Eastern Europe and Central Asia. CEEHRN members and their allies seek to reduce drug-related harm, including the transmission of HIV/AIDS and other blood-borne diseases, through facilitating the use of less repressive and less discriminative policies with respect to drug users and other vulnerable groups and populations.

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Disclaimer

The content and conclusions drawn in the report are based on data received through pre-meeting assessment, presentations and discussions of the meeting, as well as external sources where indicated so. Information, views and comments presented in the report do not necessarily reflect views and position of CEEHRN or donors and should not be associated directly and individually with any of participants.

CEEHRN does not guarantee the accuracy of the information provided by external sources cited in the report, and accepts no responsibility or liability for any consequences arising from the use of such data or links.

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Abbreviations

AIDS - Acquired Immune Deficiency Syndrome
ASUD - Association for the safety of drug users
CEE – Central and Eastern Europe
CEEHRN – Central and Eastern European Harm Reduction Network
DU – drug user
EATG – European AIDS Treatment Group
EC – European Commission
ECDC – European Centre for Disease Control and Prevention
EMCDDA – European Monitoring Centre for Drugs and Drug Addiction
ENDIPP – European Network on Drugs and Infections Prevention in Prison
EU – European Union
HAV – hepatitis A virus
HBV – hepatitis B virus
HCV – hepatitis C virus
HIV - human immunodeficiency virus
IDU – injecting drug user
IHRD – International Harm Reduction Development Program of OSI
NGO – non-governmental organization
OSI – Open Society Institute
PLWHA – people living with HIV/AIDS
STI – sexually transmitted infection
UN – United Nations
UNAIDS – Joint United Nations Programme on HIV/AIDS
US – United States of America
WHO – World Health Organization
WIAD - Scientific Institute of the German Medical Association

Executive summary

About 200 million people are living with hepatitis C (HCV) worldwide. However, society awareness of and political commitment to the issue of this epidemic are low. Prevention targeting vulnerable groups, like injecting drug users (IDUs), who account to 60-90% of new HCV cases, remains insufficient in most Central and Eastern European countries. In Eastern Europe and the Baltics with high HIV/AIDS rates among IDUs, HCV co-infection is extremely high among HIV-positive people, which means that addressing HCV is even more challenging. Despite being the group in biggest need for HCV treatment, in many countries drug users (DUs) and even people with past illegal drug use are excluded from treatment due to supposedly poor compliance, drug interaction and possibility of re-infection.

To address hepatitis C Central and Eastern European Harm Reduction Network (CEEHRN) organized a regional consultation on HCV and drug use in Central and Eastern Europe on March 10-11, 2006.

The meeting in Vilnius, Lithuania aimed to identify main issues, challenges and possible enhancements in services, policies and advocacy for effective prevention, diagnostics, care and treatment for drug users with HCV through (a) sharing of lessons learned and best practices in and outside the focus region; (b) agreeing on main components of comprehensive response to HCV among DUs (prevention, testing and diagnostics, care and treatment, drug users' community mobilization); and (c) elaboration of recommendations on enhancement of services, healthcare, prison healthcare and policies on HCV and drugs.

The program of the two-day meeting combined plenary sessions filled with presentations by experts and followed by working groups to further discuss issues building on plenary sessions and develop recommendations for action. Five topics were addressed: (1) spread of HCV; (2) commitment, policy and rights; (3) prevention and testing; (4) access to HCV treatment and comprehensive care for DUs (including those with HIV co-infection); and (5) role of DU community and liver patient organizations.

The event gathered 36 healthcare professionals, service providers, researchers, human rights activists, drug users and people living with HCV from 18 countries of Europe and the US. The main geographical focus was given to 12 Central and Eastern European countries, including 8 new EU member states, 2 accessing countries and 2 neighboring countries (Belarus and Russia).

The consultation was organized in the framework of AIDS Action & Integration projects, a joint initiative by French NGO AIDES, AIDS Action Europe, European AIDS Treatment Group and CEEHRN. Financial support was provided by the European Commission (DG Sanco) through AIDS Action & Integration projects, as well as by Roche, AIDS Action Europe/Soa Aids Nederland, the East East Program of the Open Society Fund Lithuania, and French Embassy in Vilnius, Lithuania.

Outputs and follow-up:

- Electronic version of meeting report developed in English and Russian;
- Information about the meeting disseminated through CEEHRN website (www.ceehrn.org) and listservs of more than 600 addresses in Russian and English, and through partners;
- CD with presentations and additional materials (in English and Russian) disseminated to participants, donor organizations and key partners;
- In-depth report on HCV situation among drug users to be developed by CEEHRN in English and Russian in the beginning of 2007;
- Fact sheet with recommendations for actions (in 2006) and key fact and summary of report (in the beginning of 2007) in Russian and English.

Outcomes:

- Meeting served as a space for exchanging experiences and establishing links among different countries (including “old” and “new” EU countries) and among different stakeholder groups (prevention services, treatment professionals and persons from affected communities);
- The consultation and pre-meeting assessment led to identification of the main common issues faced in the field and ways how these issues could be effectively addressed;
- Recommendations on further actions developed for policymakers, international organizations and donors, health care authorities, service providers, prison system and researchers as a result of the pre-consultation assessment and the meeting.

Key recommendations:

- Policymakers should acknowledge the need for, and express a greater level of commitment to HCV prevention and treatment, developing programs and strategies addressing HCV and liver diseases;
- Repressive legislation on drug use and drug users should be revised and should reflect a non-stigmatizing approach based in public health and human rights. Public policy should support the implementation and scale up of diverse harm reduction services and ensure access to health and social services for all members of society;
- International organizations (like EU and the UN) in cooperation with national governments and civil society representatives, should initiate and adopt recommendations and/or declarations of commitment to hepatitis with clear accountability mechanisms at international, regional and national levels;
- Guidelines on HCV treatment should be based on results of recent medical research and reflect international good practices which recommend to include drug users in treatment based on clinical criteria, deciding on treatment eligibility on a case-by-case basis, therefore national meetings of medical professionals delivering HCV treatment should be organized preferably involving drug addiction treatment specialists and drug user activists to agree on HCV treatment and care guidelines;
- Health care institutions should work together with low-threshold service providers to develop systems of referrals from low-threshold facilities to medical care institutions in order to establish comprehensive responses to HCV and increase access to care for IDUs and people with liver diseases;
- Low-threshold services should be expanded and have to include HCV counseling, needle and syringe exchange, distribution of condoms, cookers and other injection equipment, free, voluntary HCV testing along with counseling, as well as HAV and HBV vaccination, substitution treatment, information and skills building on safer injection and drug use. HIV testing should be always offered to clients with HCV;
- Prevention services in prisons should be equivalent to those provided in the community. If needle exchange is not immediately possible in prisons, bleach or other disinfectants should be provided, alongside relevant training for prisoners and staff on proper sterilization techniques in order to reduce the risk of HCV;
- Prisons and pre-trial detention institutions should also develop and implement treatment programs for drug dependent prisoners, including the use of substitution treatment;

Full document with recommendations in the form of fact sheet are available for download in English or Russian in word and pdf formats at <http://www.ceehrn.org/index.php?ItemId=15861>.

BACKGROUND

First identified in 1989, hepatitis C (HCV) is acknowledged as one of the leading cause of cirrhosis and liver cancer. It is increasingly a major cause for liver transplantation. Currently there is no vaccine. While there is a significant increase in treatment success, HCV remains incurable and can lead to chronic illness and morbidity.

According to the estimates 200 million people are living with HCV worldwide (WHO, [“Hepatitis C” World Health Organization Fact sheet No. 164](#), 2000). Up to 60–90% of new HCV cases are registered among people injecting drugs occurring due to sharing of injecting equipment. HCV prevalence among injecting drug users (IDUs) in the European Union (EU) is common and reaches up to 90%, depending on country and setting (EMCDDA, [Statistical Bulletin 2005](#), 2005); moreover 50–80% of IDUs get infected with HCV within first five years of injecting. It is not clear how many IDUs are living with the virus in Central and Eastern Europe, since data on HCV among IDUs in the region is quite scarce and testing on HCV is fragmental, it is known that prevalence among IDUs varies from 29 to more than 90% (EMCDDA, [Statistical Bulletin 2005](#), 2005). For example, up to 95% of IDUs obtaining services in low-threshold facilities in Estonia are seropositive for HCV (EuroSurveillance [Surveillance Report Vol. 11, issue 1](#), 2006). There is an alarming potential of HCV outbreak in the new EU member states and neighboring countries with emerging drug use epidemics and where sharing of injecting equipment is still quite common, making IDUs the largest risk group for HCV transmission.

Despite the fact that IDUs are the group most affected by HCV, harm reduction remains controversial; lack political support and harm reduction interventions are limited in scope in most countries of the region. Moreover, at least part of people using drugs cannot access primary healthcare as they do not have neither social security nor financial means to get private services; also even if they access healthcare they are discriminated due to stigma attached to drug use. Active or past IDUs also frequently lack access to HCV treatment in most new EU member states and neighboring countries, as guidelines recommend not to treat drug users before they have come off drugs or have been stable on an oral substitution treatment for a period of time that can vary from six to twelve months from country to country. At the same time, empirical studies on the HCV treatment of active drug users show that treatment success is feasible and comparable to that of non-drug users and number of recently developed guidelines, like pan-European guidelines developed during Consensus meeting, state that active drug use can not be used as a criteria excluding people from treatment (European Consensus Conference, [Short statement of the first European Consensus Conference on the treatment of chronic hepatitis B and C in HIV co-infected patients](#), 2005). In practice, even in the “old” EU member states (before May 1, 2004) the treatment of IDUs is limited in some countries (EMCDDA, [Annual report 2004: the state of the drugs problem in the European Union and Norway](#), 2004).

Better understanding of how HCV spread and what is being done to halt HCV is an important step to prevent morbidity and mortality associated with HCV. Therefore raising awareness among both public and mobilizing professionals, service providers and people affected by the virus is a key component in effective prevention and management of HCV.

Therefore an event devoted to HCV among IDUs was planed and organized by Central and Eastern European Harm Reduction Network (CEEHRN) in Vilnius, Lithuania on March 10 – 11, 2006. The consultation Hepatitis C and Drug Use: Toward Awareness and Action” became a third event organized in the framework of AIDS Action & Integration Project, a joint initiative of NGO AIDES, AIDS Action Europe, CEEHRN, European AIDS Treatment Group (EATG), and local HIV & AIDS organizations from across the enlarged EU. The Integration Project is

designed to promote best pan-European practices on HIV/AIDS prevention and support, sexual health and reduction of drug related harms in Central and Eastern Europe, especially in the new and future EU member states.

THE ORGANIZATION OF THE CONSULTATION

Goal and objectives

The main **goal** of the meeting was to: stimulate the capacities in service provision and advocacy for effective prevention, diagnostics, care and treatment for DUs in the new EU member states and neighboring states by providing the opportunity to share existing experiences and practices from the region, Western Europe and the US.

The **objectives** of the event:

- To access the challenges existing and needs of people working on HCV among DUs in countries of the region;
- To introduce and share good-practice examples in HCV prevention, diagnostics and treatment targeting drug users from Europe and US;
- To discuss main components of comprehensive response to HCV among DUs (prevention in community and prison setting; testing and diagnostics; care and treatment) and develop a model of effective comprehensive response to HCV among DUs;
- To elaborate recommendations regarding further actions in HCV prevention and treatment for different groups involved;

Participant and geographical scope

The primary geographical scope of the meeting was the new EU member states of Central and Eastern Europe, accessing and neighboring countries: the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia, Slovenia, Bulgaria, Romania, Belarus, Russia and Ukraine. Also the meeting was joined by experts from Western Europe and the US.

No open call was made to select the participants; the goal of the consultation was to gather together representatives from health care institutions and civil society that work in the field of HCV with existing knowledge and/or work experience in the fields of HCV prevention, testing, care and treatment or advocacy for HCV prevention and management specifically among DUs. The participants were selected on the basis of recommendations from CEEHRN Steering Committee members, projects' steering committee, and regional/international experts and partners of CEEHRN.

Participants' geography:

New EU member states + Bulgaria and Romania (EU priority countries): Bulgaria, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Slovakia, Slovenia	24
Other eligible countries under the Public Health Action Programme: Belgium, France, Germany and the United Kingdom	7
Non-EU countries, priority group outside of the Public Health Action Programme: Belarus and Russia	3
Outside EU Public Health Action Programme: US and Switzerland	2

List of participants is presented in Annex 2, page 29

Expectations of participants

Main expectations outlined by participants:

- *Information, experience sharing, meeting new people.* Overall participants wanted to get to know the situation with HCV in the region, meet their peers in other countries and have the opportunity to share and gain experience on responses to HCV in neighboring countries and internationally.
- *Ongoing activities on HCV in the region, following the meeting.* Some participants expressed hope that the meeting will be a step towards regional mobilization of activists around the issue and CEEHRN in the future could become a basis for informational networking on HCV related issues and provide technical support related to HCV (especially advocacy).
- *Information and experience sharing on HCV treatment of IDUs.* Since most of IDUs have no access to treatment in the region, participants expected to gain information on how to deliver treatment to IDUs, what are existing practices in other countries and how to include IDUs in treatment programs, how to advocate for treatment for active IDUs and clients of substitution treatment programs on national level, effects of drug addiction treatment on HCV treatment. People from countries with high HIV prevalence among IDUs also hoped to get more information on existing practices of HIV/HCV co-infection treatment.

The evaluation of the meeting by participants is presented in Annex 3, page 30

Key materials and information

All materials included into the consultation participants' materials kit were translated by CEEHRN prior the consultation and made available in English and Russian.

Prior the meeting, CEEHRN made a **situation assessment** with the goal to collect data on HCV situation, prevention, treatment and care interventions targeting IDUs in the new EU member states and neighboring countries.

Assessment done in two steps:

- Assessing the existing data from "secondary sources", including WHO, EMCDDA, ENDIPP, WHO Collaborative Centre for Control and Prevention of Viral Hepatitis (Unit of Epidemiology and Social Medicine University of Antwerp) and others, who provided data related to HCV in the region;
- Standardized questionnaire developed and supplied to consultation participants with the goal to collect additional data.

Information collected through out December 2005 – March 2006 and covered issues of (1) HCV situation in targeted countries; (2) commitment and policy; (3) prevention measures and testing; (4) access to HCV treatment for IDUs. Data was included in participants' materials kit and should have helped people to get an overview of situation with HCV among IDUs in targeted countries during the discussions.

List of materials:

- Agenda;
- List of participants with contacts;
- Brief information about organizer and partner organizations;
- Guidelines for work in groups;
- Print-outs of presentations, made in plenary session;
- Fact sheet on hepatitis C, hepatitis A, B, C at a glance (adopted from Centers of Disease Control and Prevention);
- Data collected during the mapping done by CEEHRN;

- “Overcoming Barriers to Prevention, Care, and Treatment of Hepatitis C in Illicit Drug Users” by Eldin, Brian R. in *Clinical Infectious Diseases* 2005:40 (Suppl. 5);
- “Treating Hepatitis C Virus Infection in Active Substance Users” by Sylvestre, Diana L. in *Clinical Infectious Diseases* 2005:40 (Suppl. 5);

Additional materials provided by EMCDDA and disseminated during consultation (in English):
 EMCDDA (2003) “Hepatitis C: A hidden epidemic” *Drugs in focus* No. 11. European Monitoring Center for Drugs and Drug Addiction, Lisbon, 2003.

EMCDDA (2004) “Hepatitis C and injecting drug use: impact, costs and policy options”
 EMCDDA Monographs No. 7. European Monitoring Center for Drugs and Drug Addiction, Lisbon, 2004.

Program of the consultation

The main focus of the event was HCV prevention, treatment and care for active IDUs, though it was equally important to address HCV among past injecting drug users and non-injecting drug users, since access to HCV treatment is still frequently withdrawn for clients of substitution treatment programs and ex-drug users or is limited throughout the region and drug users sharing non-injecting equipment, like sniffing straws are also at risk of HCV. It was important to address those issues during the meeting, therefore organizers and partners decided to call the event HCV and drug use instead of injecting or active drug use, as was planned in the beginning. The topics of the consultation were structured around five issues: (1) HCV situation; (2) commitment, policy and rights; (3) prevention and testing (among injecting and non-injecting drug users); (4) access to HCV treatment and comprehensive care for DUs (with special focus on active injecting drug users); and (5) role of DU community and liver patient organizations, with the goal to present a comprehensive overview of situation and interventions related to HCV in the region and discuss what political/legal framework should be in place, HCV prevention services should be organized and treatment delivered taking into account the special needs of IDUs with the goal to effectively address HCV.

The structure of the meeting had to provide the opportunity for participants to actively participate in the consultation combining plenary sessions with working groups.

Four plenary sessions on:

- (1) HCV situation;
- (2) Prevention and testing;
- (3) Comprehensive care and access to HCV treatment for IDUs;
- (4) Role of DU community and liver patient organizations;

Working groups on:

- (1) Prevention;
- (2) Commitment, policy and awareness;
- (3) Testing and human rights issues;
- (4) Comprehensive care and access to HCV treatment for IDUs (for English speakers);
- (5) Comprehensive care and access to HCV treatment for IDUs (for Russian speakers);
- (6) Role of DU community and liver patient organizations;

Detailed agenda is presented in Annex 1, on pages 26 - 28

Organizers and partners

Organizer:

- *Central and Eastern European Harm Reduction Network (CEEHRN) (organizer and host)*

The main activities of the network include advocacy for better policies on HIV/AIDS and drugs, informational support and exchange, and capacity building of members and other organizations involved in the field of reduction of drug-related harm in Central and Eastern Europe and Central Asia. CEEHRN members and their allies seek to reduce drug-related harm, including the transmission of HIV/AIDS and other blood-borne diseases, through facilitating the use of less repressive and less discriminative policies with respect to drug users and other vulnerable groups and populations, including sex workers. CEEHRN strives to work together with regional and national advocates and policymakers to ensure that national drug and HIV-related policies are rational, effective, and humanitarian—and based on scientific evidence. All policies should also protect the human rights of individuals.

More information at: www.ceehrn.org (available in English and Russian).

Key partners:

- ***NGO AIDES***

The biggest French and one of the biggest European non-governmental organizations in AIDS field. It works for policy enhancement, provides health, social, legal and psychological services in HIV and hepatitis. It primarily works in France and in developing countries (French-speaking African countries). From 2001 it initiated work with Central and Eastern European countries to enhance their preparation for the EU membership, specifically in HIV prevention and treatment policies and services. AIDES coordinate three year AIDS Action & Integration project together with AIDS Action Europe, CEEHRN and European AIDS Treatment Group, which supports the development of quality NGO-based prevention, support, and advocacy in Central and Eastern Europe for HIV/AIDS, reproductive health and hepatitis.

More information at: www.aides.org (available in French). More about AIDS Action & Integration Projects at www.integration-projects.org (available in English).

- ***European AIDS Treatment Group (EATG)***

European AIDS Treatment Group is pan-European patient organization working with intergovernmental, international, pan-European and EU agencies as well as private sector and non-governmental organizations for improving access to HIV treatment and care and enhancing rights of HIV affected people. It is a member of the EU Think Tank on AIDS and together with AIDS Action Europe coordinates Civil Society Forum on AIDS, which is consultative body to the European Commission.

More information at: www.eatg.org (available in English and in Russian).

- ***European Monitoring Center on Drugs and Drug Addiction (EMCDDA)***

European Monitoring Centre for Drugs and Drug Addiction is the EU agency on drug issues. Through its national focal points and its Lisbon-based centre, EMCDDA monitors and analysis policies and practices in drug addiction and drug control (law enforcement), as well as drug related harms and crimes in the EU member states, Norway and future EU members. It is a key agency to coordinate implementation of the EU Drug Strategy 2005-2011 and the EU Drug Action Plan 2005-2008, which are legally binding documents endorsed by governments through European Council.

More information at: www.emcdda.eu.int (available in official EU languages).

- ***NGO Odysseus***

It is leading Slovak non-governmental organization in AIDS, hepatitis and drugs field. It provides health promotion and social services primarily among the most disadvantaged groups (drug users, injecting drug users, sex workers, Roma and prisoners). Besides direct services, Odysseus is active in advocacy and policy work at local, national and international levels. Their director is the only civil society representative in the National AIDS Commission.

The director of Odysseus, Katarina Jiresova is a member of National Committee on HIV/AIDS Prevention in Slovakia and a member of CEEHRN Steering Committee.

Management

Overall activities coordinated and implemented by CEEHRN staff member Simona Merkinaite, under the guidance of CEEHRN director, Raminta Stuikyte. Local logistics related to the meeting implemented by Agne Jacynaite, another staff member of CEEHRN.

The representatives of key partner organizations acted as steering committee members of the consultation. Steering committee members helped to identify main objectives, key speakers, topics and materials to be used in mapping and disseminated to participants during the consultation. A pre-consultation meeting with steering committee members was organized 4 months before the consultation.

Steering committee members:

Cynthia Benkhoucha, NGO AIDES France;
Dagmar Hedrich, EMCDDA;
Joan Tallada, European AIDS Treatment Group, Spain;
Katarina Jiresova, NGO Odysseus, Slovakia;

A number of regional and international experts and organizations were involved in program preparation and helped to identify speakers and materials to be used during situation assessment:

Matt Curtis, IHRD/OSI (US);
Daniel Raymond, Harm Reduction Coalition/Hepatitis C Project (US);
Tracy Swan, Treatment Action Group (US);
Jeffrey Lazarus, WHO Regional Office for Europe;
Monique Munz, WHO Regional Office for Europe;
Lucas Wiessing, EMCDDA;
Gerry Stimson, International Harm Reduction Association;
Pierre Van Damme, WHO Collaborating Centre for Control and Prevention of Viral Hepatitis;
Martina Melis, European Network on Drugs and Infections Prevention in Prison;
Magda Ruzkowska-Cieslak, European Network on Drugs and Infections Prevention in Prison;
Centers for Disease Control and Prevention (US);

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- East East: Partnership Beyond Borders Program of Open Society Fund-Lithuania;
- AIDS Action Europe, Soa AIDS Netherlands;
- French Embassy in Vilnius, Lithuania.

DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

(1) Spread of HCV

HCV is more prevalent than HIV in almost all regions of the world (except Africa). It is estimated that about 9 million Europeans are living with the virus (<http://www.hep-links.com>). HCV prevalence is higher in Eastern Europe than in Western. In most countries of Western Europe (except France) HCV prevalence is below 1%, while in Eastern Europe prevalence vary from 1 to 2.49%.

IDUs represent the group most hit by HCV. In all EU countries the incidence of HCV among IDUs is extremely high, ranging from about 30% to over 90%, accounting for about 60 – 90 % of new registered HCV cases (EMCDDA, [Drugs in Focus No.11 "Hepatitis C: a hidden epidemic"](#), 2003). Injecting drug use and sharing of injecting equipment is identified as the main route of HCV transmission (WHO, ["Hepatitis C" World Health Organization Fact sheet No. 164](#), 2000). A small percentage of people (estimated 1-3%) may contract HCV through sexual intercourse, while mother-to-child transmission before or during birth is less than 5% (Hepatitis C Support Project, [A Guide to Understanding Hepatitis C](#)). Health care workers are at risk for HCV infection because needle-stick accidents however transmission among health care workers was reduced in early 1990s, due to safer practices.

Data about HCV in the new and future EU member states is limited. However it is believed that HCV is widespread among IDUs in countries with ongoing injecting drug use epidemic. For example in Estonia, HCV infection among IDUs reaches more than 90.5%. Overall from the new EU member states and assessing countries of Bulgaria and Romania, Baltic States are the most affected by HCV (EMCDDA data of 2000 – 2003, taken from [National Reports to EMCDDA 2003, 2004](#)).

HIV is transmitted in similar ways to HCV, so co-infection is quite common. HIV/HCV co-infection occurs among IDUs in countries with ongoing HIV epidemics, like Russia, Ukraine or Estonia. In St. Petersburg (Russia) HCV among IDUs in contact with mobile outreach program is more than 70%, among people, living with HIV – more than 75%; testing among drug using prisoners in Riga (Estonia) showed that 97.5 % of all tested had HCV and HIV. HIV speeds up the process of liver damage and liver disease is currently the number one cause of death amongst HIV patients (<http://www.hep-links.com>).

Despite low HIV prevalence rates among IDUs, Central European countries and Balkans where also face HCV epidemic. For example, prevalence of HCV among IDUs in Bulgaria is about 85%, compared to around 1% HIV prevalence (HIV prevalence is higher and reaches about 5% among IDUs in Roma community). In the Czech Republic, where HIV prevalence among IDUs is also below 1%, anti-HCV prevalence among IDUs reaches 34.97% ("Hepatitis C virus infection among injecting drug users in the Czech Republic – prevalence and associated factors", by T. Zabransky, V. Mravchik, B. Korcsova, V. Rekah in *European Addiction Research*, 2006;12:151-160).

It also should be noted that the figures most probably do not reflect the real situation, since harm reduction services are limited in scope and do not reach sufficient number of IDUs (especially young and experimenting users) and routine testing is not carried out in most of Central and Eastern European countries.

HCV is transmitted easier than HIV and as a result most of IDUs get infected at very young age. Prevalence of HCV in new injectors (those who have been injecting for less than two years) suggest prevalence of 40% (EMCDDA estimate of 2003). Data from treatment programs indicate that HCV infection in young IDUs (under 25 years of age) varies from 12% in Tampere, Finland (data of 2001), to around 60% in Dublin, Ireland (data of 1997), and Italy (data of 1999) (Scientific Institute of Public Health [Study on HCV, HBV and HIV seroprevalence in a sample](#)

[of drug users in Belgium, 2004 - 2005](#), 2005). Centers for Disease Control and Prevention (US) estimated that HCV prevalence among IDUs reached 50 – 90 % during five years of injecting.

About 80% - 85% of newly infected patients progress to develop chronic infection with 56% of them needing HCV treatment, cirrhosis develops in up to 20% of persons with chronic infection and liver cancer develops in 1% to 5% of persons with chronic infection over a period of 20 to 30 years (WHO, [“Hepatitis C” World Health Organization Fact sheet No. 164](#), 2000).

Conclusions and recommendations:

- IDUs is the group the most hit by HCV epidemic, accounting for about 60 – 90% of new identified cases, largely affecting countries with ongoing injecting drug use epidemics, therefore more targeted prevention measures are needed;
- Most IDUs get infected at the very early stage of injecting – prevention should include strategies to reach young and experimenting drug users and also should include education on safer drug use techniques;
- Surveillance of HCV is inconsistent from country to country; overall, comparability of data on European level is low. The real number IDUs living with HCV and HIV/HCV co-infection in the region is not known as well as data on routes of transmission (though injecting and non injecting drug use) is limited – more research in the areas of surveillance, epidemiology, and on development of better practice in prevention strategies should be done in the region;
- About 80 – 85 % of those infected will develop chronic HCV and will need HCV treatment, which means increasing treatment demand among IDUs – the strategies to include IDUs into HCV treatment programs and prepare them to treatment should be in place.

(2) Commitment, policy and rights

“National drug prevention policies and drug control agencies should reinforce evidence-based and pragmatic approach by supporting harm reduction activities like needle/syringe exchange and substitution treatment”.

*- Dr. Audrone Astrauskiene, director of Drug Control Department
Under the Government of the Republic of Lithuania
at the opening session of the consultation*

There is a low level of awareness about HCV and evident lack of political commitment to the issue. On the international level there are no declarations of commitment to fight HCV and improve treatment and care services for people living with HCV.

At the EU level HCV prevention is a part of drug policy and is related to prevention of other infectious diseases, like HIV and sexually transmitted infections (STI). [EU Action Plan on Drugs \(2005 – 2008\)](#) calls member states to establish and sustain comprehensive programs on HIV/AIDS and HCV and for cooperation between all service providers. Comprehensive programs should include wide access to harm reduction measures, like substitution treatment and needle/syringe exchange. In [Council Recommendation of June 2003 on prevention and reduction of health-related harms associated with dependence](#) European Council recommends to provide IDUs with access to HBV vaccination and testing of HCV, as well as equalize preventive measures in prisons to the ones provided in community. However, there are no specific document/recommendations concerning HCV, calling for coordinated actions and accountability on national and regional level.

Out of 25 EU member states + Bulgaria and Romania in 22 countries there is a specific strategy at national level for prevention of drug related infectious disease among drug users; most

countries do mention HCV prevention as part of drug strategy along HIV and STI prevention; at this moment only the UK and France have a specific strategy to prevent HCV.

One of the key factors in effective HCV prevention and management is drug policy. Existent repressive national drug policies (especially policies that lack of differentiation between people dependent on narcotic substances and drug dealers, existent in some countries of the region) also restricts the ability and willingness of drug users to obtain health services and fewer people using drugs contact low-threshold and especially health care institutions, which makes HCV prevention and management among even harder.

Despite harm reduction is seen as part of effective and comprehensive drug policies in most Western European countries and on the EU level in some countries of Central and Eastern Europe harm reduction approach lacks acknowledgement and support on political level. For example, substitution treatment with methadone is not available in either Belarus or Ukraine, and is illegal in Russian Federation. Even in the new EU member states like Lithuania in 2005 harm reduction came under public attack with the demands by the commission on drugs in the parliament to close country's substitution treatment programs.

Moreover, the rights of IDUs to health care and treatment of HCV are frequently denied in most countries of Central and Eastern Europe, since most guidelines (whenever they are available at all) do recommend not to treat active drug users or people, undergoing substitution treatment. In some countries of the region, like Bulgaria or Belarus internationally funded projects are the only opportunity for drug users to undergo treatment, since there is no possibility to undergo free treatment, since government do not compensate the treatment (*more information about access to treatment is presented in [Section 4: Comprehensive care and access to HCV treatment for IDUs](#)*). Drug users also often face stigma and discrimination from the society and from the health care professionals and are denied care, which means that health, social and other needs of drug users with HCV are not met and IDUs do not have the access to primary health care. Even pregnant women with HCV are frequently denied health care and support due to drug use, or in some cases are denied to have their babies in hospitals.

Drug policy model: example of Switzerland

Presented by Ambros Uchtenhagen, Research Institute for Public Health and Addiction (Zurich, Switzerland)

In Switzerland drug policy is based on active involvement of National Government; evidence-based policies, based on implementation of diverse harm reduction measures including needle and syringe exchange programs, establishment of safe injecting rooms, provision of low-threshold specialized medical care, testing for blood born infections and HBV vaccination; zero-tolerance approach for open drug use, while tolerating use in private and also in specialized places, like safe injecting rooms. One of the basic approaches - equality of services in community and prisons: substitution treatment, safety kits including condoms, bleach and information how to use it is available extensively in most prisons across the country; needle and syringe exchange in a few prisons and a special unit for heroin-assisted treatment in one prison. Treatment for chronic HCV is available in 84% of Swiss prisons.

Specific actions related to HCV:

- National meetings/consultations of professionals working in the field;
- Awareness campaigns;
- Access to variety of information related to the issue (including printed materials and sustained, regularly updated electronic resources related to HCV);
- Specific education programs for professionals involved in the field;

Conclusions and recommendations (developed following the discussion on working group):

- Legal tools should be used extensively by activists. All available (legal, financial, media-related) resources should be provided to those directly affected by existing repressive drug policies and decide to take legal actions against national governments at any level with the goal to put pressure on governments to implement more pragmatic and human rights based policies, focusing on services for vulnerable populations, including DUs.
- HCV awareness message should be linked and incorporated in HIV advocacy. Whether HBV and particularly HCV are seen as “the junkies’ thing”, HIV is rarely associated only with drug use and HIV/AIDS advocacy is much better developed and strong lobbying groups are already active in the area, thus, to merge efforts of HCV advocacy with HIV promoting “one blood-borne diseases package” should be effective in rising awareness about HCV. At the same time other routes of transmission, apart from drug use should be pointed out, with the goal to reduce stigma associated with drug use.
- Partnership between health care providers, drug users and their relatives should be used as a lobbying strategy. There are some cases of good practice involving drug users in lobbying process and advocacy activities (Canada, Australia, Netherlands, Ireland) more effective partnership can be the one between health care providers and relatives of IDUs: drug users usually do not pay taxes and do not vote in the elections, whether their parents do – politically their opinion is more relevant and important to state and local policymakers (the strategy was successfully applied in Switzerland advocating for improvement of health services for IDUs).
- Increasing use of cost-effectiveness arguments. In the developed countries with universal health insurance as well as in market-oriented countries, economic arguments should be used extensively advocating for access and availability of HCV related care and treatment for drug users and ex-drug users pointing out the advantage of (1) early treatment over late treatment strategies, (2) lost productivity resulting from premature deaths.
- Facilitation of cooperation between professionals and IDUs. With the goal to establish partnership/links between professionals working in the field (experts in infectious diseases, doctors prescribing HCV treatment) and affected communities, like IDUs, active support for and involvement of IDUs in various event, seminars and conferences for health care authorities and experts should be ensured.

(3) Prevention and testing

Existing prevention strategies in the EU countries:

- Prevention of drug use and injecting;
- Access to adequate treatment, including substitution;
- Information, education and counselling (IEC);
- Access to sterile syringes and other injecting equipment;
- Outreach work to establish contact with “hard-to-reach” and “high risk” groups, safer drug use trainings;
- Incentives to infectious disease screening and vaccination (VCT);
- Access to medical treatment of infectious diseases;

According to EMCDDA data, while needle and syringe exchange is extensively used strategy to prevent infectious diseases among IDUs (overall in the EU, not comparing the availability in Western and Eastern part of EU), VCT is not a priority in 15 out of 25 EU member states + Bulgaria and Romania, peer education, routine screening, safer injecting training is low prioritized in countries of EU.

In most Central and Eastern European countries harm reduction activities remain limited in scope due to lack of acknowledgement of harm reduction by policymakers and insufficient financial resources. For example in Romania where the estimated number of IDUs reaches 24 000 there is only two needle exchange programs and only in the capital city of Bucharest and one substitution treatment program with total capacity of 400 clients (Information of Romanian Association against AIDS); the major substitution treatment program in Hungary has stopped enrolling new clients in 2006, due to the lack of funding and according to the estimates its coverage is 6 – 10% of all people in need of substitution treatment. In EU neighboring Russia with estimated 1.98 million IDUs, substitution treatment remains illegal and only estimated 2% of IDUs are reached by needle/syringe exchange programs (IHRD/OSI [Harm Reduction Developments 2005](#), 2006). Overall, according to the estimates only 7.6% of drug users have access to harm reduction services in Eastern Europe (UNAIDS [Intensifying HIV prevention. UNAIDS policy position paper](#), 2005), better access is seen Central Europe.

Situation in prisons is quite similar in all countries of the region: no needle exchange is available in the new EU member states (though available in neighboring Belarus), disinfectants like bleach are available only in Estonia, Latvia and Slovenia (only the last two countries provide information on how to use bleach effectively). Substitution treatment is provided only in some prisons of Czech Republic, Poland and Slovenia.

It also should be noted that there is a lack of data about quality of harm reduction services through out the whole region.

Free, voluntary, low-threshold testing for HCV in the new EU member states is also limited in scope and is not available at all in Latvia, Poland and Slovakia, whether in Russia and Belarus free testing is available with a referral by GPs; in this case a person usually must have health insurance. In prisons testing is usually limited due to lack of funding and in most new EU member states+ Bulgaria and Romania. The most common practice applied in the region – testing whenever the symptoms become visible; in the Czech Republic testing is mandatory to all risk groups, including IDUs. Testing on admission is recommended in prisons in the Czech Republic, Slovenia, Slovakia; only in Latvia testing is suggested to prisoners living with HIV/AIDS. HCV testing in prisons is also limited because it is associated with drug use, the problem often neglected by policymakers and prison administrations. However, imprisonment sometimes is the only opportunity to get tested for HIV and HCV or start treatment, as IDUs are often not reached by low-threshold services and because free testing is not available widely in all countries and all cities.

Even more concerning is the fact that most vulnerable to HCV parts of society like IDUs have no proper information and education about HCV, such as possibility of infection by sniffing, sharing of injecting equipment, other than needles (such as spoons and filters), possibility of re-infection and proper use of disinfectants and sharing of injecting equipment is still common practice through out the region. For example Bulgarian Drug Users Health and Rights NGO Hope-Sofia reports that most IDUs are not afraid to share needles, due to low HIV prevalence in the country and often do not know about HCV risk.

HCV testing among DUs: survey among drug users in France

Presented by Giedrius Likatavicius, National Institute for Public Health Surveillance, Saint-Maurice, France

Since 1993 French health authorities implement a national risk reduction program based on: (1) easy access to needles and syringes; (2) extended use of opiate substitution treatment; (3) testing and counseling on HIV and HCV.

A study to evaluate the effectiveness of harm reduction policy, to identify risk behavior and main trends of HCV and HIV among DUs was carried out in September – December 2004 by National Institute for Public Health Surveillance.

Methods: DUs were recruited from 5 cities through low-threshold facilities, needle exchange programs, drug treatment centers and through general practitioners, prescribing substitution treatment. The participant (all together 1462 people) were selected by sampling, stratified by city and type of service provided and had to fill in the questionnaire, 79% of them also agreed to pass tests for HIV and HCV.

Results:	In %
HIV prevalence	10.8% (in age group less than 30 years – 0.3%)
HCV prevalence	59.8% (in age group less than 30 years – 27.8%)
HIV/HCV co-infection	10.2%
Previously underwent HIV testing (at least one in a lifetime)	95%
Previously underwent HCV testing (at least one in a lifetime)	91%
Drug use during last month	crack- 30%; cocaine - 27%; heroin - 20%;
People in substitution treatment programs	71%
Risk behavior (a month prior the study)	12% shared syringe(s); 38% - other injecting equipment; 25% - sniffing equipment;

Conclusions:

The study confirmed that harm reduction is more evident in HIV than HCV prevention. According to other data available - HIV prevalence among DUs in France decreased (40% in 1988 vs. 20% in 1996) while HCV keeps rising (51% in 1993 vs. 57% in 1996);

A study also suggests that self-reporting was reliable for HIV (only 2% were not aware of HIV status) but not for HCV (27% wrongly reported that they are not HCV positive) which implies the need for routine HCV testing among DUs;

HCV is more widespread among young DUs (in age group < 30) rather than HIV. High HCV prevalence among young DUs suggests the need of more intensified information, education and counseling programs, peer education and outreach;

A certain level of awareness about the risk of sharing of needles and syringes is in place due to HIV prevention, however risk behavior persists, especially high risk behavior related to HCV transmission (like sharing of injecting equipment other than syringes and sniffing equipment and other).

Conclusions and recommendations:

- HCV is transmitted easier than HIV (not only by sharing needles but also can be contracted by sharing cookers, spoons, filters, straws) and needle exchange may have smaller impact on HCV than HIV and can not effectively prevent HCV alone. Therefore other prevention measures (dissemination of information, counseling, peer support, routine testing, vaccination for HAV and HBV) should be incorporated in to low-threshold services and needs to be intensified in all EU countries, access and availability to existing services (like needle and syringe exchange) should be increased in new EU member states;
- Since risk behavior, like needle sharing is common among IDUs, extensive application of substitution treatment is needed to achieve broad coverage of IDU population as one of the means to reduce risk behavior and transmission of infectious diseases;

- A lot more effort should be put in reaching young and experimenting IDUs and youth at risk. One of the main strategies should be peer education and involvement of DUs and people living with HCV in prevention activities;
- Information and education efforts should be intensified and should target DUs, DUs living with HCV and their relatives, service providers, medical and prison staff on issues related to primal and secondary prevention (possibility of re-infection), treatment and care and life with the virus). Information should include information on possibility of re-infection, safer injection practices, and proper use of disinfectants. Also best practice examples in HCV prevention, care and treatment among IDUs should be disseminated between key stakeholders and made available and accessible for use;
- Because of frequent HCV co-infection with HIV among IDUs and health complications arising in people co-infected, free, voluntary and anonymous testing should be promoted and provided at easy accessible and client friendly sites, like harm reduction programs (including needle exchange and substitution treatment programs). Rapid tests can be used with the goal to bring testing closer to the target group whenever laboratory testing is not available/not accessible, while assuring quality of tests and results and providing counseling;
- Since HIV/HCV co-infection among IDUs is also common, HCV testing and counseling should be promoted together with HIV testing by health care workers, staff of harm reduction programs, doctors treating HIV and drug dependence;
- Access to prevention measures in prisons should be equalized to the ones in community. HCV testing should be a part of health policy in prisons and should be promoted at the admission and upon release along with counseling.

(4) Comprehensive care and access to HCV treatment for IDUs

Although IDUs are a major risk group and a group needing HCV treatment the most, active drug use still is an excluding criteria when deciding on treatment eligibility. Reasons include poor adherence, side effects, risk of re-infection, cost-benefits and lack of urgency given the greater risks of drug use. Lack of pre-treatment counseling and support leads to increasing number of cases of treatment drugs being sold on black market and this is also used as an argument of why treatment should not be provided to IDUs (example from Russia).

There is no common practice - recommendations for HCV treatment of active injecting drug users vary substantially, from lack of recommendations and outright treatment disapproval to recommendations for treatment under specified circumstances. In old EU member states guidelines differ from country to country and include the following practices:

- (1) Abstinence only: Catalonia in Spain (2003), Finland (2003), Denmark (2001), Scotland (2000), Sweden (2003);
- (2) Abstinence is required for some period of time (from 6 to 12 months): Germany (1997), Portugal (2002);
- (3) Permitted to the people in substitution treatment programs: Austria (1999), UK (2004), pan-European consensus paper (2002);
- (4) IDU permitted under certain conditions (assessing eligibility on a case-by-case basis, considering clinical criteria, risks and benefits, patient's motivation, mental and social stability of the person): France (2002) and recently reviewed pan-European consensus paper (2002/2005). Treatment guidelines qualifying for a higher quality level and/or published recently are more likely to allow treatment for IDUs under specific conditions and/or under substitution treatment. However, this may not be true for the Scandinavian countries where abstinence is generally required as treatment prerequisite.

Among the new EU member states and neighboring countries guidelines are developed in Estonia, Bulgaria, Hungary and Romania. Some of the countries rely on international guidelines, for example the Czech Republic reportedly uses pan-European guidelines (Consensus paper),

however in the Czech Republic active IDUs are not eligible for treatment. Hungarian guidelines are based on [American Association for the Study of Liver Diseases \(AASLD\) guidelines](#) and despite the fact that AASLD clearly states that treatment can not be withdrawn from active injecting drug users and clients of substitution treatment programs, in Hungary IDUs do not have access to HCV treatment. Overall most countries of the region lack comprehensive guidelines on HCV treatment, HCV and drug dependence treatment and HIV/HCV co-infection treatment.

In practice, active IDUs are non-eligible for treatment in Bulgaria, the Czech Republic, Estonia, Hungary, Lithuania, Romania, Slovakia, Belarus and Russia (most often abstinence from 6 to 12 months is required to be accepted to HCV treatment program) with limited access for people undergoing substitution treatment in the Czech Republic, Hungary and Romania. High cost of treatment and reimbursement policies can also restrict access to treatment. For example in Bulgaria or Belarus (in Belarus HCV treatment is free for children) expenses for HCV treatment is not covered by health care insurance and possibility to receive free treatment depends on international funding whether in Russian co-infection with HIV is the only opportunity to receive free HCV treatment.

What works in delivering HCV treatment to active IDUs

*Presented by Tracy Swan, Treatment Action Group,
New York, US*

Studies show that satisfactory response to treatment among active IDUs can be quite the same as among non-drug using population (eg. according to one study: 33% active drug users achieved SVR comparing to 37% of non-drug using patients) when treatment is adopted to the needs of drug users:

- Applying individualized approach with flexible eligibility criteria taking into account patient willingness/interest in treatment and clinical criteria;
- Applying comprehensive approach addressing multiple health problems that can arise during treatment including medical and mental health care, comprehensive education about HCV, risks and benefits of treatment, and peer support;
- Treatment programs are specifically designed for drug users, offering directly observed weekly pegylated interferon injections allowing the providers to monitor side effects: one study reported that the adherence rate reaches 90% among weekly clinic visitors;
- Linking HCV treatment to drug treatment. Treatment success is interdependent with (1) drug treatment availability including availability of substitution treatment (according to data available 78% of IDUs receiving buprenorphine treatment were adherent to HIV treatment compared with 65% of former IDUs (Overcoming barriers to prevention, care and treatment of HCV in IDUs” B. R. Eldin and others in CID 2005:40 (Suppl 5)) (2) implementation of preventive measures, including provision of safe injecting equipment, demonstration of safer injection techniques and education on how to avoid re-infection;
- Discomfort and low satisfaction rates among physicians treating drug and/or alcohol users have been documented due to the specifics of work with IDUs; these improve when training on drug/alcohol dependence is provided to specialists in infectious diseases and doctors providing HCV treatment.

People undergoing HCV treatment frequently experience adverse effects, like depression, anemia or weight loss. This can compromise both: quality of life of people in treatment and reduce treatment efficiency. Therefore, management of adverse events related to HCV treatment should be integrated in the therapeutic process. Comprehensive care and support services that can help prevent and manage adverse effects include:

- Psychological or psychiatric support (before, during and after the treatment);

- Specific medical care to address side effects like anemia, weight loss, neutropenia, depression, co-infections, etc.;
- A close monitoring of HIV and HCV treatment interactions, as it is harder to treat HCV in HIV co-infected patients;
- Access to HAV, HBV vaccination for risk groups (including IDUs);
- It is also important to work with dependence specialists and address drug and alcohol use: give help regarding excessive alcohol and drugs use; provide targeted support during the treatment period;
- Before deciding on treatment, it is important to assess and take into account patient's motivation to be treated.

One of the milestones in support and care among IDUs is peer support and education provided by people living with the virus, DU and liver-patient based organizations. Liver patient organizations and DUs should also make public authorities and health care professionals sensitive to these challenges and problem people undergoing treatment face.

Conclusions and recommendations:

- IDUs, as a group most needing HCV treatment, should have equal access to medical evaluation from a specialist, which includes evaluation for liver damage, cirrhosis, liver cancer etc. and equal access to HCV treatment. Guidelines have to be reviewed in most countries/or developed in countries of EU (not only the new member states) and neighborhood, including IDUs into treatment process and should rely on latest research data and expert opinions, including specialist providing drug treatment and correspond to best practice examples in HCV treatment;
- Treatment activists should disseminate existing best-practice models in treatment provision to active injecting drug users, as well as to document what is being done, so people know what works and what doesn't;
- With the goal to make treatment efficient and improve the quality of life of people with HCV, infrastructure to support HCV treatment among active drug users should be in place: site clinics in addiction treatment units/needle exchange programs/low-threshold facilities – providing treatment in places where patients are instead of waiting for people to come to hospital;
- Addiction treatment specialists, social workers, psychiatrists, service providers, DU's self-support groups and people living with HCV should be involved in treatment-preparedness process (including counseling on risks and benefits of treatment, nutrition and life with HCV as well as impact of alcohol and drug use on the liver, side effects of any non-prescribed drugs) and in management of adverse effects and deliverance of care during treatment course;
- It is also important to address HAV and HBV among people with HCV, since hepatitis A and B can be more severe among people living with HCV. People undergoing treatment should be tested for HAV and HBV (especially IDUs); access to vaccination should be increased with the goal to prevent hepatitis co-infection;
- More effort should be put in training of professionals – general practitioners, addiction treatment specialists, service providers, DUs and their relatives should be educated about HCV treatment; specialists in infectious diseases should also be educated about drug dependency and drug treatment. Consensus paper with recommendations on HCV and addiction treatment developed by EASL would help to promote experience sharing and dissemination among addiction and infectious disease specialists across Europe and standardization of treatment process.

(5) Role of DU community and liver patient organizations

HCV treatment for IDUs is still much debated and controversial matter, therefore it is also hard to link drug users' self-support groups to liver patient organizations advocating for improved health and care services for people with HCV. Overall there are no good examples of self-organization of DUs around HCV issue in the region. There are some good examples of DU community self – organization in the region around HIV issue, but not HCV. One of the main reasons is that there is no international documents calling for commitment and action on HCV and partly due to the fact that HCV treatment is not accessible for IDUs and there is no experience of HCV related advocacy actions. Moreover, stigma of people using illegal drugs by society and health care workers and harsh drug policies both create a barrier for self-organization of IDUs.

However drug users and people living with HCV can and should play a key role in both organizing the prevention services for IDUs and delivering HCV treatment and care, by means of peer support, education and outreach work. IDUs also should participate in advocacy efforts for affordable and accessible HCV treatment and expanded prevention measures.

Strategies for meaningful involvement of IDUs:

- Involvement of drug users in civil society actions:
 - DU self-support groups and organizations and international HIV/AIDS networks, addressing drug use issue, networks on drug related harms should include HCV in their agenda, declare their commitment to HCV issue and develop guidelines/statements calling for action on HCV;
 - Further these organizations should involve IDUs in their work on all levels and play a crucial role in building capacities of IDUs around HCV issue;
- Involvement of drug users on the political level:
 - IDUs should be involved in formulation of all policies, affecting their health, wellbeing and rights by state and local government officials. IDUs can provide “insight” into the problem that will help to develop the most effective strategy for prevention of infectious diseases and drug use.
 - State and local government should also provide funding to groups of people who use drugs, liver patient organizations and to low-threshold facilities as part of drug prevention and infectious disease management policy;
- Advocacy and rising the awareness:
 - DUs should take actions in rising massive public awareness of the problem, but not by causing fear of HCV, even more stigmatizing people with the virus, but making the issues of rights and health people with HCV face sound to the public and policymakers;
 - Along with service providers (and other partners) advocate for effective prevention measures (including provision of injecting equipment, substitution treatment, education and counseling especially on safer injecting techniques) to be included in primary prevention;
 - Along with treatment activists to advocate for available and financially affordable treatment for everybody who needs it; adopting and promoting the “treatment for all” message;
- Research and evaluation:
 - Service providers and legal experts should cooperate with IDUs with the goal to access the impact of repressive drug policies on drug use phenomenon, prevalence of infectious diseases among IDUs and drug related crimes;
 - In epidemiological research increased emphasis on surveillance among IDUs is needed, there is a significant gap in research concerning vulnerable groups, like IDUs, IDUs living with HIV, IDUs in prisons.

In the long term it is also important to address systemic barriers to greater involvement of IDUs by:

- Creation of more pragmatic and human rights based drug policies with clear distinction between drug user and drug trafficker, combating stigma and discrimination against people using drugs at all levels;
- Increasing availability of harm reduction services and accessibility to low-threshold and primal health services which would serve as a basis for IDUs to meet and get organized. Availability of substitution treatment is crucial in self-organization of DUs, since it helps drug users to overcome their dependency, get stabilized and help them to re-integrate into the society and get involved in the representation of their rights and interests.

It also should be noted that the issue of greater involvement of DUs and their role was viewed as a key component in effective HCV prevention, treatment and care and partly appears through out the summary and recommendations of other four topics, presented above.

RESULTS, SUCESSSESS, CHALLANGES AND FOLLOW-UP

Outputs

- Electronic version of meeting report developed in English and Russian;
- Information about consultation disseminated through CEEHRN website (www.ceehrn.org) in Russian and English, listservs of more than 600 addresses in Russian and English and publications of partners (ex. European Network on Drugs and Infections Prevention in Prison Newsletter "Connections" No. 19 available in English and Russian at www.endipp.net);
- CD with presentations, additional materials and sources developed in English and Russian and disseminated to participants and donors;

Outcomes

- Meeting served as a space for exchanging experiences and establishing links among different countries (including "old" and "new" EU countries) and among different stakeholder groups (prevention services, treatment professionals and persons from affected communities);
- The consultation and pre-meeting assessment led to identification of the main common issues faced in the field and ways how these issues could be effectively addressed;
- Recommendations on further actions developed for policymakers, international organizations and donors, health care authorities, service providers, prison system and researchers as a result of the pre-consultation assessment and the meeting itself.

Follow-up

- A fact sheet with recommendations for further actions in English and Russian developed and disseminated in 2006. Fact sheet in word and pdf formats is now available in English and Russian at www.ceehrn.org;
- In-depth report on HCV situation among drug users (including recommendations) in new EU member states and neighboring countries to be developed by CEEHRN in English and Russian in the beginning of 2007. A fact sheet on main finding on the report will be released accompanying the report;
- Preliminary CEEHRN will further cooperate with Centre for Interdisciplinary Addiction Research, Hamburg in research reviewing guidelines on HCV treatment for IDUs in new EU member states. This cooperation established through the meeting will help to (1) evaluate existing guidelines in detail (2) create a database of key people and partners in the region (3) further involve meeting participants in the region wide activity;
- A number of international and intergovernmental organizations (DG Sanco of EC, WHO, ENDIPP, IHRD) will be informed of the results.

Successes

- **Consultation helped to identify and outline main issues people working in the field face in different countries;**
Consultation and mapping prior the meeting helped to identify main issues and challenges in the region whether together with expertise provided by regional and international experts, recommendations for further actions addressing these challenges were developed.
- **The event served as a basis to share practice among people working on the issue;**
The meeting served as opportunity for people working on the issue of HCV among IDUs to meet their peers from neighboring countries, get an overview of situation with regards to HCV in the region and to share the experience and best practice examples in HCV prevention and management (especially among “old” and “new” EU members states).
- **The event gathered together health care professionals and representatives of civil society, including representatives of DU community and people living with HCV;**
It is internationally recognized that a hallmark of effective advocacy is active involvement of people directly affected by the issue on all levels. Therefore the involvement of representatives from DU community as well as people living with HCV was a major success, especially while developing recommendations for action.
- **International experts (from outside the region) were involved in the initiative;**
A number of experts with best practice examples, experience in advocacy, service delivery or treatment provision to IDUs were involved in the meeting, its preparation and follow-up and were introduced to the situation and problems of the region.
- **Active involvement of participants in the work of the meeting;**
Participants from the region involved in pre-meeting activities while assessing the situation in countries; 6 participants from countries of Central and Eastern Europe also gave presentations during the meeting, which also helped to ensure the dissemination of experience gained in Western as well as in Central and Eastern Europe;

Challenges

- **Involvement of liver patient organizations;**
Drug users as well as people living with HCV attended the consultation; no representatives of liver patient organizations joined the meeting. Joint work of drug users’ community and liver patient organizations remains to be a challenge;
- **Involvement of affected communities;**
At the same time, not all people, representing drug users’ community and people living with the virus could attend the meeting due to health conditions. This should be kept in mind while organizing such meetings;
- **Not all target countries were represented at the consultation;**
No representatives from Poland and Ukraine attended the meeting which means that input from the biggest new EU country (Poland) and the country with ongoing drug use epidemic and one of the biggest HIV epidemics in Europe (Ukraine) was not provided;
- **Due to the limited time some issues were not given enough attention;**
Little focus was given to different legislation strategies affecting HCV and services, diagnostic strategies and evaluation of the liver damage and effects of drug treatment on HCV treatment (this issue was identified as one of expectations by participants);
- **Limited up-to-date epidemiological data presented during the meeting;**
No professional epidemiologist working on the international level attended the meeting.

Annex 1: Agenda

Day	Time	Session	Speakers
DAY 1 March 10, 2006	7.30 - 8.30	Breakfast	
	8.30 – 9.00	Registration	
	9.00 – 10.30	OPENING SESSION Moderator: Tomas Zabransky, Charles University, Czech Republic	
	9.00 – 9.10	Welcoming note	Audrone Astrauskiene, Director of the Drug Control Department under the Government of the Republic of Lithuania
	9.10 - 9.30	Real life experience	Milena Naydenova, “Hope-Sofia”, Bulgaria
	9.30 - 10.00	Hepatitis C in harm reduction agenda	Andrej Kastelic, National Center of Addiction Treatment, Slovenia
	10.00 - 10.10	Goals and objectives of the seminar	Katarina Jiresova, NGO “Odysseus”, Slovakia
	10.10 - 10.20	Program and logistics	Simona Merkinaite, Central and Eastern European Harm Reduction Network (CEEHRN), Lithuania
	10.20 – 10.30	Q&A	
	10.30 – 11.00	Coffee break	
	11.00 – 12.30	PLENARY PANEL 1: The situation with hepatitis C among drug users Moderators: Tomas Zabransky, Charles University, Czech Republic, Katarina Jiresova, NGO “Odysseus”, Slovakia	
	11.00 - 11.20	Overview of the epidemiology of hepatitis C	Peter Michielsens, University Hospital Antwerp, Belgian Association for the Study of the Liver, Belgium
	11.20 - 11.40	Good practice model in data collection and testing	Giedrius Likatavicius, Institute de ville sanitaire, France
	11.40 - 12.00	Human rights and effectiveness of research in hard-to-reach populations	Tomas Zabransky, Center for Addictology, Charles University, Czech Republic
	12.00 - 12.30	Q&A, discussion	
	12.30 – 14.00	Lunch	
	14.00 – 15.30	PLENARY PANEL 2: Prevention and testing Moderator: Bernd Schulte, Centre for Interdisciplinary Addiction Research of Hamburg University, Germany	
	14.00 - 14.20	Prevention of infectious diseases among drug users in European Union countries –focus on HCV	Abigail David, EMCDDA
	14.20 - 14.40	Swiss drug policy model in term of hepatitis C prevention	Ambros Uchtenhagen, Research Institute for Public Health and Addiction at Zurich University, Switzerland
	14.40 – 15.00	Challenges of testing and diagnostics in prisons. Experience of Hungary	Laslo Huszar, Hungarian Prison Service

	15.00 - 15.30	Q&A, discussion		
	15.30 – 16.00	Coffee break		
	16.00 – 17.30	WORKING GROUPS I		
		1. Hepatitis C prevention		Katarina Jiresova, Odysseus, Slovakia
		2. Hepatitis C testing, diagnostics and human rights		Giedrius Likatavicius, Institute de Ville Sanitaire, France
	3. Policy, awareness and commitment		Tomas Zabransky, Center for Addictology, Charles University, Czech Republic	
17.30 – 18.30	CLOSING PLENARY: Results from working groups			
20.00 - 21.00	Dinner			

DAY TWO March 11, 2006	8.00-9.00	Breakfast	
	9.00 – 10.30	PLENARY PANEL 3: Access to Hep C care and treatment for drug users (part 1) Moderator: Tracy Swan, Treatment Action Group, US	
	9.00 - 9.10	Introducing the objectives of the session	Tracy Swan, Treatment Action Group, US
	9.10 – 9.40	What is comprehensive care and support and what should be in place	Cynthia Benkhoucha, AIDES, France
	9.40 – 10.00	Policies on access to hepatitis C among IDUs	Bernd Schulte, Centre for Interdisciplinary Addiction Research of Hamburg University, Germany
	10.00 – 10.30	Q&A	
	10.30 – 11.00	Coffee break	
	11.00 - 12.30	PLENARY PANEL 3 Access to Hep C care and treatment for drug users (part 2) Moderators Abigail David, EMCDDA/Tracy Swan, Treatment Action Group, US	
	11.00 - 11.15	Hepatitis C treatment availability in CEE (results of the CEEHRN situation assessment)	Raminta Stuikyte, CEEHRN, Lithuania
	11.15 - 11.55	IDUs and hepatitis C treatment	Tracy Swan, Treatment Action Group, US
	11.55 - 12.30	Q&A, discussion	
	12.30 - 14.00	Lunch	
	14.00 – 15.30	PLENARY PANEL 4 Role of drug user groups and liver disease patient organizations Moderator: Ambros Uchtenhagen, Research Institute for Public Health and Addiction at Zurich University	
	14.00 – 14.20	Overall vulnerability to hepatitis C	Milena Naydenova, “Hope-Sofia”, Bulgaria
	14.20 – 14.40	Self-support	Fabrice Olivet, ASUD (Association for the Safety of

			Drug Users), France
	14.40 – 15.00	Needs of people with co-infection of hepatitis C and HIV	Vladimir Musatov, Charitable Fund “Humanitarian Action”; Botkin Infections Disease Hospital, Russia
	15.00 – 15.30	Q&A, discussion	
	15.30 - 16.00	Coffee break	
	16.00 – 17.30	WORKING GROUPS II	
		1. Access to treatment and comprehensive care (English)	Tracy Swan, Treatment Action Group
		2. Access to treatment and comprehensive care (Russian)	Vladimir Musatov, Charitable Fund “Humanitarian Action”; Botkin Infections Disease Hospital, Russia
		3. Role of drug user groups and liver disease patient organizations	Milena Naydenova, “Hope-Sofia”, Bulgaria
	17.30 - 18.30	CLOSING PLENARY Results from working groups and conclusions	
	20.00 - 21.00	Dinner	

Annex 2: List of participants and organizers

Country	Name	Organization
Belarus	Nikolai Goloborodko	Infectionist; Belarus State Medical Academy, Minsk
Belgium	Peter Michielsen	Division of Hepatogastroenterology of the University Hospital Antwerp; Belgian Association for the Study of the Liver
Bulgaria	Milena Naydenova	“Hope-Sofia” Foundation, Sofia
Czech Republic	Vratislav Rehak	Hepatology, Remedis, Nusle Clinic, Prague
	Tomas Zabransky	Center for Addictology, Charles University, Prague
Estonia	Victoria Vincler	NGO Convictus, Tallinn
	Valentina Tefanova	National Institute for Health Development, Tallinn
France	Cynhia Benkhoucha	NGO AIDES, Paris
	Giedrius Likatavicius	Institute de ville sanitaire, Paris
	Fabrice Olivet	ASUD (Association for the Safety of Drug Users), Paris
Germany	Bernd Schulte	Centre for Interdisciplinary Addiction Research of Hamburg University, Hamburg
Hungary	Istvan Takacs	Drug Prevention Foundation (needle exchange service); Hungarian Civil Liberties Union, Budapest
	Laslo Huszar	Hungarian Prison Service
	Eszter Csernus	Hungarian Civil Liberties Union, Budapest
Latvia	Inga Bulmistre	Latvian AIDS Prevention Center; NGO “Dia+logs”, Riga
	Olita Mengote	Latvian Hepatitis C Association, Riga
Lithuania	Audrone Astrauskiene	Drug Control Department under the Government of Lithuania
	Arvydas Ambrozaitis	Department of Infectious Diseases and Microbiology at Vilnius University
	Agne Jacynaite (<i>logistics</i>)	Central and Eastern European Harm Reduction Network
	Vladas Kasperunas	Prisons Department under the Ministry of Justice, Vilnius
	Alvydas Laiskonis	Infections Clinic, Kaunas Medical University, Kaunas
	Agne Marudinaite	NGO Coalition for vulnerable populations “I Can Live, Vilnius”
	Raimonda Matulionyte	Vilnius Infections Disease Hospital, Vilnius
	Simona Merkinaite (<i>Coordinator</i>)	Central and Eastern European Harm Reduction Network
	Irina Skriabina	Drug users organization “Tavo Drugys”, Vilnius
Portugal	Raminta Stuikyte	Central and Eastern European Harm Reduction Network
Romania	Abigail David	European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), Lisbon
	Eduard Paris	Infection Disease Hospital; Romanian Association against AIDS, Bucharest
Russia	Bogdan Istrate	Romanian Association against AIDS, Bucharest
	Vladimir Musatov	Charitable Fund “Humanitarian Action”; Botkin Infections Disease Hospital, Saint Petersburg
Slovakia	Petr Nikitenko	Charitable Foundation “For a Healthy Society”, Moscow
	Katarina Jiresova	NGO Odysseus, Bratislava
Slovenia	Peter Lazovy	NGO Odysseus, Bratislava
	Andrej Kastelic	South Eastern European – Adriatic Addiction Treatment Network; drug treatment expert, Ljubljana
Switzerland	Ambros Uchtenhagen	Research Institute for Public Health and Addiction at Zurich University
UK	Richard Marley	Gastroenterology & Hepatology St Bartholomews and The Royal London Hospitals
US	Tracy Swan	Treatment Action Group, New York

Annex 3: Evaluation of the meeting by participants

After the meeting participants were asked to fill in the standard evaluation form where they had to indicate (1) the usefulness of the sessions and topics (2) what the consultation lacked (3) what additional skills they would like to gain in the future.

Usefulness of the sessions:

Session	Very useful	Somehow useful	Not useful
HCV situation among drug users in targeted countries	64%	36%	0
Prevention and testing	60%	40%	0
Access to treatment and comprehensive care	90%	10%	0
The role of the HCV patient and drug users community	70%	30%	0

Most of participants indicated that the session on access to treatment was the most interesting and the most useful for them, especially presented research results of treatment successfulness among IDUs comparing to non-drug using population and how best to deliver treatment to IDUs with the goal to achieve positive results. The other component of the meeting proved to be the most useful was work in groups, where issues raised during plenary sessions were discussed in detail in small groups and presented possibility to meet better people working in the field from other countries. According to participants one of the successes was that professionals, experts working in the field and DU community representatives were involved in the meeting and had the time and space to express their positions. This was indicated as one of the most useful thing in further advocacy work, combining scientific and professional arguments with the argument presented by the people directly affected by HCV.

Less interesting and less useful parts were presentation on testing and diagnostics in prisons, French case study on self-support and partly issue of comprehensive care, which was viewed by some participants as an issue to be addressed only when more progressive, human rights based policies are in place and where there is at least some availability and accessibility to harm reduction services and HCV treatment for IDUs.

Some of the participants also indicated that the agenda was very intense and full, which made it hard to follow and actively participate in discussions at the end of the meeting and there was not enough time to ask all the discuss all the questions in detail during plenary sessions.

Most of people from CEE indicated that further they need to build skills in advocacy and skills on how to establish partnership with government officials. For this purpose unified information source or publication providing regional situation overview with best practice examples existing in the region and internationally identified as a tool to build advocacy strategies and links with national stakeholders. Others expressed hope that the meeting will serve as a basis for further networking and mobilization of activists in the region. Participants also indicated the need in technical support working in the different areas (providing treatment to IDUs/ex-drug uses, building advocacy strategy, promoting prevention activities and harm reduction, etc.).

At the same time they indicated a need to gain experience in work with IDUs, preparing them for treatment process, providing information related to treatment and support during the treatment course (including the need of experience in HVC/HIV co-infection management, HCV and drug treatment) and building work with different health care professionals.