

Hep C

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**Among Injecting Drug Users
in the New EU Member States
and Neighboring Countries:
SITUATION, GUIDELINES AND RECOMMENDATIONS**



Central and Eastern European
Harm Reduction Network

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Situation, Guidelines and Recommendations

About the Central and Eastern European Harm Reduction Network

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 and 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 in Central and Eastern Europe and Central Asia. The network's members come from both the public and private sectors and include government agencies, drug treatment and HIV professionals, 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 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 and drugs, informational support and exchange, and capacity building of members and other stakeholders 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 and other blood-borne diseases, through facilitating the use of less repressive and less discriminative policies with respect to drug users and other vulnerable populations.

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Acronyms

AASLD	American Association for the Study of Liver Diseases
ART	antiretroviral treatment
CEEHRN	Central and Eastern European Harm Reduction Network
DCR	drug consumption room
EASL	European Association for the Study of the Liver
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
ENDIPP	European Network on Drugs and Infections Prevention in Prisons
ESLD	end-stage liver disease
EU	European Union
EVR	early virological response
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GP	general practitioner (family doctor)
HAV	hepatitis A virus
HBV	hepatitis B virus
HCV	hepatitis C virus
IDU	injecting drug user
ICE	information, education and counseling
NEP	needle and syringe exchange program
OST	opioid substitution therapy
PEG-IFN	pegylated interferon
PLWH	people living with HIV
PLWHA	people living with HIV and AIDS
RBV	ribavirin
RNA	ribonucleic acid
SVR	sustained virological response
WHO	World Health Organization

1. Executive Summary

Hepatitis C (HCV) presents an important public health problem globally and particularly in the region of Central and Eastern Europe. Infection with the hepatitis C virus causes chronic infection in about 85% of those infected, and among those chronically infected, cirrhosis may eventually develop in from 5 to 20% (Edlin, 2004). Estimated 250 000 people die annually of HCV-related causes (Lavanchy, 2004). It is already the most common cause of chronic liver disease and the most common reason for liver transplantation in some countries, morbidity and mortality from HCV infection are rising and are expected to continue rising in the coming decades (Edlin, 2004).

The infection spreads rapidly among injecting drug users (IDUs) due to its high infectivity (about 10 times higher than human immunodeficiency virus (HIV)), and—unlike HIV—it can be transmitted by sharing not only needles and syringes but also other injecting equipment (e.g., water, cotton, etc.) which comes into contact with and carries infected blood particles (Hagan, 2001). As a result, international studies suggest that about 50–95% of IDU populations may be infected with HCV (Hagan, 1998). Because HCV and HIV have similar routes of transmission (particularly through needle sharing), HCV/HIV co-infection is also common among IDUs. Co-infection causes further complications, accelerates HCV progression and complicates HIV treatment, which also makes HCV a concern in HIV prevention and HIV treatment advocacy for IDUs.

At the same time, HCV often presents no symptoms, and the vast majority of infected people are not aware of their status. This is even more common among IDUs, since a large part of this group is not reached by services and remains outside of the health care system. Besides, as experiences from different countries show, even if diagnosis and implications for treatment are clear, IDUs are often excluded from HCV treatment, despite recent evidence that HCV treatment is feasible and effective when special needs, such as drug addiction or treatment side-effects, are addressed.

This combination of factors makes HCV prevention and treatment one of the top priorities on the harm reduction agenda all over the world and particularly in the region of Central and Eastern Europe. An effective policy for the control of HCV will require implementing prevention, treatment, care and support programs designed specifically for IDUs.

To help assess the situation related to HCV among IDUs in the region, the Central and Eastern European Harm Reduction Network (CEEHRN) carried out a survey in 13 countries of the European Union (EU) and neighboring countries, looking at the availability of HCV prevention, treatment, care and support for IDUs. The countries assessed were: Belarus, Bulgaria, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Russia, Slovenia, Slovakia, and Ukraine.

The key finding of the report is that in most countries HCV among injecting drug users is a neglected problem. Stigma and discrimination against drug use mean that those with the greatest need for HCV support, treatment and care are often denied these services. Besides, policy and advocacy efforts do not adequately address this issue and significantly more effort is needed in order to bring the issue up on the Public Health policy agenda.

Key findings and issues

- **HCV spreads rapidly among people injecting drugs**

According to various estimates, there could be between 2.1 and 3.3 million IDUs in the 13 countries of the region. Studies among drug injectors from these countries show quite diverse prevalence rate of HCV, varying from 14–97% in different settings.

The rates for HCV are commonly higher in the Eastern part of the region, with the highest rates - from 70% to over 90% - reported in Estonia, Lithuania, Russia and Ukraine.

Significantly lower rates of HCV are reported from countries of Central Europe where HIV prevalence among IDUs is also low – the Czech Republic, Hungary, Romania, Slovenia and Slovakia. However, HCV prevalence of more than 60% was found in studies from Bulgaria, Poland and Romania, showing that in fact HCV prevalence is high among IDUs compared to HIV prevalence throughout the region.

A study among people living with HIV and AIDS (PLWHA) seeking care showed that prevalence of HCV (over 50%) is high mainly in Eastern European countries (Estonia - 80%; Latvia - 61%; Russia - 52%; and Ukraine - 77–80%).

Increased risk of HCV can be associated with sharing needles, syringes and other injecting equipment, and a history of imprisonment. The association between HCV infection and duration of injecting or age group is contradictory - a study in Estonia showed higher prevalence among young IDUs and those injecting for less than five years, while the results of testing in Hungary and Slovenia showed the highest HCV prevalence in IDUs who were older than 34 years of age.

- **Limited political commitment**

Most countries have expressed a commitment to fight HIV and have established national programs to prevent and manage HIV and AIDS. However, this is not the case with HCV, and most countries do not have specific strategies to address hepatitis related issues. Despite recommendation of the World Health Organization (WHO) to adopt national plans for HCV, only 2 of the 13 countries (Romania and Slovakia) have specific national documents that address hepatitis.

Political commitment at the international level is also limited. Regionally, there is no EU strategy or recommendations on standardizing diagnostics and treatment practices among EU countries, and improving access to prevention, diagnostics, treatment and support for those in need.

- **Limited availability of low threshold testing for IDUs**

HCV antibody testing by general practitioners (GPs) or specialists is widely available, but this is often considered to be high threshold form of testing, which is less accessible for IDUs. Anonymous and free-of-charge testing remains limited throughout the region.

HCV testing and counseling is poorly linked to already established services for IDUs such as needle and syringe exchange programs (NEPs) and opioid substitution therapy (OST) programs. Testing at either NEPs or ST sites provided in 5 of the 13 countries assessed in this study. In some countries (the Czech Republic, Slovakia and Slovenia) testing for HCV is provided upon entrance to drug treatment and in Latvia free HCV testing is offered as part of primary HIV diagnostics.

IDUs have low level of knowledge about HCV. Service providers from different countries noted that many IDUs who are tested for HCV assume that they are chronically infected, and many remain uninformed or misinformed about the virus due to lack of proper pre- and post-test counseling. This may result in high-risk behaviors among IDUs.

- **Low prioritization of HCV testing among prisoners**

In most countries assessed HIV testing is suggested upon admission to prison. However such testing for HCV is provided only in some prisons in 3 of 13 countries - the Czech Republic, Poland, Slovakia. Most commonly HCV testing in the region is provided only when symptoms occur. In Slovakia, HCV testing is offered to all suspected, diagnosed and self-reported drug users. And in Slovenia it is available for PLWHA or those testing positive for HIV in prison. In both countries, testing is voluntary. From countries surveyed only in the Czech Republic testing is mandatory for all suspected or self-reported drug users and those diagnosed with addiction.

Despite limited availability of HCV testing in prisons, sometimes they provide the only opportunity for drug users to get tested due to the lack of anonymous and free of charge testing in community settings.

- **Falling short in prevention measures**

In the new EU Member States and neighboring countries governments and health care providers are still not committed to provide prevention services that target IDUs. Established HIV prevention measures such as NEPs in many countries can provide only a small part of the necessary clean syringes. However the coverage of NEPs between countries differs substantially reaching up to 50–60% of the IDU population in the Czech Republic and Estonia, but less than 10% of IDUs in Belarus and Russia. Only a few countries provide sterile injecting equipment other than needles and syringes, and none of the new EU countries have needle and syringe programs in prisons.

OST in community settings (outside prisons) is available in 12 countries (out of 13), but the coverage varies. For example, in Hungary in 2005, a mere 4% of all addiction treatment providers offered methadone maintenance (Gerevich, 2006), while the major OST program stopped enrolling new clients in 2006. There are only two OST programs in Romania and they are limited to the capital Bucharest.

OST in prisons is legal in about half of the countries surveyed but with the exception of the Czech Republic, Poland and Slovenia it is neither widely available nor accessible for most drug-dependent inmates.

- **Availability of antiviral treatment for HCV**

In accordance with international guidelines, all 13 countries offer treatment by genotype, and, with the exception of Belarus and Romania, indicate availability of treatment with pegylated interferon (PEG-IFN) and ribavirin (RBV).

However, the availability of PEG-IFN treatment, which can increase the chances of sustained virological response and chances for recovery, can be limited in some countries, most often because a limited number of PEG-IFN treatment courses can be reimbursed by the state.

- **Discrimination against drug users prevents access to HCV treatment**

International guidelines - such as those issued by the European Association for the Study of the Liver (EASL) on hepatitis and HIV co-infection treatment, and the World Health Organization's protocols on HCV and HIV management - state that drug users cannot be excluded as a group, and the eligibility of drug users for treatment should be assessed on a case-by-case basis, as it is among the non-drug-using population.

HCV treatment guidelines exist in virtually all countries of the region, though in Ukraine guidelines are only at draft stage and in Hungary new guidelines are pending approval. While

guidelines in most countries support the provision of qualified and effective treatment, they seldom reflect international guidelines when it comes to treatment access for drug users. In all 13 countries drug use is generally considered a contraindication to treatment and this was found to be the case in practice as IDUs rarely receive treatment. The only exception is Slovenia where drug users with health insurance can access treatment and be treated by multi-disciplinary teams of specialists of infectious diseases and addiction treatment.

Some countries report individual cases when drug users are included in HCV treatment based on the decision of individual doctors. Commonly in all countries abstinence period of at least six months is required.

Though most guidelines do not address the treatment of OST clients, access to HCV treatment is higher for those on OST. In number of countries people stabilized on OST can have access to HCV treatment (in Bulgaria, the Czech Republic, Hungary, Lithuania, Romania, Slovakia, Slovenia). However, most often the treatment is limited and can be refused by doctors. Better access to treatment for OST clients is seen in the Czech Republic where HCV treatment is linked with drug treatment and low threshold services.

Restrictive guidelines present one of the barriers limiting access to HCV treatment for drug users. Often even where treatment is available IDUs are not a priority or are excluded from treatment due to prejudice on the part of health care providers and lack of training on drug use and addiction treatment among infectious diseases specialists. Other key barriers include:

- lack of cooperation between drug treatment and infectious diseases specialists;
- limited access to primary health care for IDUs;
- limited access to additional care and treatment - such as OST and antiretroviral therapy (ART) for people co-infected with HIV;
- stigma and discrimination against IDUs - often negative attitudes of medical professionals towards drug users

- **Overall limited availability of HCV diagnostics and treatment**

The cost of HCV treatment in most of the world is relatively high. In the new EU Member States and neighboring countries a 53-week course costs an average of EUR 12 600. As a result, cost is one of the primary barriers to treatment not only for IDUs but also for the general population.

The practices of reimbursement by the state vary from country to country. In 9 (out of 13) countries the treatment costs are fully covered by the state, most often by health insurance. However, the ability and readiness of states to reimburse treatment remains limited. For example, in Bulgaria only 50–60 people can get state-financed treatment. Treatment is partly covered by state in two countries - Belarus and Latvia. However the standards of treatment provided and covered by the state may significantly differ from the European standards, for example in Belarus doctors still prescribe interferon monotherapy. Modern combination therapy is not covered by state in Russia or Ukraine.

In theory, HCV treatment should be available in prisons in Bulgaria, Hungary, Lithuania and Poland. In practice, however, it is rarely available and, although data are limited, it appears that very few inmates receive treatment, which most often is due to lack of funds for treatment and/or diagnostics. More commonly, prisons in most countries have an established practice of providing only symptomatic treatment to HCV patients.

Access to diagnostic tests (confirmatory antibody test, RNA and genotype test) varies across the region and in some cases also is an impediment to access to treatment. Confirmatory tests, RNA and genotype tests are reimbursed in most countries, except Ukraine. In Russia, antibody

tests are free of charge for patients with health insurance, but they must pay for all other tests. In Lithuania diagnostic tests are purchased centrally by the state, therefore a limited number of people can undergo diagnostic tests each year. By the end of 2006 a shortage in tests was reported by medical professionals.

The differences in access in different cities were not assessed but, according to respondents, there are inequalities in access to diagnostics between regions and cities within countries.

- **Treatment for people co-infected with HIV is a priority**

Most often, co-infected people need treatment more urgently than mono-infected people, and five countries do report having specific guidelines for the treatment of hepatitis/HIV co-infection either within their hepatitis or HIV treatment guidelines or in a separate document. Yet in some countries surveyed, such as Belarus, co-infection is an excluding factor when considering HCV treatment.

In some countries, co-infection with HIV is the only way to get state-funded treatment. In Russia, where free-of-charge treatment is not available, guidelines allow to provide it to people with a disability, which includes people living with HIV (PLWH) registered at AIDS Centre. This usually is also true in practice. .

Countries with high HIV prevalence and those receiving international funding from large donor organizations such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), offer a possibility of HCV treatment to PLWH. For example, in Belarus in 2007 it is planned to provide treatment for 40–50 co-infected people as part of the project funded by the GFATM. A pilot program to provide HCV treatment to PLWH is also planned to be implemented in 2007 in Ukraine. The program, which will enroll about 200 people into treatment, will be supported by the World Bank and partly by the state (34–35 people). As of February 2007 the drugs had still not been purchased.

- **Vaccination for hepatitis A and B**

Among the 13 countries surveyed, only Slovenia and Romania have hepatitis A (HAV) vaccination targeting IDUs at no cost. In Romania vaccination for drug users is a part of GFATM funded project.

Hepatitis B (HBV) vaccination is more widely available than HAV vaccination and is provided at some low threshold facilities in the Czech Republic and Romania, also in some cities of Russia and Slovakia (upon registration at the Center for the Treatment of Drug Dependencies), but is still limited for drug users.

HAV vaccination in prisons is available only in Slovenia and the Czech Republic; HBV vaccination for drug users in prisons is much more widely available than HAV vaccination. It tends to be more accessible than in communities and in some cases is provided for free in Bulgaria, the Czech Republic, Estonia, Hungary, Lithuania and Slovenia. In Slovakia vaccination at cost can be provided upon request.

Recommendations for further actions:

- 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;

- A supportive environment for services that reduce vulnerability related to HCV and risk behavior should be created, including revision of drug policies which would reflect a non-stigmatizing approach based on public health interests and human rights and greater support for comprehensive, pragmatic prevention, treatment, care and support services;
- Protect the human rights and legal interests of those affected by HCV and meaningfully involve drug users and people with liver disease in developing policies and practices;
- International organizations (like the EU and the United Nations), in cooperation with national governments and civil society representatives, should initiate and adopt recommendations and/or a pan-European strategy on 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 including drug users in treatment programs based on clinical criteria, deciding on treatment eligibility on a case-by-case basis. Drug addiction treatment specialists and representatives of affected communities should be involved in the development of guidelines;
- Health care institutions should work together with low threshold service providers and representatives from communities affected by HCV or IDU to establish comprehensive responses to HCV and increase access to care for IDUs and people with liver diseases;
- Low threshold services, often being the main services in contact with IDUs, should be expanded and include HCV counseling; distribution of needles, syringes and other injecting equipment; free, voluntary HCV testing along with pre- and post- test counseling; HAV and HBV vaccination; and information and skills building on safer injection and drug use;
- The most effective treatment must be made available for all who need it, including IDUs and clients of OST programs;
- Comprehensive care should be provided to address complications and side-effects of treatment, to maintain quality of life of people in treatment, and to enhance treatment outcomes. This involves cooperation between liver disease doctors, infectious disease specialists, social workers, psychologists and psychiatrists, patients, their relatives and peer support organizations;
- Ensure that the availability of preventive measures and treatment, care and support in prisons is equal to that provided in the community.

2. Introduction

The Hepatitis C virus (HCV) is highly infectious and is transmitted through direct contact with infected blood. Unlike HIV, HCV can be transmitted through sharing not only needles but also other injecting equipment, including cookers, cotton, spoons or water that is used while preparing the drugs, which raises the standards needed for safer injection practices (Hagan, 2001). The infection spreads rapidly among IDUs, who account for about 60–90% of newly identified cases in the European Union (EU). This makes HCV a top-priority issue for the drug-related harm reduction agenda, and it should be prioritized in national drug and infectious diseases policies. “Controlling the HCV epidemic, therefore, will require developing, testing, and implementing strategies for the prevention, care, and treatment of hepatitis C that will be effective for IDUs”, (Edlin, 2005)

While most countries in the region have finally expressed political commitment to addressing HIV and AIDS, HCV is still very much a neglected issue on both international and national levels: few countries in the region have specific strategies addressing hepatitis in community settings and/or in prisons. Although the consequences of HCV infection are particularly troubling: HCV is one of the leading causes of severe liver cirrhosis and liver failure—second only to alcohol (Wong, 1998)—and is the main reason for liver transplantation (EMCDDA, 2006a). End-stage liver disease caused by HCV co-infection has become one of the leading causes of death among people living with HIV and AIDS (PLWHA) in Europe (Bica, 2001; Martin-Carbonero, 2001). HCV-related health care costs are also high. The estimated annual future cost of treating drug-related HCV, HBV and HIV infections in 10* out of 27 EU countries is EUR 1.89 billion, with HCV accounting for almost 40% of these costs (EMCDDA, 2004). Although there is no analysis available for health care costs in the new EU Member States or for the Central and Eastern European region specifically, the more extensive disease burden and limited access to health care in the region means that health care costs are expected to be much higher.

Despite effective HCV treatment exists, it is still restrictively expensive in most countries. HCV treatment is even more limited for IDUs, who as a rule are excluded from treatment, despite the fact that drug users can be successfully treated for HCV (for example, see Van Theil, 2003; Cournot, 2004; also see Table 10 in the Appendices). Even clients of opioid substitution therapy (OST) are often denied the right to treatment. Reasons for excluding IDUs include a fear of non-adherence, side-effects, drug interaction and possible re-infection among IDUs who continue to inject during and after an antiviral treatment course for HCV and often negative attitude of health care professionals towards drug users. “The truth is that the HCV treatment costs around EUR 20 000 per year as yearly there were 50-60 slots for treatment so the decision-makers don’t want to waister them on “socially unreliable” people”, Milena Naydenova, NGO Hope-Sofia, Bulgaria at regional consultation “Hepatitis C and Drug Use in the New EU Member States and Neighborhood” Vilnius, March 11, 2006. “Substantial barriers to providing effective care and treatment for IDUs with hepatitis C stem from characteristics of the disease, patients, providers, and the health care system. As a result, although a large proportion of IDUs with hepatitis C express willingness to undergo treatment, a disproportionately low number of IDUs have actually received antiviral

* Belgium, Denmark, France, Germany, Greece, Italy, the Netherlands, Portugal, Spain, the UK.

therapy for HCV infection”, (Stein, 2001). Together with the lack of targeted prevention measures and low threshold testing for HCV, limitation of treatment and care for IDUs contributes to ongoing high rates of transmission, lead to health complications and mortality.

Few IDUs have access even to primary health care services, often because they do not have health insurance or the financial means to get services. Also IDUs frequently experience discrimination due to the stigma attached to drug use and/or HCV infection. Aggressive policing and/or stigmatization may also have a negative impact by leading IDUs to engage in hurried injection behaviors, to share syringes more often, to inject in high-risk environments and, in addition, to impede the creation or functioning of NEP, drug treatment or other programs to improve users’ health (Friedman, 2006).

Neglecting the health and other needs of IDUs has already resulted in high HIV prevalence related to injecting drug use, as documented in Eastern European countries. While reliable estimates of HCV for the region are not available, the fact that HIV spreads among IDUs through sharing injecting equipment partly reflects the relative prevalence of HCV. In fact, the HCV rates are likely to be even higher than HIV because of the higher infectivity of HCV. While HIV prevalence related to injecting drug use is high in Eastern Europe, data presented in this report suggest that HCV among IDUs is spreading steadily in most countries of the region, including in those where reported HIV levels are low. Moreover, HCV is often asymptomatic, which increases the likelihood of being undiagnosed.

As the EU borders expanded in May 2004 and January 2007 to encompass Central and Eastern European countries, there were expectations that HCV prevention, treatment and care would be addressed in the context of EU health policies. Unfortunately, data show that in the 15 countries that were part of the EU before the 2004 expansion, treatment for HCV is also hard to access and often limited, especially for IDUs (EMCDDA, 2004). HCV was only recently put on the EU agenda: the European Parliament adopted a declaration that called on the European Council to adopt recommendations on HCV, ensuring early diagnosis and wider access to treatment. The European medical community is also increasingly recognizing HCV as a key health issue. The World Health Organization (WHO) has developed protocols on hepatitis in co-infection with HIV. However different diagnostic, treatment and care practices across EU countries prove the need of EU strategy on hepatitis: “A global European Commission Strategy to fight hepatitis in the European Union and neighboring countries – that is evidence based, using the best scientific knowledge in epidemiology, public health, behaviour, treatments and using the involvement of Civil Society and community – we do have an expertise based on direct experience that nobody else possesses. And the public powers who ignore the best knowledge available in defining public policies will fail to deliver good governance answers”, Luís Mendão, European AIDS Treatment Group, during the Press Conference for World Hepatitis Awareness Day, September 28, 2006.

2.1 Background to the report

In March 2006, the Central and Eastern European Harm Reduction Network (CEEHRN) organized a regional consultation to discuss the most urgent problems and share experiences related to HCV prevention, treatment, care and support for drug users. Participants included health care professionals, researchers, community activists and representatives of the affected community. The

consultation demonstrated that there is a lack of data on HCV prevalence, prevention and treatment interventions in the region as well as lack of capacity to address the issue by service providers.

With this in mind, the report aims to summarize the realities of the HCV epidemic as well as governmental responses that specifically target IDUs. It also seeks to provide evidence for action and to outline the potential roles that decision-makers, service providers, donors, prison services, activists and researchers can play in addressing the epidemic. Emphasis has been given to the following:

- access to HCV prevention, diagnostics, treatment and care;
- testing, treatment and care for the most vulnerable members of society—those with the highest prevalence of HCV;
- the role of governments, international institutions and agencies, health care specialists, service providers and those affected by the virus.

The following principles form the basis of the information in this report:

- HCV transmission, associated illnesses and mortality can be reduced through measures focusing on the most-at-risk populations;
- Not only do IDUs have the same rights to health care as all other members of society, but the involvement of IDUs and people living with HCV in shaping policies that affect their health is essential;
- IDUs can adhere to HCV treatment and achieve the same sustained virological response (SVR—no detectable HCV in the bloodstream six months after completion of HCV therapy; many experts regard SVR as a cure) as non-drug users when treatment is adapted to their needs, and when possible complications and side-effects are addressed;
- With the goal of ensuring cost-effective and efficient treatment, access to and widespread use of the most effective treatment currently available—pegylated interferon (PEG-IFN) and ribavirin (RBV) treatment—should be provided.

Geographic focus of the report:

This report is focused on 13 countries: 10 new EU Member States (Bulgaria, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Slovenia and Slovakia) and 3 neighboring countries (Belarus, Russia and Ukraine).

2.2 Report structure

Section 1 is the Executive Summary.

Section 2 gives an introduction, and information about background and methodology.

Section 3 provides an overview of HCV transmission routes, trends and the extent of HCV and HCV/HIV co-infection associated with injecting drug use in the region. It also summarizes risk behaviors among IDUs in the region. Most data in this section are derived from selected studies in countries, studies done by other agencies, including the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) and WHO, as well as testing data presented by studies in the focus countries.

Section 4 summarizes information on HCV prevention interventions targeting IDUs based on various studies from around the world, and provides guidelines on what should be in place in the

community settings and in prisons. It presents an overview of interventions related to prevention and testing in target countries; their extent, availability and accessibility for drug users in communities and prisons; and short overview of barriers to prevention interventions among IDUs. It also gives a brief evaluation of existing policies and political commitment to the issue.

Section 5 focuses on treatment targeting IDUs. It reviews the existing scientific data regarding treatment compliance among IDUs compared with compliance levels among non-IDUs, and discusses the conditions that help improve SVR and adherence rates among IDUs. It presents an overview of guidelines and what they indicate about HCV treatment and drug use and access to treatment for IDUs. The section also aims to identify existing barriers that restrict access to HIV treatment among drug users. It discusses the availability of PEG-IFN and RBV treatment in community, in prisons and reimbursement policies; examples from countries that illustrate different approaches to treatment are also presented.

Section 6 provides information and guidelines on support for people living with HCV and how their needs can be addressed. It discusses the involvement and role of IDUs and people who are living with HCV, especially in advocacy and lobbying actions.

Section 7 includes conclusions and recommendations for improving HCV policies and interventions among drug users in the region.

The **Appendices** contain information and data summarized in tables and figures that are referenced and discussed throughout the report.

2.3 Report methodology

The report data and analysis came from three primary sources:

- **The regional consultation on Hepatitis C and Drug Use in the New EU Member States and Neighborhood**—this meeting served as a basis to share experiences among health care professionals, service providers, researchers, human rights activists, drug users and people living with HCV from 13 countries of the region, Europe and the United States. Participants discussed key issues, challenges, information gaps and possible enhancements in services, policies and advocacy for effective HCV prevention, diagnostics, care and treatment for IDUs. This information served as a guideline for developing the structure of this report and collecting data from countries.
- **Assessment of existing data**—secondary sources assessed, including data of WHO, EMCDDA, European Network on Drugs and Infections in Prison (ENDIPP), WHO Collaborative Centre for Control and Prevention of Viral Hepatitis (Unit of Epidemiology and Social Medicine, University of Antwerp) as well as printed research literature, country assessments and reports in English and Russian.
- **Survey**—this focused on issues not covered by existing literature and involved administering a standardized two-part questionnaire to national respondents in each country of the region via email and follow-up by email or phone. Some of the information was collected before the regional consultation and some after the meeting. Most respondents joined the regional consultation. The survey focused on:
 - national regulations related to HCV;
 - studies on HCV and HCV/HIV prevalence among IDUs;

- medical and low threshold services related to HCV prevention, treatment and care in community and prisons;
 - availability and accessibility of testing and diagnostics of HCV for IDUs in community and prisons;
 - guidelines and practices on access to HCV treatment and HCV/HIV treatment for IDUs, former IDUs and clients of OST programs;
 - comprehensive care, availability of vaccination for HAV and HBV, and support and self-support for drug users with HCV.
- **Involving expert opinion** – a group of experts was engaged to co-write and review Section 3 on epidemiological overview, Section 4 on prevention among IDUs, Section 5 on HCV care and treatment for IDUs, and Section 6 on support for people with HCV, and to review the recommendations.

All data collected for this report cover the period up to January 2007. Although information and data may not be suitable for in-depth analysis, they meet the report's overall goals of providing an overview of HCV among IDUs in 13 countries of the region, summary information that can be used as an advocacy tool and to fill in the knowledge gaps among activists in countries.

2.4 Limitations

CEEHRN acknowledges that there are additional risks of HCV transmission associated with drug use, including non-injecting drug use. This survey focused mainly on injecting drug use because data indicate that sharing needles and other injecting equipment accounts for the majority of cases of HCV (for example, see Fuller, 2004). This means that IDUs are at higher risk of HCV infection, although the proportion of HCV cases among non-IDUs and the risks for this group needs additional analysis.

Due to financial limitations, a lack of established work with HCV-infected IDUs in the countries surveyed and other factors, this report does not present a comprehensive analysis of parallel issues related to and affecting HCV transmission among IDUs. The report does not include information about the quality of harm reduction and other low threshold services, nor close examination of drug policies or social and economic factors that affect the possibility and ability of IDUs to get access to HCV prevention, treatment and support and other health care services.

Since this report has been developed in the framework of the EU-funded, EU-wide project AIDS Action & Integration, its main focus is the new EU Member States. CEEHRN acknowledges that the problem of HCV is not exceptional for countries assessed in this survey and that the same problems exist to a greater or lesser extent throughout Central and Eastern Europe and Central Asia. Further analysis is needed to assess the situation in the remaining 15 countries of the region, and additional efforts are needed to raise awareness of the HCV epidemic among IDUs throughout the region.

3. Epidemiological overview: hepatitis C, injecting drug use and related issues

Worldwide, HCV has one of the highest prevalence rates of all infectious diseases—according to WHO, around 3% of the world’s population (approximately 180 million people) are infected with HCV. By contrast, estimates show that 34.1–47.1 million individuals are living with HIV worldwide (UNAIDS & WHO, 2006). It is estimated that 130 million people are chronic carriers of HCV (WHO, n.d.) with estimated 250 000 people dying annually of HCV-related causes (Lavanchy, 2004). At least 4–5 million people are co-infected with HIV and HCV (Alter, 2006). HCV prevalence varies widely by country, from less than 0.1% in Scandinavian countries to 20% in Egypt (Handysides, 1999; Mohamed, 2006).

3.1 Natural history of HCV

The association of HCV genotype and disease progression is still controversial among some experts, but it is important in the prediction of HCV treatment response. At least 6 genotypes and more than 100 subtypes of HCV are known today, with genotypes 1–3 being the most common worldwide, including in Europe.

Not all people who test positive for HCV will develop chronic infection, as it may spontaneously resolve during the acute phase. Some studies have shown that treatment of acute HCV infection can result in viral clearance (Edlin, 2005). However, in 55–85% of cases, HCV infection will become chronic (EMCDDA, 2004). In the long run, infection can progress and bring about serious complications, such as cirrhosis (occurring in 10–20% of infected people within 10–20 years), liver cancer (5–10%) or end-stage liver disease (CDC, 2005). Due to the specific conditions and lifestyles of IDUs—including polydrug use (the use of two or more psychotropic substances, including alcohol, in combination), nutritional condition and limited access to health care—several experts suggest that HCV and liver diseases progress faster in IDUs than in non-drug users (Edlin, 2002; Cooper, 2006).

3.2 HCV transmission and risk factors

Before 1990, exposure to contaminated blood and injecting drug use were the main causes of HCV transmission. The introduction of blood screening for HCV dramatically reduced viral transmission through transfusion of infected blood, leaving **injecting drug use** as the main cause of transmission. Data show that IDUs now account for up to 60–90% of newly identified cases of HCV in EU countries (EMCDDA, 2004b); in Canada three out of four new infections are related to injecting drug use (Remis, 2004).

Due to the high infectivity of the virus, HCV can be transmitted not only from sharing needles and syringes but also from sharing other injecting equipment. A study among IDUs tested for HCV in Russia showed increased transmission of HCV associated with the use of communal spoons or glasses used for mixing and cooking the drug solution (Rhodes, 2006).

Other important factors associated with an increased likelihood of HCV among IDUs are: increasing length of injecting career, daily injection, polydrug use and history of imprisonment (Van Beek, 1998; Judd, 2005; Zabransky, 2005).

Infection can also occur while sharing any equipment used for tattooing and piercing, and straws used for drug sniffing (Hagan, 2001), making non-IDUs vulnerable to HCV as well. However, HCV incidence studies show much higher prevalence among IDUs than among non-IDUs—for example an assessment among drug users in New York showed estimated 60-100% prevalence among IDUs, compared to around 5% among non-IDUs (Fuller, 2004).

Sharing of personal items, such as razors or toothbrushes, is a less likely but possible transmission route for HCV (Yee, 2001). Sharing of tattooing needles also increases the HCV risk, especially in prisons, where HCV prevalence may be related to sharing tattooing needles, rather than drug injecting.

People with compromised immunity may be at higher risk of contracting HCV, making PLWHA highly vulnerable to HCV infection (Highleyman, 2002).

HCV is also transmitted through **sexual contact**, although to a much lesser extent than through drug use and other associated risk behaviors: 0–3% of people contract HCV through unprotected sexual intercourse (Highleyman, 2002). Nevertheless, high-risk sexual activity increases the risk of infection, making sex workers and people with multiple partners more vulnerable to infection. Sexual transmission of HCV has been reported among HIV-positive men who have sex with men and are practicing high-risk behavior, such as unprotected sex with multiple partners.

Mother-to-child transmission, though documented, is unusual, except in babies born to mothers with very high levels of HCV ribonucleic acid (RNA), including women co-infected with HIV. It has been estimated that the likelihood of perinatal infection is around 5% (Mazza, 1998; Conte, 2000; Dienstag, 1997). This risk probably increases in cases of HCV/HIV co-infection, but the availability of HIV antiretroviral therapy (ART) has lowered this risk significantly.

Currently, in about 20–40% of all therapy cases, no recognized source of infection is identified (Karmochkine, 2006).

3.3 IDU, HIV and HCV in the new EU Member States and neighboring countries

The 13 countries surveyed for this report—Belarus, Bulgaria, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Russia, Slovakia, Slovenia and Ukraine—have a combined population of almost 270 million people (World Bank, 2006). According to various estimates, there could be between 2.1 million and 3.3 million IDUs. This is between 0.7% and 1.1% of the total population of the region, though these are only estimates and actual numbers could be even higher. The number of IDUs as a percentage of the population of each country ranges from 0.05% in Bulgaria to as high as 2.22% in Estonia (for more details see Table 1 in the Appendices).

It is estimated that in 2006 there were 270 000 new **HIV infections** in Eastern Europe and Central Asia, making the total number of HIV-infected people in the region close to 1.7 million, with Russia and Ukraine accounting for about 90% of all cases (UNAIDS & WHO, 2006). The vast majority of the cases in the East are related to the use of non-sterile injecting equipment. Central Europe records much lower numbers of HIV infection and reports sexual transmission as the main transmission route. These regional differences in HIV epidemics are reflected also in HIV prevalence studies among IDUs, which show relatively low infection levels in Central Europe (e.g. 0.4% in Slovenia, and 0.7% in Bulgaria and the Czech Republic) and much higher levels in many cities and regions of Ukraine, Russia, Estonia, Latvia and Poland, for example: 16% in Poland; 12.1–58.3% in Ukraine; 3.1–58.4% in Russia; 54.3% in Estonia; and 14.6–22% in Latvia (see Table 2).

HIV and HCV share common routes of transmission, yet there is one crucial difference—HCV is about 10 times more infectious than HIV (Michielsen, 2005). Although there are no regional estimate for **HCV infection**, data from needle and syringe exchange programs (NEPs), other low threshold facilities and drug dependency treatment sites from 13 countries (see Table 3) show a lower average prevalence of HCV in Central Europe than in Eastern Europe (with exception of Poland, where the prevalence ranges from 55 to 68%), which follows the same pattern as HIV prevalence in the region (see Table 2). Available data show prevalence of 18–59% in the Czech Republic; 14–24% in Hungary; 46% in Slovakia; 40% in Slovenia. HCV prevalence among drug users is higher in countries with already documented outbreaks of HIV among IDUs. Studies have shown high HCV prevalence in Estonia and Lithuania reaching up to 80–90% in some studies from Estonia and Lithuania. Estonia has the second highest prevalence of HIV in Europe and one of the highest levels of opiate use in the world (UNAIDS & WHO, 2006). Estonia also has the highest prevalence of HCV among all 12 new EU Member States (EMCDDA, 2006b). In the neighboring Russia and Ukraine, HCV prevalence is at similar or even higher levels, ranging from 60% to over 90% among IDUs. Limited data available for Belarus suggest that this country with a high HIV burden might have managed to keep one of the lowest rates of HCV prevalence in the region (32%)

At the same time prevalence over 60% reported from studies in Central European countries including Bulgaria, Poland and Romania, suggesting that HCV infection is spreading among IDUs at a much higher pace than HIV throughout Central and Eastern Europe (see Table 2 and Table 3, also see Box 1: Prevalence of HBV and HCV and HIV prevalence in IDUs and attribution to age group in Kharkiv, Ukraine).

Substantial differences in HCV prevalence in different cities and settings are also documented (see Table 3). In Russia, a study conducted in three different regions showed a prevalence of 67% in Moscow, 70% in Volgograd and 54% in Barnaul. In Romania, the testing between clients of two different OST programs in Bucharest showed a prevalence rate of 80% in one program and 48% in another. In the Czech Republic, prevalence of HCV was about 30% among the clients of low threshold facilities, while it is nearly twice as high among the clients of OST programs.

Box 1: *Prevalence of HBV, HCV and HIV in IDUs and attribution to age group in Kharkiv, Ukraine*

By Volodymyr Kurpita, World Health Organization Country Office in Ukraine; Valeriya Shaginyan, Yuri Kruglov, Anatoly Gural, Yuri Kobyshcha, Violetta Martsinovska, Gromashevsky Institute of Epidemiology and Infection Diseases, Ukraine

HIV sentinel surveillance studies showed that HIV prevalence among IDUs varied from 11–66% in different settings in recent years. However, much less is known about HBV and HCV prevalence in this population. In 2004, 450 IDUs attending an outreach site in Kharkiv city (Eastern Ukraine) were tested to determine HIV, HBV and HCV prevalence.

Results showed the highest prevalence of HCV among the people tested—60.9%—while prevalence of HBV was found to be a bit lower (48.4% of the study participants). The prevalence of HIV was much lower than both HCV and HBV: 16.0% of IDUs were HIV-positive. The results proved that the risk of IDUs being infected by HCV was 7.6 times greater than the risk of being infected by HIV; and the risk of IDUs being infected by HCV was 3 times greater than the risk of being infected by HBV.

The lowest prevalence rates were found in the 15–19 year age group: HIV prevalence was 5.0%, HBV—43.3 % and HCV 56.7 %. The highest rates were detected in IDUs over 35 years of age: HIV prevalence was 16.7 %, HBV—5.0 % and HCV 89.5%.

About 68% of the IDUs tested had co-infections. The most common co-infection was that of HBV and HCV: 47.8% of study participants. HCV mono-infection was observed in only 15.1% of participants, HBV in 4.9% and HIV in 2%.

This study confirmed high HIV prevalence in the IDU population (16% versus 1.46% in the general population). It also demonstrated consistent and very high rates of both HBV and HCV in IDUs compared to HIV infection. While ART is increasingly becoming available for the IDU population (in 2006, around 40% of all people on the therapy were active or former IDUs), hepatitis, especially HCV, will increasingly emerge as a primary public health problem, and there is a great need for more drugs to treat it at lower prices.

3.4 HIV and HCV co-infection

HCV co-infection with HIV is common particularly among active and former IDUs, who acquire both viruses from injecting drugs. Such co-infection reduces the chance of recovery from acute HCV, compromises the effectiveness of existing HCV treatment, and accelerates the progression of HCV infection to cirrhosis (Graham, 2001) and liver failure (Eyster, 1993). On the other hand, liver disease is becoming one of the lead causes of death in PLWHA. In Western Europe, where ART is widely accessible, the most frequent causes of death in co-infected people are related to liver disease—more often than to AIDS-defining infections. This trend represents a striking change in the epidemiology of HIV and AIDS-related deaths, which previously were due more to opportunistic infections rather than co-infections (Lazarus, 2007).

In contrast to the rest of the world, the prevalence of HCV infection in PLWHA in Europe is particularly high and still rising, with about 80–90% of cases occurring among IDUs (WHO, 2006b). In a EuroSIDA study with a large cohort of around 5000 patients, the highest prevalence of HCV co-infection was found in Eastern Europe (47.7%), presumably due to the high rates of injecting drug use in the region (Rockstroh, 2005).

According to a WHO survey on hepatitis among PLWHA seeking treatment in the new EU and neighboring countries, the prevalence of HIV and HCV co-infection varies substantially from country to country: from 20–40% in Belarus, the Czech Republic and the Russian Federation; to more than 40% in Latvia and Lithuania; and is close to 80% in Estonia and Ukraine (see Table 4). In most Central European countries (except the Czech Republic and Poland) HCV co-infection rates were usually lower than 5%.

3.5 Injecting drug use and HCV-related risk behaviors

In Central and Eastern Europe, such unsafe practices as sharing needles are common. For example, results of an extended study among IDUs in the Czech Republic showed that in 2003:

- 77.1% of 760 IDUs tested have reused a syringe;
- only 20.8% reportedly have never shared injecting equipment;
- 77.9% of the respondents have shared other injecting materials with someone else;
- 25.1% of the respondents stated that they knew that they had used a syringe after an HCV-positive person (Reitox—the Czech Republic, 2005).

In three cities in Ukraine, 60–80% of IDUs who were surveyed reported sharing syringes, and only 15–20% reported using a new syringe for each injection. Moreover, 38–50% of IDUs bought ready-to-use drugs in syringes that might have been used before (Drug Law and Health Policy Network, 2002).

While sharing injecting equipment is common, there are additional factors that might influence unsafe practices. It was noted that sharing injecting equipment is usually found more often in closed settings, marginalized communities and among some ethnic minorities. For example, this is the case among Roma drug users, who are particularly vulnerable to HCV and other blood-borne infections, as they tend to have a lower level of knowledge and awareness of the disease and limited access to information and medical services (Reitox—Poland, 2005; Reitox—Hungary, 2005).

3.6 Injecting drug use and HCV-related risk behaviors in prisons

High HCV prevalence among prisoners is no surprise: overcrowded conditions, lack of prevention services combined with high-risk behaviors, create an opportune environment for the transmission of blood-borne viruses. Despite efforts to keep drugs from entering prisons, drug use among prisoners persists. Besides additional risk behaviors for HCV transmission that occur in prisons, such as tattooing and piercing, access to clean syringes and needles is extremely unavailable or limited, and sharing injecting equipment is the norm. Moreover, criminalization of drug users

and increased law enforcement is resulting in the systematic incarceration of people who inject drugs, thereby increasing the number of incarcerated injectors and the likelihood of unsafe injecting practices in prisons (Stöver, 2006a). On the other hand, some prisoners start using drugs while in prison (Canadian HIV/AIDS Legal Network, 2006a). IDUs typically inject less frequently in prisons (Dolan, 1996), although studies have demonstrated that drug use that occurs within prisons tends to be in higher-risk conditions and manner than injections in community settings (Darke, 1998; Malliori, 1998).

According to the EMCDDA, in the EU countries, 8–51% of inmates have used drugs within prisons; 10–42% report regular drug use; and 1–15% have injected drugs while in prison (EMCDDA, 2006a). Surveys carried out in the new EU countries of the Czech Republic (1996–2002), Hungary (1997–2004) and Slovenia (2003–2004) show an increase in the levels of various types of drug use among detainees (EMCDDA, 2006b). Injecting drug use in prisons was also associated with an HIV outbreak in Alytus prison in Lithuania (Caplinskas, 2002).

Available data from neighboring countries also provide evidence of drug injecting in prisons. A study performed in 2000 in 10 penitentiary institutions in Russia showed that 10% of surveyed prisoners reported injecting at least once, with nearly 2% of the total prison population injecting on a regular basis. Furthermore, 13.5% of IDUs started injecting in prison (Médecins Sans Frontières, 2000). Risk-taking behaviors in Russian prisons were confirmed by more recent studies (Frost, 2002; Sarang, 2006). In a study undertaken in a number of prisons in Ukraine in early 2005, a significant number of prisoners admitted to injecting and sharing injecting equipment in prisons (Canadian HIV/AIDS Legal Network, 2006b).

Tattooing is another activity that involves sharing needles and exposes a person to HCV. Possession of tattooing equipment is illegal in most countries, and, as a result, tattooing in prison often takes place under unsanitary conditions, where blood-borne diseases are more likely to spread.

Overall the average of 20–40% of prisoners are infected with HCV, and the rates of HCV among prisoners who inject drugs is usually two to three times higher than among prisoners who have no history of injecting drug use (WHO, 2005). Moreover, HCV prevalence rates among prisoners are higher than HIV (Canadian HIV/AIDS Legal Network, 2006b).

Data about rates of HCV prevalence among prisoners in surveyed countries are limited, in part because of the limited availability of HCV testing. But the data that are available show a wide range—although overall high rates—of HCV prevalence among prisoners (see Table 5). Data from Estonia suggest that there is a high prevalence of HCV among inmates—from 82% to up to 97.4% (though sample sizes were small)—while none of the inmates in the sample tested positive for HIV. In several other studies from the Czech Republic, HCV prevalence was also high (18–78%).

There is a need for further assessment of HCV prevalence among prisoners in the region, especially because of the close association between history of imprisonment and higher HCV prevalence, which was reported, for example, in a study in the Czech Republic (Zabransky, 2005) and elsewhere in the world (Beek, 1998; Judd, 2005).

4. Hepatitis C prevention among IDUs

“It is conceivable that HCV prevention has failed not so much because the wrong strategy was pursued, but because efforts have been too small-scale and therefore weak in relation to the number of factors favoring HCV transmission”, — Hagan, 2005.

While there is a large body of evidence supporting effectiveness of harm reduction interventions in HIV prevention among IDUs (Center for AIDS Prevention Studies, 1998; WHO, 2004a; WHO, 2004b; IHRD/OSI, 2004), preventing HCV is a different matter. The effectiveness of harm reduction measures on the prevention of HCV has been explored to a lesser extent, and their effectivity seems to be lower. This is due in part to the efficiency with which HCV spreads through the sharing of injecting equipment, and in part to the fact that rarely all associated risks are addressed. Yet research data from around the world can provide guidance on interventions for preventing and reducing further incidence of HCV among IDUs, including the reduction of the risks for HCV transmission and the prevention of progression of the virus.

4.1 What works in HCV prevention among IDUs: guidelines and suggestions

4.1.1 Low threshold testing and counseling

Conducting surveillance and testing among IDUs is a challenge. Some IDUs cannot access primary health care, as they do not have medical insurance. Even when there is access to health care, most drug users avoid contact with state health care institutions, often fearing stigma, possible inclusion on a drug user register and in some countries subsequent transfer of their data to law enforcement agencies. Drug users who seek out testing tend to go to low threshold facilities and avoid other venues where they are not guaranteed confidentiality and/or cannot afford to pay for tests.

Therefore testing targeting IDUs should be low threshold, confidential and voluntary. It also should be linked to other existing drug-related harm reduction services, like NEPs and OST, outreach programs and existing anonymous, voluntary HIV testing and counseling sites which are the core services establishing and maintaining contact with clients. This would help to increase access to HCV testing and information.

Rapid tests can also help to increase the accessibility of testing for IDUs. First, they are done quickly and a person does not have to return at a later date to get the results. Second, rapid tests can be done in a variety of settings where IDUs gather, so that providers do not have to refer clients to a testing center or laboratory. On the other hand, rapid tests are less accurate, regularly more expensive than laboratory testing, and where rapid testing is administered, it is more challenging to ensure that appropriate pre- and post-test counseling is provided and that clients are prepared for a positive result.

Most low threshold facilities use HCV antibody test, which will detect whether or not a person has been infected with HCV. However, antibody test does not distinguish a chronic

HCV infection from a prior, spontaneously cleared infection. A viral load (HCV RNA) test is necessary to confirm or rule out chronic HCV infection. Many IDUs assume that they are chronically infected, and many remain uninformed or misinformed about the virus due to a lack of proper **pre- and post-test counseling**. This may result in high-risk behaviors between “running partners”—people who cooperate to obtain drugs and then usually inject together and often share injecting equipment, and who assume that both are HCV-positive (for example, see Box 2: HCV testing in the context of an outreach project in Bratislava, Slovakia). Therefore, pre- and post-test counseling is imperative for ensuring that people understand the meaning of a positive antibody test and the consequences of ongoing high-risk behavior.

Box 2: *HCV testing in the context of an outreach project in Bratislava, Slovakia*

By Katarina Jiresova, NGO Odyseus, Slovakia

Odyseus is a non-government organization, established in 1997, which provides low threshold services primarily for (injecting) drug users, sex workers, children and young people. The organization has been running the “Protect Yourself” outreach project since 1998, with the aim of eliminating the social exclusion of IDUs and sex workers. This is done mainly by providing harm reduction services through an outreach approach. Since HCV is among the risks associated with injecting drug use, one of the project’s objectives is to increase access to HCV-related services for IDUs.

Access to HCV testing helps people to find out their status, and it is also a tool to educate and counsel most-at-risk people on HCV. By working with IDUs in the “Protect Yourself” program, two distinct groups have been identified with regard to HCV: those who have been tested for HCV before, and those who have not been previously tested.

People who have been tested. In case of negative results, testing provides a good ground for counseling on HCV and safer drug injecting. The majority of Odyseus clients who had a history of HCV testing either did not know the result of the test or did not receive enough information on what the test’s result meant. Drug users who tested positive for HCV often saw it as a “terminal disease” and lost hope. This happened for different reasons, for example, because they were not given correct information about HCV, were not given adequate counseling, or had no access to and/or could not afford treatment. The belief that their HCV diagnosis is tantamount to a death sentence can lead to dangerous practices, such as continuation or increase of needle sharing and other risk behaviors. Outreach workers play a key role in changing this attitude.

People who have not been tested. When asked why a person has not yet gone for testing, the typical answer is that all of the existing testing possibilities are too high threshold for them, for example, people have to register with the drug treatment service, and/or they have to have a health insurance card. These requirements serve as major obstacles to IDUs getting tested.

The project involved the implementation of several strategies, which helped to address the needs of both groups. For the people who were already living with HCV, Odysseus helped to negotiate the means for them to get access to care and treatment. These efforts have so far been unsuccessful, mainly because IDUs are excluded from HCV treatment unless they abstain from drug use for at least six months, which is an unrealistic target for most of them, at least in the short term. For people who wanted to be tested for HCV, the organization established contacts with different health institutions in which they would be allowed to take tests even without health insurance. This was also unsuccessful, in part because IDUs always had to be accompanied by an outreach worker to make sure that s/he reached the institution, and also because testing was only available at high threshold service points.

Finally, support from Greece's Ministry of Foreign Affairs has allowed Odysseus to include low threshold testing in the outreach project since April 2006, and to offer accessible and qualified testing to more IDUs.

Thanks to strong support from the licensed laboratory HPL s.r.o.—which lowered prices for testing—the strong involvement of nurses and paramedics, who mostly worked free of charge, and the involvement of Odysseus's staff, the organization have been able to provide tests for more infections, including HIV, syphilis, HBV and HCV.

Testing is being provided at a mobile needle exchange point as part of a standardized procedure comprised of a **pre-test phase** and a **post-test phase**. The tests are anonymous, voluntary and free of charge for clients. Each person chooses which infections s/he wants to be tested for, and the entire procedure takes place inside the van. Blood samples are delivered immediately after the session to the specialized licensed laboratory for analysis. The absolute majority of people finds out about their testing results, as the mobile unit stops in accessible areas and provides a range of services, including access to clean needles, condoms, counseling etc.

Pre-test counseling is carried out by specially trained social workers and nurses/paramedics. Pre-test counseling covers issues such as: how the tests work; information on infection and treatment; and next steps. Clients also receive a brochure with information on infections and whether or not more in-depth counseling is available.

Post-test counseling is carried out only by specially trained social workers or specially trained medical staff and includes information about the infections, what the results mean (each person receives a closed envelope containing their results, and they are strongly encouraged to open it in the van in the presence of trained staff), followed by counseling on the results, including what to do next (treatment options, prevention of re-infection, living with HCV, how to stay infection-free in case of a negative result, etc.). The clients also receive printed material covering these issues.

4.1.2 Education and outreach to injecting drug users

“Knowing that even in countries with relatively easy access to substitution programs, more than 50% of IDUs are outside of the health care system. Outreach interventions of primary prevention directed towards active IDUs are fundamental for the reduction of HCV transmission rates”, Luís Mendão, European AIDS Treatment Group, on Press Conference for World Hepatitis Awareness Day, September 28, 2006.

Community-based outreach programs are effective at helping drug users reduce risk behaviors for acquiring blood-borne viral infections (Coyle, 1998). “Drug users are suspicious of the health care system because of their past experiences. Peer outreach and interventions are crucial. Peer educators are a bridge between IDUs, street living and a more regular life; they can reach people” (Sylvestre, 2006). Outreach programs must (1) educate IDUs about how to avoid acquiring and transmitting HCV infection, (2) support behavior change to reduce high-risk behavior, (3) provide client-centered counseling, and (4) provide linkages to services, including HCV testing and care for infected persons (Edlin, 2004).

While outreach work can be carried out by professionally trained program staff, there is evidence that IDUs can play a larger role in service delivery through **peer-to-peer work**. “Peers are more likely to be able to engage with other peers, reinforcing safer injecting practices and connecting IDUs to services, reaching large and more diverse groups of IDUs, and doing so at lower costs”, (Aggleton, 2005). Also, direct involvement of drug users in designing educational materials (as well as service provision) is critical to ensuring that messages are appropriate for, and well accepted by, the target audience.

One way to increase the literacy of IDUs about HCV is to combine it with education on the practical skills related to risk behavior and its reduction, such as education and training on **safer injecting techniques**.

An additional service that can be used to reduce risk behavior are **drug consumption rooms** (DCRs), which can also serve as a gateway to safer injecting education since drug users are able to inject using clean equipment under the supervision of medically trained personnel. However, DCRs remain relatively controversial, and they operate in few countries. There is minimal research on whether or not the availability of DCRs reduces the incidence of HCV among IDUs, as currently DCRs are serving a relatively small number of IDUs, and in the countries where they exist DCRs are only part of well developed services for IDUs. However, it is plausible that DCRs can contribute to a reduced incidence of HCV, because numerous surveys show that high-risk IDUs use such centers and report significant reductions in blood-borne virus risk behavior (Wright, 2006). In general, DCRs are shown to bring about significant reductions in overdoses, and changes in injecting behaviors (Petrar, 2006), and are known to connect IDUs to drug treatment services (Roberts, 2004).

4.1.3 Providing sterile needles, syringes and other injecting equipment

4.1.3.1 Improving access to needle and syringe exchange

A review of 190 studies from 101 cities worldwide found that HCV prevalence was lower in cities with NEPs than in those without them. Among new injectors (those injecting for three years or less), this review found an average HCV prevalence of 25% in cities with NEPs compared to 66% in those without (Commonwealth Department of Health and Ageing, 2002). The study found that overall NEPs do help prevent new infections among IDUs, however the impact of NEPs on HCV prevalence among IDUs remains less feasible than on HIV, with median HCV prevalence of 60%. Additionally the study concluded that NEPs help to improve the quality of life of IDUs and avoid deaths.

For NEPs to be as effective as possible, they have to reach a substantial part of the drug-injecting population, for which several steps are needed. First, NEPs should be diversified by offering fixed, mobile, pharmacy- and peer-based distribution that can reach more IDUs. Second, needle and syringe exchange and distribution programs must be widely expanded, publicly supported and funded.

4.1.3.2 Providing other injecting equipment

Another potential explanation for the limited effectiveness of NEPs in stopping transmission of HCV is that, despite access to sterile needles, borrowing and sharing among IDUs persists (Hahn, 2001) as well as sharing other injecting equipment apart from needles, which also is associated with HCV transmission (Hagan, 2001; Thorpe, 2002). To effectively prevent HCV transmission, access to needles, syringes and other injecting equipment, such as sterile cotton swabs, alcohol wipes, water and cookers, should be increased. Other authors (for example see Koester, 2003), stress that injection equipment other than syringes is often shared after a single syringe has been used to prepare and measure the drug solution. The solution is squirted either directly into another syringe or into a cooker for other drug users to then draw into their own syringes. Therefore, providing sterile injecting equipment must be linked with other interventions such as outreach and education on safer injecting techniques to reduce the risks associated with drug cooking and drug sharing itself.

In vitro studies have shown that **bleach** is effective for deactivating many pathogens, including HIV and HBV (Rutala, 1998). However, relatively little is known about the deactivation of HCV by chemical germicides (Sattar, 2001), and the evidence that is available about the effectiveness of bleach (for example Kapadia, 2003) appears to be very limited, statistically insignificant and even contradictory. Apparently, bleaching cannot provide the same level of safety as new, unused needles, therefore providing new needles and other sterile injecting equipment should always be a priority. In fact, bleaching can lead to a false sense of safety, reducing the effectiveness of health advice about the importance of never sharing injecting equipment and reducing the health policy imperative to ensure that sufficient needles are distributed. Therefore, if and when bleach is provided, it should always be accompanied by counseling on its effectiveness and additional risks and/or guidelines on how to use it properly.

4.1.4 Opioid substitution therapy

OST (with either methadone or buprenorphine) reduces the frequency of injecting and needle sharing (WHO, 2004b). Several studies assessing HIV risk behaviors found that IDUs who do not enter OST programs are six times more likely to contract HIV than those who participate in or have completed OST (WHO/UNODC/UNAIDS, 2004). Data suggest that adequate dosage, when combined with access to counseling and medical and psychiatric care, leads to a reduction in daily opioid use from 100% of people entering treatment to less than 20% within one year (Kreek, 2000). Additionally OST is associated with a reduction in sex work and criminal behavior and thus rates of imprisonment. Since correctional facilities lack HCV prevention services, lowering incarceration rates among IDUs helps to maintain regular contact with and access to health services.

OST also helps to improve the uptake of HCV treatment among IDUs (for more information, see section 5.1.4 Opioid substitution therapy and HCV).

As with NEPs, OST seems to be less effective in reducing HCV incidence than HIV (Wright, 2006), partly because most IDUs contract HCV in the early stages of drug injecting but do not get into an OST program until years later, when they are more likely to already be infected (Ward,

1998). This challenge should be addressed by significantly increasing and intensifying interventions that provide information, education, outreach and peer support to new, young and experimenting drug users, which is covered in the following section.

4.1.5 Reaching young IDUs and preventing the initiation of injecting

A number of studies identified young age to be one of the risk factors for HCV infection—HCV can be rapidly acquired after the onset of injection drug use (Garfein, 1996; Lorvick, 2001). Some studies show that HCV infection occurs within a period of a few months to about three years from the first drug injection (Hagan, 2004; Garfein, 1998). Therefore efforts to control HCV must include both helping people who do not inject drugs avoid starting to do so (Fuller, 2004; Oliveira, 2006) and interventions reducing risks for people who start injecting.

Effective strategies for preventing drug use among young people include educating and training parents, strengthening families, providing alternative venues for building skills and confidence, mobilizing and empowering communities, and other structural approaches. At the same time qualitative studies must be done to develop a clearer “social portrait” of groups of young people and better understand the social and risk context of the transition to injecting (Howard, 2003).

Outreach programs must be specifically designed for young IDUs and those who have recently begun injecting, to provide information on risk behaviors, prevention and drug treatment options. A combined set of interventions—outreach along with other services, such as needle and syringe provision, condom distribution, OST programs and involvement of young IDUs in service planning—can help to ensure effectiveness and increase the responsiveness of young people. At the same time, non-IDUs should be informed of other risks of HCV transmission from sharing items such as sniffing straws, razors, toothbrushes and non-sterile tattooing equipment that may draw blood.

A review of studies on the natural history of HCV (Freeman, 2001) concluded that there also is a strong indication that the younger the age at infection, the longer it takes for the disease to progress and the lower the risk of developing end-stage liver disease. Therefore outreach along with motivation to undergo testing among young IDUs can become crucial in early detection of the virus and the prevention of HCV disease progression.

4.1.6 Providing vaccination for HAV and HBV

HAV and HBV are important public health concerns for IDUs infected with HCV because of the increased risk of severe liver disease posed by HBV (Sterling, 2004) and HAV (Vento, 1998), therefore offering vaccination against HAV and HBV can help to prevent the infection progression to chronic HCV. Vaccination should be offered to IDUs in the same manner as testing and counseling: accessible and free of charge at low threshold facilities to insure the greatest effectiveness in reaching IDUs (See Box 3: The Netherlands: HBV vaccination among vulnerable groups).

Box 3: *The Netherlands: HBV vaccination among vulnerable groups and determination of factors influencing program coverage*

A detailed description of this program is available through the EMCDDA Exchange on Drug Demand Reduction Action (EDDRA) database.

Additional information: Andre Gageldonk, Netherlands Institute of Mental Health and Addiction (Trimbos Institute)

The vaccination of risk groups (IDUs, people with multiple sex partners, including sex workers and men who have sex with men) against HBV, implemented by the National Coordination Center for Communicable Diseases, began in October 1998 in four regions, which included both big cities and rural areas (in line with a recommendation from the Dutch Health Council, free vaccination of these risk groups has been taking place nationwide since 2002). In 2004, vaccination also started in 50 penitentiary institutions, and now 12% of all participants in the project have been vaccinated. Before this, immunization programs against HBV for most-at-risk groups were non-existent in the country.

IDUs are most frequently approached by low threshold and drug treatment facilities and general practitioners who work with drug users in the local methadone maintenance treatment program. From November 2002 until the end of September 2006, 10 502 drug users received a first vaccination. Compliance of IDUs with the indication for a second vaccination was 82.5%. Compliance for the third vaccination (six months after the first vaccination) is currently 57.4%. As it is currently unclear whether an incomplete series of vaccinations (one or two vaccinations) may also be effective, in which case the actual number of protected drug users may be higher*.

During the vaccination procedure a blood sample is also taken to test for HBV. Among people who tested positive for HBV a continued screening was carried out to determine if the patient had chronic infections, and if so, s/he was offered a follow-up counseling session and a referral to regular health care.

To assess the effectiveness of the HBV vaccination campaign, the number of reported acute HBV infection cases in Amsterdam has been measured for the six years before and the six years since the start of the vaccination program. Overall, there was a significant decrease in the incidence of reported acute HBV infection in Amsterdam. However, the contribution of the vaccination program to the decrease in acute HBV infection in IDUs may be limited, since the program reached only 16% of the estimated total population of 4500 drug users in Amsterdam. This could be explained in part by a decrease in the popularity of injecting drug use in the same period.

General practitioners rarely reached drug users (and sex workers). Rather, municipal health services (including the methadone maintenance treatment program in Amsterdam) and addiction care organizations had the highest coverage of IDUs for first vaccination. This showed that providing vaccination in places that are easily accessible to drug users

(through addiction care services and on the street) increased the completion rate. It was also noted that when health education was added to vaccination, the program coverage increased considerably, especially among groups with low motivation such as drug users. In regions where education is being provided the number of participants is three times higher than in regions without health education activities.

** The data presented are preliminary and subject to change, since the campaign is ongoing.*

4.1.7 Preventing HCV in prisons

Prevention measures described above—access to sterile injecting equipment, testing along with counseling and education, OST and vaccination for HAV and HBV—are in community settings as well as in prison. While a number of countries have been innovative in implementing prevention services for prisoners and have proved to be successful, the vast majority are still slow to respond to epidemics of viral infectious diseases and injecting drug use.

There are several distinct barriers to prevention in prisons, making implementation of these interventions difficult. They include:

- a refusal by many prison officials to acknowledge that drugs even exist in prisons;
- prison policies that restrict access to prevention measures, such as sterile syringes and equipment;
- the reluctance of prison administrations to provide regular testing and testing upon release, out of fear that it would provide proof of drug use in prisons;
- fears that needle and syringe exchange programs will increase drug use or even endanger prison staff or other inmates (by inmates using syringes as weapons);
- negative public attitudes toward prisoners, which are barriers to objective and pragmatic discussions about prison health policy.

4.1.7.1 OST, needle and syringe programs in prisons

Evidence supports the numerous benefits of OST programs in prisons just like in communities, including reduced rates of heroin use, drug injection and sharing of injecting equipment. Moreover, disrupting OST upon entering prison can lead to physical and psychological problems, an increase in injection and sharing injecting equipment, and can result in overdose (Stöver, 2006a). Therefore, it is very strongly recommended that OST be provided to everyone who has already received it before entering prison, and for those who become addicted in prison, as a way to prevent relapse and high-risk behavior after release. OST can lead to increased participation in drug treatment following release from prison, and a significant reduction in drug charges. Overall, offenders participating in OST programs were less likely to re-offend. More broadly, the prison system benefits through a reduction of withdrawal symptoms upon admission, a restricted drug trade and increased productivity among prisoners. Additionally, the specific treatment needs of women must be met according to the complexity and severity of the drug use of women admitted to prisons (Stöver, 2006b).

Even though the substantial scientific evidence discussed above predominantly speaks in favor of prison-based OST, the often negative attitudes of prison staff towards OST are a serious

barrier to treatment implementation. In this context, cooperation between community drug services and prisons, including educating prison staff, appears to be helpful (Stallwitz, 2007).

If OST is slowly starting to find its way into prisons, needle and syringe programs remain by far the most controversial measure in prisons. However, the evidence from six European countries (Belarus, Germany, Kyrgyzstan, Moldova, Spain and Switzerland) with needle and syringe programs proved that they:

- do not increase drug consumption or injection;
- reduce risk behavior and transmission of HIV and HCV;
- do not undermine abstinence-based programs;
- create other positive health outcomes for prisoners, including reduction in overdose and increased referrals to drug treatment programs (Lines, 2006).

However, the effectiveness of needle and syringe programs also depends on the support of prison administrations and staff, since different methods of distribution can influence the success of the program. For example, a study in Moldova—one of the few countries in the region where there are needle and syringe programs in prisons—showed that only 25–30% of prisoners known to inject drugs used needles distributed through hand-to-hand needle distribution carried out by the prison medical unit. The main reasons for such a low rate of use were thought to be the lack of confidentiality and the limited hours of availability of needle exchange. When the needles and syringes began to be distributed by peer volunteers, uptake rose to 65–70% (Canadian HIV/AIDS Legal Network, 2006b).

4.1.7.2 Additional guidelines and advice for prevention in prisons

- Vocational training on the nature, prevention and treatment of HCV for prison staff;
- Cooperation and collaboration between prison doctors and medical staff and specialists in infectious diseases should be established;
- Provide of and access to bleach and disinfectants only when and where no safer alternatives are provided for decontaminating spills, surfaces or equipment, and education about effects and the proper use of bleach;
- Free razors and toothbrushes made available for every inmate, and the removal of razors and toothbrushes left in ablutions areas;
- Prevention measures should be linked to the services for drug users outside prison setting.

4.2 Prevention interventions and policies in the new EU Member States and neighboring countries

4.2.1 Political commitment to HCV

Political support for programs aimed at the prevention of HCV among IDUs is imperative. In many countries, general strategies aimed at reducing infectious disease are geared primarily towards HIV. Back in 1999, WHO recommended in its report on global surveillance of HCV that all countries develop a separate plan for prevention, counseling and treatment of hepatitis. In the EU, France and England have both established full-scale HCV prevention strategies: *Plan National Hépatites Virales C et B* and *Hepatitis C: Action Plan for England*, respectively. Germany is planning

to adopt an HCV strategy in the near future. Assessing whether and/or how prevention of HCV and other infectious diseases among drug users is being addressed at national level in the new EU Member States and neighboring countries can provide a measure of political commitment to addressing the disease and, therefore, to the effectiveness of prevention efforts.

At the time of survey, only Romania and Slovenia had specific national strategies in response to hepatitis. Romania's program was adopted in 1998 by the Ministry of Health which, among other things, aimed to provide qualified, free treatment for people with health insurance. Slovenia has a specific HCV prevention strategy, which includes:

- training for health care professionals;
- awareness raising for the public;
- clinical and public health activities to identify, counsel and test at-risk individuals;
- medical evaluation or referral;
- outreach and community-based programs to prevent risk behavior;
- surveillance to monitor disease trends and evaluate prevention and medical care;
- research to better guide prevention efforts.

Most other countries have national drug strategies, documents issued by Health Ministries, HIV and AIDS prevention strategies, donor programs or public health programs that address infectious disease prevention, including HCV. Overall, obvious political commitment to preventing HCV is limited at best in the region, and in most cases is wholly insufficient, especially when it comes to measures targeting such high-risk groups as IDUs and prisoners.

Even where policies specifically mention HCV or harm reduction, such as in Hungary's National Public Health Program and its National Drug Strategy, prevention efforts may be hindered by other factors. In Hungary's case, drug use is treated as a criminal matter, where possession of small amounts of drugs for personal use is prosecuted. This limits the effectiveness of HCV prevention efforts, since fear of imprisonment deters drug users from seeking out services, even at low threshold facilities where testing and other services are anonymous. It is also likely to decrease the frequency with which drug users visit these facilities, especially among young users (Zabransky, 2001).

Some respondents from the new EU Member States suggested that the lack of recommendations and political action at the EU level affects the ability of activists to advocate for more political commitment at the national level.

4.2.2 HCV testing and counseling in community and in prisons

Testing protocols for hepatitis do exist in 6 of the 13 countries in this survey. Where there are such protocols, it can indicate an awareness of the need for HCV surveillance and testing on the part of government and health care systems. Yet, despite the existence of protocols, HCV testing, especially among IDUs, is still limited. This is due mostly to a lack of funding for free testing services, while paid testing is often too high threshold for IDUs.

Most other countries reported limited availability of free-of-charge testing, including Estonia, Hungary, Lithuania, Romania and Russia (see Table 6). For example, in some countries (Belarus, Poland, Russia and Slovenia), testing is free of charge when a person is referred by a general practitioner (GP). In other countries, IDUs are tested for free when they enter drug treatment programs (the Czech Republic, Slovakia and Slovenia). In Lithuania, there is an agreement between the Lithuanian AIDS Center and the Vilnius Center for Addictive Disorders whereby IDUs can be referred from the Center for Addictive Disorders to the AIDS Center for free testing at least once a year. However, this can be considered as one of the factors limiting the extent of testing among IDUs since, at times, it is also difficult for them to make follow-up visits or to go from one place

to another—in other words, it can sometimes be considered to be too high threshold for IDUs. According to the testing protocols in Ukraine, all PLWHA should be tested for HCV when they are registered, but this is done on a limited basis due to a lack of funds for tests.

Testing at NEP and OST sites is also limited (see Table 6). NEP sites in Bulgaria and the Czech Republic offer HCV testing, while there is limited availability in Estonia, Hungary, Lithuania, Russia and Slovakia. OST programs in Bulgaria, the Czech Republic, Hungary and Slovenia reportedly offer HCV testing, but in some cases can also be limited in terms of coverage. For example, in the Czech Republic, a 2004 survey of 92 low threshold facilities showed that only about half of these facilities actually carried out free HCV and HIV testing (Reitox—the Czech Republic, 2005). Only 17% of all low threshold facilities in the country indicated that drug users are actually tested (provided by respondent in country).

Various special interventions for providing testing to IDUs also are implemented in the region, allowing more people to get low threshold testing. For example, in Vilnius, Lithuania, in 2005, the Vilnius Center for Addictive Disorders carried out testing for HIV, HCV and HBV as part of a project on improving health care among IDUs and their integration into the health care system. Testing (using rapid tests) was offered as a service at mobile needle exchange points, where pre-test counseling and information on HCV was provided. Post-test counseling was also provided, and information was given on how to reduce drug-related harms. Clients testing positive were encouraged to visit the AIDS Center and undergo another test to confirm the diagnosis. This project helped reach IDUs at the places where they gather, and the clients usually came back for needles, which enabled personnel to provide a more comprehensive counseling and education services. In a number of countries, testing is also being carried out in low threshold facilities when they receive special grants (for example see Box 2: Hepatitis C testing in the context of an outreach project in Bratislava, Slovakia).

Rapid tests, which can potentially increase the number of people tested, are available in the Czech Republic, Romania and Slovenia, and in limited situations in Estonia, Hungary and Lithuania. In Ukraine, rapid tests are registered as a means for testing in the country, but they are not used.

While the availability and accessibility of testing for IDUs vary in different countries, pre- and post-test counseling is limited and not always provided during testing, or often is not qualitative enough. Service providers from some countries, specifically from Slovakia and Romania, reported that at times people who get positive results often panic and try to get treatment immediately, even though a positive result does not necessarily mean they need treatment right away or will ever need treatment. This is an indication that pre- and post-test counseling is not being delivered effectively. Among the countries studied, only Slovenia reported that pre- and post-test counseling is regularly provided at its Centers for the Prevention and Treatment of Drug Addiction and Clinic for Infectious Diseases. In Belarus, usually only post-test counseling is provided and only when the result is positive, which means that people are not informed about how to prevent possible infection in the future. In a few countries, such as Russia, counseling may not be provided because there are no medical regulations mandating its provision.

Testing in prisons is also limited, though considering the lack of access to and funding for free-of-charge, low threshold testing in most communities, prisons can provide only opportunity to get tested (see Table 6). Most countries in the region (10 of the 13) provide testing when an inmate exhibits symptoms of HCV. Otherwise, HCV testing is sporadic and provided under limited circumstances.

The criteria for testing in prisons can provide some indication of the priority given by prisons to health issues. For example, if testing is provided upon admission and/or release from prison.

Testing for HIV on admission is suggested in most countries, whether testing for HCV is suggested in limited number of prisons in the Czech Republic, Poland and Slovakia. In Belarus, testing for HIV and syphilis, but not HCV, is offered upon admission. None of the countries assessed offer HCV testing upon release.

Whether or not HCV testing is provided to most-at-risk groups, such as IDUs and PLWHA, can be another measure of the priority given to HCV in prisons. In Slovakia, HCV testing is suggested for all suspected, diagnosed and self-reported drug users. And in Slovenia, a country with a low HIV prevalence, it is available for PLWHA, or those testing positive for HIV in prison. In both those countries, testing is voluntary. Of all the countries surveyed, only in the Czech Republic is testing mandatory for all suspected, self-reported drug users and those diagnosed with addiction. HCV testing is medically indicated for HIV-positive inmates in Lithuania, while in Hungary, testing for HCV, HBV and HIV is available to inmates when they donate blood and is often seen by the inmates as an opportunity to get tested.

4.2.3 Availability of and accessibility to HCV prevention programs and services

4.2.3.1 Needle and syringe exchange and other sterile injecting equipment

While a detailed analysis of NEPs was not possible in the context of this survey—including an analysis of the quality of NEPs and their ability to reach IDUs—the data do provide a limited picture of the situation in the region (see Table 7). The type of NEPs that exist in a particular country can help to determine the accessibility of the service for IDUs. In the majority of countries, both fixed and mobile NEPs are present in some communities. Still only few countries, namely Bulgaria, the Czech Republic and Slovenia, also have pharmacy-based NEPs, administered either by staff or vending machines. Hungary has pharmacy-based NEPs as well, but there is evidence from that country that many pharmacy staff members feel hostile toward IDUs and refuse to give them needles. This could indicate a need for more training of pharmacy staff. The Estonian National HIV/AIDS Strategy for 2006–2015 foresaw development of pharmacy-based NEPs, but it is not yet in place.

With regard to the coverage of NEPs it is different throughout the region. Wherever the coverage estimates are available they show a greater access to NEPs in Central Europe, such as the Czech Republic and Slovenia. For example, in the Czech Republic, the number of syringes exchanged between 2003 and 2004 increased by 32% even though the estimated number of IDUs did not increase, which indicates a measure of success of NEPs. In Estonia—which is one of the few countries that managed to ensure state funding for NEPs—about 50–60% of the total population of 13 800 IDUs are in contact with NEPs and/or low threshold facilities.

Among the three neighboring countries of Belarus, Russia and Ukraine, NEPs have the highest coverage in Ukraine: 21% (IHRD, 2006). In Russia, with an estimated 1.98 million IDUs, NEPs reached only about 2% of IDUs by the end of 2005 (IHRD, 2006). In Belarus, according to the NGO Positive Movement, NEP coverage of IDUs in Minsk is only 5–9%, while according to the National Epidemiologic Surveillance Agency, it is 13.5%. In Bulgaria, NEPs are estimated to reach 15% of IDUs.

Most countries report limited availability of other injecting equipment apart from needles and syringes, usually through NEPs and anonymous consultation points (see Table 7). In Hungary in 2004, however, only one NEP provided a wide range of injecting equipment, including:

- tourniquet;
- spray;
- sterile water;

- ascorbic acid;
- vein care ointment;
- spoon;
- filter;
- water container (Racz, 2003).

Needle and syringe programs in prisons are virtually not-existent—none of the 10 new EU Member States provide needles and syringes in prisons (see Table 6). In Belarus a pilot project in one prison began in 2003 and, despite plans to expand the program to other prisons, the program ended in 2006. Needle and syringe pilot projects are to start in two penal institutions in Ukraine in September 2007.

In most countries, there is no practice of **distributing disinfectant** to drug users in prisons (see Table 8). In Belarus, however, disinfectants are available upon request; in Estonia disinfectants are provided to inmates, but without guidelines for use; and in Lithuania and Slovenia, both disinfectants and usage guidelines are provided in prisons.

4.2.3.2 Opioid substitution therapy

OST is available in most countries in the region (see Table 8) through specialized out-patient programs, and in about half of the countries where it is available it is also provided through in-patient programs. In Slovenia, OST is offered by GPs. In the Czech Republic it is offered through both GPs and psychiatrists. It is still unavailable (illegal) in Russia—one of the most highly affected countries—is very limited in Ukraine, where it started only in 2003, and by the end of 2006 was still unavailable in Belarus.

There were hopes that joining the EU will have a favorable influence on governmental resistance to OST and NEPs, since harm reduction was strongly supported when the Council of Europe endorsed the Drugs Action Plan in June 2005, calling for greater emphasis on scientific evidence in the formation of responses to illicit drug use. Apparently, though, much work remains to be done. For example, in Hungary in 2005, a mere 4% of all addiction treatment providers in Hungary offered methadone maintenance (Gerevich, 2006), while the major OST program in Hungary stopped enrolling new clients in 2006 due to a lack of funding (provided by respondent in country). In Romania, with an estimated population of 90 000–112 000 IDUs (see Table 1), only two OST programs operate in the country, and they are limited to the capital, Bucharest.

However, in a few countries progress has been made. For example, in the Czech Republic, the estimated number of opiate users in OST programs increased from 18% in 2003 to 20–30% in 2004; this was possible partly due to the increased prescription of both methadone and buprenorphine (Reitox—Czech Republic, 2005).

OST guidelines exist in most countries, including the Czech Republic, Estonia, Latvia, Poland, Slovakia and Slovenia, and guidelines for methadone alone exist in Hungary, Lithuania and Slovenia.

OST programs that are primarily government funded can generally be interpreted as a sign of a more sustainable program, which is more likely to be successful over the long term. Despite the fact that in most countries OST has been provided since the mid- 1990s, the funding of OST programs by international donors can indicate a lack of commitment on the part of governments and a potentially unsustainable program. This can significantly reduce the effectiveness of prevention efforts. In the region, OST is most commonly funded through social or medical insurance, while patients themselves and the state also provide funding in about half the countries. Two countries

(Estonia and Ukraine) rely to some degree on international donor funding or the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM).

In prisons OST is legal in about half of the countries surveyed but, with the exception of the Czech Republic, Poland and Slovenia, it is neither widely available nor accessible for most inmates. Where OST is available in prisons, admission criteria determine how accessible it is; for example, in the Czech Republic and Estonia inmates must have been in an OST program before entering prison if they are to receive OST in prison. In Poland and Slovenia, on the other hand, the admission requirements for OST treatment are no different than outside prison, making OST much more accessible for a wider range of inmates and, therefore, much more effective at helping to prevent HCV.

4.2.3.3 Vaccination against HAV and HBV

Among the countries in the region, only Slovenia and Romania are reported to have services for HAV vaccination specifically targeting drug users (see Table 9). In Slovenia, the service is available to high-risk groups, including drug users, and upon request. In Romania free HAV vaccinations is provided in the framework of grant from Global Fond to Fight AIDS, Tuberculosis and Malaria (GFATM), but is provided only in the capital city of Bucharest.

HAV vaccination is extremely limited in the rest of the region. For example, in Belarus HAV vaccination is possible at a cost of EUR 30–40 for one vaccination, a price out of reach for most drug users. And some low threshold facilities in the Czech Republic offer HAV vaccinations but it is not free of charge.

HBV vaccination is more widely available than HAV vaccination (see Table 9) but still limited for drug users. In Slovakia, free HBV vaccination is available to all people who register at the Center for the Treatment of Drug Dependencies, a requirement that might discourage IDUs from using the service.

In Belarus, HBV vaccination has been available since 1991 for “high-risk” groups, which includes sex workers and men who have sex with men, but not IDUs. Some health care centers in Belarus offer HBV vaccination, but this depends on vaccine availability, the motivation of individual doctors, and also on the client’s ability to pay: vaccination costs EUR 10–15 for each of the three required doses.

Limited HBV vaccinations are available for IDUs at low threshold facilities in the Czech Republic, and vaccinations are available for a fee in Bulgaria and Estonia. One low threshold program provided HBV vaccination in Hungary in 2004, while free HBV vaccination is available in Bucharest, Romania, through GFATM grant.

HAV vaccination is available **in prisons** only in Slovenia and the Czech Republic; in the latter the availability is the same in prisons as in the community, where the service is available for at-risk groups and upon request. HBV vaccination for drug users in prisons is much more widely available than HAV vaccination and tends to be more accessible than in communities. It is available in Bulgaria and is free for at-risk groups and/or upon request in the Czech Republic, Estonia, Hungary and Slovenia. Free HBV vaccination has begun in some prisons in Lithuania, while it is available at cost and upon request in Slovakia (see Table 9).

4.2.3.4 Other prevention measures

Most countries provide some form of **information, education and counseling (IEC)** related to HCV, although the effectiveness or quality of this provision was not possible to determine in the context of the survey. Roughly half of countries report some form of IEC related to HCV **in prisons**.

This is limited in Hungary and Romania, and in Lithuania it comes in the form of lectures and printed materials on communicable diseases.

Five countries in the region provide some form of training on **safer injecting**. For example, in Belarus this consists only of printed information distributed at NEPs, and in Slovenia it is available at five or six drop-in centers. In prisons, training on safer injecting is not available in the majority of countries, with the exception of Belarus and Estonia.

Most countries in the region provide **condoms** at low threshold facilities to encourage safer sex practices and help reduce risk behavior. This is especially important in prisons, where inmates may be at greater risk due to a lack of specific prevention measures. Condoms are available to some degree in most prisons, but they usually must be purchased in shops, a situation that deters safer sex practices. In prisons in Belarus and Estonia, condoms are more available, distributed by special health units, volunteers or through outreach programs (see Table 7). Distribution through health units, however, can be a barrier to uptake, since many IDUs do not want to share personal information with health care providers.

5. Hepatitis C care and treatment for IDUs

IDUs represent the majority of people infected with HCV, therefore providing HCV treatment to IDUs should be viewed as imperative by governments, medical professionals, and agencies. Unfortunately, IDUs are often denied HCV treatment, regardless of clinical indication, willingness to undergo therapy, and accumulating data on the safety and efficacy of HCV treatment in this population (see Table 10). Most often, where treatment is available, IDUs are not a priority, or are not considered eligible for treatment due to prejudice on the part of health care providers and policymakers, and for the reasons such as:

Restrictive treatment eligibility and guidelines are major barriers to treating HCV in IDUs. According to Dr Brian Edlin, who has treated drug users for HCV, “Medical providers must be able to address substance use issues, to determine whether they are likely to be an obstacle to adherence. ...If you tell people that they have to enter drug treatment before being treated for HCV, and drug treatment is not available, you have made a tacit decision to withhold HCV treatment indefinitely,” (Edlin, 2006).

The prevalence of chronic HCV and of HIV/HCV co-infection among current and former IDUs warrants a less rigid approach to treatment eligibility, such as the framework shown in Figure 1: Determination of HCV Treatment Eligibility, Advisability and Acceptability, which classifies contraindications for HCV treatment as modifiable versus non-modifiable. Moreover, international medical experts, including the American Association for the Study of Liver Diseases (AASLD), EASL and WHO, have developed HCV treatment guidelines that support treating drug users.

Concerns about re-infection are often used as a rationale for withholding treatment, despite data suggesting that re-infection is uncommon when patients who continue to inject are taught how to avoid re-infection (Backmund, 2004; Dalgard, 2005). “Injectors need to understand safer injection to avoid re-infection. ...Physicians and pharmacists should be educated to provide access to sterile syringes and to teach safe injection techniques, both of which are lifesaving interventions,” (Edlin, 2002). Clinicians can minimize the risk of re-infection by: informing IDUs about the risk of re-infection; demonstrating safer injection techniques; referring IDUs to syringe exchange programs when available; prescribing or providing syringes and other injection equipment when feasible; providing methadone and/or buprenorphine when possible.

Concern about relapse to drug use is another major barrier to treatment. Some physicians and former IDUs worry that interferon treatment may precipitate a relapse to active drug use, since the side-effects of interferon are similar to those of opiate withdrawal. Providers can begin by acknowledging the difficulty of remaining drug-free and giving support. HCV treatment should not be stopped if relapse to drug and/or alcohol use occurs, since intermittent drug and/or alcohol use is not always associated with a significant decrease in response to HCV treatment (Backmund, 2001; Schaefer, 2003; Sylvestre, 2005a; Sylvestre, 2005b). Prescribing methadone or buprenorphine may help to avert relapse, and increasing methadone dosage upon request may support adherence to HCV treatment (Litwin, 2005; Van Theil, 2003). Clinicians may also refer patients to counseling, peer support and, if requested, to drug treatment.

Physicians' concerns about treatment adherence may prevent IDUs from accessing treatment. The assumption that IDUs will not adhere to HCV treatment is often used to justify withholding it, although physicians are notoriously poor at predicting adherence. In fact, some studies have reported that adherence among current and former IDUs was comparable to that of non-users, including one in which HCV was treated with daily interferon injections for at least a year (Cournot, 2004; Robaey, 2006; Van Theil, 2003). One clinician who treats multiply-diagnosed current and former drug users has reported a 99% attendance rate to weekly clinic visits for directly administered PEG-IFN (Taylor, 2005a). Another group reported a 98% adherence rate to HCV treatment among drug users in a methadone clinic, although 78% (16 of 18) were using other drugs during HCV treatment (Lindenburg, 2006).

Other barriers to antiviral HCV treatment include:

- high cost of treatment;
- lack of guidelines on diagnostics and treatment in some countries; and
- lack of access to additional care and treatment interventions, such as OST and HIV ART for people co-infected with HIV.

5.1 What works in delivering HCV care and treatment: guidelines and suggestions

Removing barriers to treatment for IDUs is one part of the solution for reducing HCV prevalence, morbidity and mortality. But additional steps must also be taken. These include training medical professionals on addiction, and developing the structures to deliver complementary care and services, such as mental health care, peer education and specialized treatment for HIV/HCV co-infection. The following sections outline some of these steps and provide advice and suggestions adapted from successful HCV treatment interventions in a variety of settings.

5.1.1 Physician training on addiction

At an HIV/HCV co-infection clinic in Providence, Rhode Island, the United States, the majority of patients are current and former drug users with co-occurring psychiatric disorders. According to the clinic's Director, Dr Lynn Taylor (2006), people must "be offered treatment for addiction during medical care; addiction is a medical issue. Opioid replacement can give people back their lives. ...It makes people feel well enough to deal with their issues. How could we treat the complications of diabetes without treating diabetes itself?"

Most physicians receive little or no training on addiction, and physicians treating drug and/or alcohol users have reported discomfort and a lack of satisfaction with their experiences, which improve when they get addiction training (Fucito, 2003; Miller, 2001; Matthews, 2002; Siegal, 2000). "The medical education system is deficient in, and resistant to, teaching about the underpinnings of addiction as a medical illness. Like diabetes or chronic obstructive pulmonary disease, addiction will respond to interventions. Yet, in addiction—unlike diabetes or chronic obstructive pulmonary disease—we hold people responsible when treatment is unsuccessful. Addiction treatment needs to be regarded in a framework of engagement, like diabetes, where people need time to become stabilized," (Sylvestre, 2006).

In some cases, staff at substance abuse facilities deliver HCV care and treatment to drug users because "nobody would do it, so we had to learn to do it ourselves rather than saying 'sorry, you're

going to die,” (Sylvestre, 2006). Clinic staff members have successfully provided HCV treatment to people on methadone maintenance, and to some people who were also using drugs and/or alcohol during HCV treatment. “Deliver a spectrum of medical interventions in a single session. ...Developing settings that can deliver integrated care is crucial. Drug users need one place they can come to,” (Sylvestre, 2006). (See Box 4: Outreach specialist addiction center in London allows effective therapy and leads to a reduction in illicit drug use.)

5.1.2 Peer outreach and education

Peer outreach and education are not only the means of prevention but also integral to delivering HCV treatment to IDUs. Treatment programs have cited peer support as essential to their success at delivering HCV treatment to mono- and HIV/HCV co-infected persons (Clanon, 2005; Litwin, 2005). Peer support remains important after treatment: “It is hard when people come off of interferon; being part of a support group, with other people who are dealing with similar issues, helps. We try to keep people coming for at least six months after they stop HCV treatment,” (Taylor, 2006).

Before undergoing HCV treatment, candidates need to be informed about a wide range of issues, which might include the following:

- HCV natural history;
- alcohol and HCV progression;
- HAV and HBV consequences, prevention and vaccination;
- HCV re-infection and how to avoid it;
- HIV co-infection;
- assessment of individual disease status (genotype, HCV RNA, and non-invasive method vs. biopsy);
- genotype and response rate;
- race/ethnicity and response rate (when relevant);
- HCV viral load and response rate;
- duration of treatment;
- side-effects and how they will be managed;
- when response to treatment will be assessed.

Successful programs provide this information to IDUs through a multidisciplinary approach, which includes care and treatment of other medical and psychological co-morbidities, adherence support and social support to address adherence, stigma and discrimination.

Box 4: *Outreach specialist addiction center in London allows effective HCV treatment and leads to a reduction in illicit drug use*

By Richard Marley, St. Bartholomews & The Royal London Hospitals, United Kingdom

In East London there is a well-established Blood-Borne Virus Team that provides an informed testing service for drug users who access the service. Many patients with chronic HCV have been identified, and attempts to enroll suitable patients in hospital-based treatment programs were unsuccessful, with very poor clinic attendance rates.

To address this problem, in 2004 the Blood-Borne Virus Team joined forces with the Liver Unit at The Royal London Hospital to provide treatment for drug users with chronic HCV. An outreach clinic in the local Specialist Addiction Unit was established and staffed by experienced blood-borne virus nurses and a consultant hepatologist. Drug users who are patients of OST programs are offered a referral to the clinic if they wish to consider therapy. For those who do not wish to undergo therapy the joint clinic ensures appropriate hepatological follow-up, and for those who wish to receive therapy the clinic offers treatment within a few weeks of the client's first visit. Patients are treated with PEG-IFN and RBV, and follow-up and support are provided by nurses who are employed by the mental health services in a facility that is designed for people with complex substance abuse problems, so there are psychiatrists available within this facility who are available to see people at very short notice.

The nurses tailor follow-up to the individual's needs. Some people are reviewed monthly, others weekly, actually coming to the treatment centre to get their IFN injections. Medical support from the liver unit is frequently provided via email and telephone discussions along with urgent clinical review, if required. Nurses also contact patients on a weekly basis to remind them to have their injections.

The service has been well received by the client group and has allowed therapy to be administered to this "difficult-to-manage" group—over 50 patients have commenced therapy. Early results show that compliance rates are very high and the early virological response (EVR) rates are in line with those seen in controlled clinical trials (EVR was 77% among patients with genotype 1, and 77% SVR among people with genotype 2/3). Several patients stopped injecting drug use during their treatment.

No gross difference was noted in response rates for those who continued to inject drugs compared to those who did not. It was noted, however, that drug use increased during the first few weeks of therapy and then decreased to below pre-treatment levels. Alcohol use did not change during therapy.

5.1.3 HCV treatment and mental health care

Numerous studies have documented a higher-than-average prevalence of depression and other mental illnesses among drug users. Since interferon has significant neuropsychiatric side-effects, IDUs with a history of psychiatric disorders are often considered ineligible for treatment, despite a patient's current stability and the availability of successful models for delivering treatment to people diagnosed with both HCV and psychiatric disorders (Backmund, 2001; Litwin, 2005; Taylor, 2005a; Taylor, 2005b; Schaefer, 2003; Sylvestre, 2005a; Sylvestre, 2005b).

Interferon treatment can cause depression, anxiety, mania, and psychosis (Constant, 2005; Kraus, 2004). In HIV, depression has been associated with poorer adherence to ART among IDUs and non-IDUs (Bouhnik, 2005; Carrieri, 2003), while treating depression has been linked with improved adherence to ART (Yun, 2005).

Since depression is far more prevalent among people with chronic HCV than the general population, and a known side-effect of interferon, it is sensible to provide HCV treatment in

conjunction with mental health care (Cruz Neves, 2006; Reimer, 2005). In fact, there is evidence that pre-treatment with anti-depressants significantly decreases the incidence of depression during HCV therapy among individuals with psychiatric disorders (Schaefer, 2005).

Pre-emptive treatment of depression is the preferred approach, since it can take time to find the right treatment or combination of treatments. However, depression that develops during HCV therapy can be successfully treated with selective serotonin reuptake inhibitors (Hauser, 2002). Irritability, anxiety, insomnia and mania have all been successfully treated, although it may be necessary to discontinue HCV treatment during treatment for these conditions (Basanth, 2006; Greenberg, 2000; Maddock, 2004; Raison, 2005).

5.1.4 Opioid substitution treatment and HCV

It is well established that OST with methadone and buprenorphine is effective for stabilizing opiate-dependent persons. In March 2005, WHO added methadone and buprenorphine to its Model List of Essential Medicines. OST has been associated with improved quality of life and decreases in drug use and syringe sharing (Fhima, 2001; Giacomuzzi, 2005; Stark, 1996), and buprenorphine and methadone have been associated with adherence to highly active ART (Moatti, 2000; Palepu, 2006). Moreover, methadone clinics are ideal venues for delivering HCV treatment, based on directly observed ART programs at methadone clinics that have been associated with good HIV treatment outcomes (Lucas, 2006; see also Box 5: Health care delivery to drug users: program of comprehensive care “PCC-Prague”, in Prague, the Czech Republic.)

Given the benefits of OST, providing additional options is desirable, such as prescription heroin. Prescription heroin has been associated with decreases in illicit drug use, HIV risk behavior and criminal activity, as well as with improvements in health and social functioning (Guttinger, 2003; Metrebian, 1998). Society benefits as well, since co-prescribing heroin and methadone is more cost-effective than methadone alone (Dijkgraaf, 2005). A recent pilot study compared the effect of medical and mental health care provided with methadone and/or heroin treatment. The study evaluated overall physical health, quality of life, frequency of drug use, HIV-related risk and illegal activity of a group of 50 opiate-dependent people who were prescribed either prescription heroin plus methadone or methadone only. Participants randomized to heroin plus methadone reported greater improvements in all areas than those randomized to methadone alone (March, 2006).

Box 5: Health care delivery to drug users: program of comprehensive care “PCC-Prague”, in Prague, the Czech Republic

by Vratislav Rehak, MD, the Czech Republic

IDUs typically and frequently suffer from a variety of health complications, including HCV, as a result of their risk behavior and lifestyle. However, IDUs are one of the hardest-to-reach groups in society, often avoiding visits to health care facilities, especially if return visits are required. With the goal of reaching drug users and offering them timely and targeted health care services, a Program of Comprehensive Care (PCC-Prague) was established in 2002. The program delivers low threshold services and specialized medical care, including HCV testing and treatment. Since its launch, more than 1000 drug users have entered the program.

The basic principles of care in PCC are:

- Low threshold access to medical services, including basic and specialized health care, testing and screening for blood-borne and sexually transmitted diseases, pre- and post-test counseling, and harm reduction services such as OST, psychosocial counseling and crisis intervention, and individualized and group psychotherapy;
- All services are concentrated within the premises of a single primary health care center that is also attended by non-drug users. This helps to prevent segregation and stigmatization of patients. Additionally, when other specialist services are needed, such as outpatient surgery, dentistry, gynecology, etc., they are available within the primary health care center;
- PCC personnel are trained and experienced to communicate effectively with drug users. The services are tailored to the needs of users (who prefer late opening hours), and the clients' visits are scheduled to accommodate several interventions in the same visit (e.g. psychotherapy and counseling, blood collection and consultations with hepatologists or psychiatrists);
- Members of staff motivate the clients to take an interest in their health. Clients are also reminded via cell phone calls or through peer messaging if they miss their visit, but full respect is paid to a patient's refusal to participate further, even though in practice it seldom occurs.

HCV testing is one of the most frequently requested services at the center. Here HCV is often diagnosed in the early stages, since wide access and availability of low threshold services motivates IDUs to undergo testing. Blood testing is generally available during the whole working week with same-day results; it is free of charge and confidential. Out of 1000 drug users tested for HCV, 67% were anti-HCV positive, 48% anti-HBcAg positive, and none of them HIV-positive.

The decision to provide antiviral treatment is made in a multidisciplinary setting by the whole PCC team on a case-by-case basis, and compliance and the ability to attend are assessed during the initial months of attendance. The main pre-treatment consideration is to assess a patient's current capability to adhere to and complete a treatment schedule to increase the odds of eradicating the infection. To date, no active drug users have been treated, since it is viewed that drug treatment will help to improve HCV treatment adherence rates. Therefore, drug users are motivated to undergo drug treatment before they begin HCV treatment; however, for those not prepared for full abstinence, an alternative OST is offered, as existing practice shows that OST helps patients to adhere to treatment. Since most PCC clients continue to obtain harm reduction services, including OST, approximately 40–50% of the center's HCV-positive patients eventually are included into HCV treatment programs.

Medical interventions are mainly covered by insurance, some diagnostic tests are covered by research grants (e.g. from the United States National Institutes of Health and the grant agency of the Ministry of Health of the Czech Republic), and a limited number of

patients were treated as part of clinical trials. The other interventions are funded in part by municipal harm reduction projects.

Among the 100 patients that have undergone treatment (those abstinent from drugs or those undergoing OST), SVR was achieved in more than 80% of HCV genotype 1 patients and in more than 90% of genotype 3 patients. High response rates have been achieved due to good on-therapy compliance by patients and particularly because of favorable biological factors, such as age (20–35), short duration of HCV infection and, usually, the absence of somatic co-morbidity. Because of close and frequent contact with PCC staff, drug relapse and treatment of side-effects in patients are managed immediately and usually successfully, and the drop-out rate from HCV treatment is very low—less than 10%.

5.1.5 HCV/HIV co-infection and antiviral treatment

HCV-associated end-stage liver disease (ESLD) has become a leading cause of death among HIV-positive people (Bica, 2001; Martin-Carbonero, 2001; Rosenthal, 2003). HIV accelerates HCV progression, particularly among people with <200 CD4 cells/ml (Goedert, 2002; Martin-Carbonero, 2004; Weber, 2006). Co-infected people are twice as likely to develop cirrhosis, and six times more likely to experience hepatic decompensation (liver failure) than those with HCV alone (Graham, 2001). HCV may complicate HIV treatment, because HCV increases the risk of ARV-induced hepatotoxicity (damage to the liver) (Sulkowski, 2000).

HCV can be treated, regardless of HIV status, although co-infected people are less likely to achieve SVR (see Table 12). Pegylated interferon-based regimens have significantly improved response rates to HCV treatment among people who are HIV/HCV co-infected (Carrat, 2004; Chung, 2004; Torriani, 2004).

However, not all co-infected people need treatment immediately. WHO has developed diagnostic algorithms for the management of HCV/HIV co-infected patients to identify people who do not need treatment for either virus, those who need HCV or HIV treatment, and those who need both. For more on this, see *Management of hepatitis C and HIV coinfection: Clinical protocol for the WHO European Region* (WHO Regional Office for Europe, 2006b).

5.1.6 Quality of care and the multidisciplinary approach to HCV treatment

Simply increasing access to HCV treatment is not enough: treatment and care must be of high quality. Multidisciplinary, co-located care has been a successful approach for treating HIV and HCV (Clanon, 2005; Fleming, 2005; Litwin, 2005; Taylor, 2005a; Taylor, 2005b), and existing programs that are successfully delivering HCV treatment to IDUs are a good model for other providers to follow.

For example, at the co-infection clinic in Providence, Rhode Island, United States, eligibility criteria are flexible and based on patient interest in HCV treatment, reasonable attendance at clinic visits, and willingness to engage in psychiatric care when indicated. Abstinence from drugs and alcohol is not required. Peer support, education and case-management services are also provided. Pegylated interferon is directly administered at weekly clinic visits, giving clinic staff a chance to closely monitor and treat side-effects. According to Taylor (2006): “We don’t want to be jailers, but

[directly administered therapy] is an opportunity to bring people in to connect with others, have a chance to talk and ask questions. We can improve the tolerability of a difficult treatment by nipping side-effects in the bud.”

Aggressive side-effects management has been associated with better HCV treatment adherence. Physicians are often reluctant to prescribe medications that alleviate some side-effects of HCV treatment if these medications have abuse potential. One option is for providers and patients to mutually develop a contract that clearly defines limits of what will be prescribed, and a plan for gradually tapering off these medications, which are generally used for pain, anxiety and insomnia.

5.2 HCV treatment and care for IDUs in the new EU Member States and neighboring countries

The prevalence of HCV among IDUs is alarmingly high in the region. HCV can be safely and effectively treated in IDUs, yet it is often withheld without careful consideration of medical implications and patient readiness, and despite recent international treatment guidelines recommending case-by-case assessment rather than excluding IDUs as a group automatically (see Table 11). Refusing to treat the highest-prevalence population is unacceptable and unheard of in other medical conditions. When programs are tailored to meet the needs of IDUs, their adherence and treatment outcomes are comparable to non-IDUs, a fact that supports broadening eligibility for HCV treatment.

There are very limited data about the actual number of people receiving HCV treatment in the new EU Member States and neighboring countries, but initial data that are available indicate that the number of people enrolled into treatment in the past 3 years is as low as 150–300 in Bulgaria and Slovakia, about 500 in the Czech Republic and Latvia, while upper estimates are around 1300 in Hungary and 4000 in Romania. However, in most of these countries active IDUs and often clients of OST do not receive treatment. Data from 2004, 2005 and 2006 also indicate that the numbers are increasing slowly but steadily.

Collecting data on treatment is difficult, which could indicate a lack of communication between medical personnel and the state health agency, or the lack of an effective national system for monitoring HCV. To explore the issue of treatment, therefore, it is crucial to look at other factors that might determine the availability of, access to and quality of treatment. These factors include:

- whether or not national treatment guidelines exist and if they include treatment for drug users, former drug users and those on OST;
- whether or not the cost of treatment is affordable, and if funding is covered by governments or other sources;
- the quality of treatment and diagnostic tests; and
- the availability of and access to treatment in prisons;
- identifying additional barriers in access to treatment.

5.2.1 Existence of national HCV treatment guidelines

Research shows that treatment guidelines can affect the way that treatment resources are provided in terms of funding, qualification, and outreach (Reimer, 2005). A 2004 study of guidelines in the 15 EU countries (before the May 1, 2004 EU enlargement) showed that practices and recommendations on guidelines vary from country to country—from abstinence requirements

to access for active IDUs and clients on OST. Overall, treatment guidelines that were considered to be of “higher quality” as assessed by the study, and/or those published more recently, were shown to be more likely to allow for treatment of IDUs (Reimer, 2005).

All countries in the region have HCV treatment guidelines in place or planned for adoption (in Ukraine) and data for Poland was not obtained (see Table 13). Generally, the existence of HCV guidelines in a country is a positive step, but the effectiveness of those guidelines must also be assessed, particularly in the context of how they approach drug use and whether or not they give drug users sufficient access to services.

In the new EU Member States and neighboring countries, most guidelines were adopted quite recently—between 2002 and 2005. There are official guidelines endorsed by Ministries of Health in Belarus, Lithuania, Romania, Russia, Slovakia and Slovenia, and in other countries adopted by professionals in hepatology and infectious diseases. In Latvia, the guidelines were approved by the State Medicines Pricing and Reimbursement Agency as an agency funding treatment.

The fact that specialists in drug treatment may not have been involved in drafting treatment guidelines may indicate why the guidelines are restrictive in terms of treatment for IDUs (see Table 13). It is also possible that specialists who were involved in drafting HCV treatment guidelines held discriminatory or other negative beliefs about IDUs, which could result in guidelines that inadequately address the needs of IDUs. However, in Slovenia, where guidelines were updated in 2006 in coordination with the Centers for the Prevention and Treatment of Drug Addiction at the Ministry of Health, there are particular guidelines for treatment of HCV-positive drug users. This includes guidelines stating that treatment should be undertaken in cooperation with drug treatment providers, and that active and former drug users and those on OST are eligible for treatment.

Based on CEEHRN survey results, Slovenia has the most comprehensive guidelines and practices related to HCV treatment in the region, and this appears to be true in prisons just as it is in the community at large. However, treatment can be discontinued for several reasons, including:

- laboratory investigations during the treatment do not indicate expected results of treatment after a limited time;
- there are side-effects that cannot be prevented with medication;
- the patient does not fulfill medical criteria for treatment (this doesn't include drug use as contraindication, as in most other countries);
- the patient does not wish to continue treatment, in spite of his/her doctor's recommendation.

In Russia, where guidelines were adopted in 2006 by the Ministry of Health and Social Development, no inclusions or exclusions are mentioned, which could imply that drug users would not automatically be excluded from treatment. However in practice, there are numerous local and regional decrees regulating treatment.

In addition to looking at treatment guidelines in terms of drug users in the region, this study surveyed the availability and accessibility of HCV diagnostics and treatment in practice for IDUs OST clients and people co-infected with HIV, as well as reimbursement options and availability of pegylated interferon treatment.

5.2.2 Eligibility for and access to treatment for IDUs

In the majority of countries—Belarus, Bulgaria, the Czech Republic, Estonia, Hungary, Lithuania, Romania and Slovakia—active injecting drug use, and often alcohol use, are considered contraindications for treatment in national HCV treatment guidelines, while the guidelines in Slovenia are an exception. Normally, this is also true in practice in those countries, and IDUs rarely

receive treatment. In Belarus, however, drug users can sometimes be treated based on the decision of individual doctors, which means that its national guidelines are more restrictive than what is happening in practice.

In addition to its national guidelines, doctors in the Czech Republic often refer to the recommendations drafted by EASL. In Hungary, medical practitioners use AASLD's *“Practice guidelines on the diagnosis, management and treatment of hepatitis C”*. However, the HCV treatment guidelines in both countries deny treatment for IDUs, despite the fact that the EASL and AASLD documents clearly state that IDUs cannot be automatically excluded from treatment.

In Slovakia, Hungary and Bulgaria, former drug users who are abstinent for at least six months are eligible for treatment, while in the rest of the countries no specific guidelines are mentioned regarding former drug users, or no data were available. However, the reality is that at least six-month abstinence period is also enforced in the Czech Republic, Estonia and Lithuania, while in Romania, Russia and Slovenia, former drug users are reported to receive treatment with no specific abstinence period identified.

5.2.3 Eligibility for and access to treatment for people undergoing opioid substitution treatment

Usually, people stabilized on OST are eligible for HCV treatment under the guidelines in Romania, Slovakia and Slovenia. In Ukraine, HCV treatment guidelines have been drafted but not yet adopted, and they state that all drug users must undergo drug treatment before starting antiviral treatment, with no specific mention of OST.

In Bulgaria, the Czech Republic, Hungary and Lithuania, national guidelines do not mention OST, but in practice a limited number of clients on OST can receive HCV treatment under limited circumstances. For example, in the Czech Republic, OST clients treated with methadone are more likely to be included in HCV treatment than those on buprenorphine. And in Bulgaria, half of the 300 patients reported to be receiving HCV treatment in 2006 were on OST. In the Czech Republic, about half of the 450 people receiving treatment in 2004, and half of the 550 people receiving treatment in 2005, were clients of OST.

5.2.4 Eligibility for and access to treatment for drug users with HCV/HIV co-infection

Since HIV accelerates HCV disease progression, PLWHA may have more urgent need for HCV treatment than mono-infected people. It is important to consider whether or not countries prioritize treatment of HCV/HIV co-infection in drug users, both in their national guidelines and in actual practice (see Table 13).

Contrary to the international recommendation to prioritize HCV treatment for PLWHA, in some countries surveyed, such as Belarus, co-infection is an excluding factor when considering treatment, which is a major barrier to effective HCV treatment. However, there are plans to provide treatment for between 40 and 50 PLWHA as part of a project funded by the GFATM in 2007.

Five countries in the region—Bulgaria, the Czech Republic, Estonia, Lithuania and Romania—provide specific guidelines for treatment of hepatitis/HIV co-infection, either within their hepatitis guidelines or in a separate document (no data were available for Latvia, Poland, Slovakia and Slovenia). However in some countries, especially countries of Central Europe, like Hungary, Bulgaria, Slovakia and Slovenia, the low HIV prevalence rate means that treatment for co-infected individuals is not seen as a priority in practice (as reported by respondents in countries). And in Estonia such treatment was not reported to be a priority. In Lithuania, doctors reported only a few cases of co-infection and no system of prioritizing people who are co-infected. In the Czech

Republic, EASL guidelines are widely used, and HCV/HIV co-infection treatment is mentioned in its national documents, and it appears that in practice priority is, indeed, given to co-infected individuals.

While the above information indicates that few countries prioritize co-infected individuals when providing HCV treatment, it is also important to consider the effects of programs that prioritize treatment for co-infected people while excluding those who are infected only with HCV. In some countries, co-infection can be a person's only chance to get treatment. For example, in Russia, co-infection is the only way to receive treatment, and people with HCV in Moscow are so desperate for HCV treatment that they are prepared to fake their HIV test results to get into a treatment program. This should be considered when developing or updating guidelines for HCV treatment and co-infection treatment.

5.2.5 Quality, accessibility and cost of HCV diagnostics and treatment

This study also looked at the quality, accessibility and cost of diagnostics and treatment in the region. In terms of quality, as the data below suggest, most countries use diagnostic tests and treatment that are consistent with those recommended in international guidelines. With regard to the accessibility of diagnostics and treatment, this was assessed based on whether or not, and to what extent, patients could be reimbursed for the cost of services by the government, insurance companies or other sources. Reimbursement varies from country to country, and it is most commonly available through insurance companies. Since most IDUs are not covered by insurance, this makes diagnostics and treatment difficult to access for IDUs.

5.2.5.1 Availability of diagnostic tests and reimbursement

In most countries, confirmatory antibody, RNA and genotype tests are used to diagnose HCV (see Table 14). These are the recommended tests in various international guidelines for HCV/HIV co-infection, such as those issued by the EASL and WHO, and guidelines for mono-infection issued by the AASLD. Liver biopsy is also used in some countries, most often before referring a patient for treatment and if there are no medical contraindications. In Slovakia, insurance companies, which cover expenses for diagnostics and treatment, require liver biopsy for diagnosis. In some countries, it is performed under limited circumstances, such as in Russia, where biopsy is routine among military conscripts suspected of having HCV, but not in the general population.

Reimbursement for the cost for diagnostics differs from country to country. Confirmatory antibody, RNA and genotype tests and liver biopsy are all paid for by health insurance in Bulgaria and Slovenia. The same is true in the Czech Republic, where liver biopsy is used to assess the severity of the disease, typically as part of pre-treatment evaluation, and all tests are widely used and covered by insurance, whether they are components of treatment or just for diagnostics. In Estonia, all types of tests are available for people with chronic HCV and before treatment, and are covered by health insurance. In Hungary, all tests are used, most often before starting treatment, and all are covered by health insurance.

However, in Latvia, confirmatory antibody, RNA and genotype tests, as well as liver biopsy, are covered by the government only if the patient is referred by a GP to a medical specialist (e.g. a specialist in hepatology). In Lithuania, testing is covered by the "State Sick Fund" through the centralized purchase of tests and equipment, often meaning that there are a limited number of tests that can be performed each year. For example, in 2006 the amount of funding provided by the Ministry of Health in Lithuania for these purchases was extremely low, and in the last few months of the year there were no tests left. In 2007, funding has been doubled, which should improve the

situation, although some patients will still have to pay for diagnostics themselves. In Slovakia, confirmatory, RNA and genotype tests are partly covered by health insurance companies and partly by pharmaceutical companies. In 2006, diagnostics were fully covered by pharmaceutical companies. In Russia, antibody testing is free of charge for people with health insurance, but patients must pay for all other tests. In Ukraine, HCV-RNA and genotype tests and liver biopsy must be paid for by the patient.

In Belarus, antibody and qualitative RNA tests are free of charge if a patient is referred by a GP; but quantitative RNA and genotype tests are only free in exceptional cases, such as if a hospital decides to cover them from its internal resources. For example, there is free genotype testing at a children's hospital in Minsk, and the RNA test is used in an infectious disease hospital in Gomelsk, though it is often limited for other people. In Belarus, the genotype of infection in most IDUs is unknown, and liver biopsy is rarely performed.

5.2.5.2 Availability of HCV treatment and reimbursement

International guidelines, such as those from EASL and WHO, recommend PEG-IFN and RBV treatment as the most effective HCV treatment, which is available in most countries in the region, with exception of Belarus and Romania (see Table 14). Through even in countries where it is available, it can be limited, most often by reimbursement policy. For example, in Lithuania, until the end of 2006, PEG-IFN and RBV treatment was provided in cases of relapse or non-response to a first course of treatment. However, due to advocacy efforts on the part of treating doctors, since the new purchase of antiviral drugs in November 2006, PEG-IFN+RIB treatment is also being provided to people with genotype 1, which is expected to increase SVR among patients. This new method is also identified in the project to draft guidelines in Lithuania, which is pending approval, though in this case the number of people receiving PEG-IFN per year may be also limited.

In terms of treatment schemes, treatment is available based on genotype, as recommended in all countries of the region. Moreover, IFN monotherapy is available in most countries and is provided when there are contraindications to RBV (see Table 13).

Clearly, the cost of treatment and whether or not it is paid for by clients themselves, the government or an external source, are important factors in determining the accessibility of HCV treatment for drug users. HCV treatment in the region ranges from EUR 2 000 for the least expensive drugs registered in Belarus, to EUR 22 800 in the Czech Republic, an average cost of EUR 12 600 for a standard year-long course (53 weeks) of treatment. In most countries, people must have health insurance to receive help paying for HCV treatment, and the majority of IDUs do not have it (the Czech Republic, Estonia, Hungary, Poland, Romania, Slovakia, Slovenia). Partial coverage by the state is available in Latvia. In Belarus, insurance does not cover HCV treatment, the Government can cover only up to the first three months of treatment; thereafter, the patient must pay.

In Bulgaria, the government will cover treatment costs only to 50–60 people for HCV treatment in 2007, though there are an estimated 200 000 people who are infected with HCV, including 15 000 IDUs and about 500 people undergoing OST. In Russia, where HCV treatment is not covered by health insurance, free treatment can be provided to people with disabilities. This includes HCV/HIV co-infected individuals who are registered with the National AIDS Center. Also in Russia, partial reimbursement is available in accordance with its Internal Revenue Code, but this is a complicated procedure that does not appear to work in practice. In Ukraine, patients are responsible for paying for HCV treatment (see Table 4). In Lithuania treatment costs are covered by State Sick Fund, through centralised purchase of drugs.

Waiting lists can indicate not only how many people are waiting to get into treatment, but

also the capacity and readiness of the government to cover treatment costs. Among the 12 countries for which data was available (no data was available for Poland), there are waiting lists in only two countries—Bulgaria and Lithuania. There was a waiting list in Hungary, but it was discontinued in 2004 by the National Health Insurance Fund. In Bulgaria, there are currently 200 people on the waiting list, though experts estimate that there are at least 15 000 IDUs with HCV that may need treatment at some point, while about 800 people undergoing OST are infected with HCV.

In light of these data, it is also important to consider criteria for inclusion on a waiting list, which can affect the number of people waiting for treatment. For example, in Lithuania, where there is a waiting list, drug use can be a criterion for excluding a person from the list, which means that the size of the waiting list probably does not correspond to the real number of people needing treatment.

5.2.6 Stated barriers to treatment

As the previous sections suggest, restrictive treatment guidelines related to IDUs, cost and other factors are all found to be barriers to HCV treatment. To help clarify the significance of different barriers, survey respondents were asked to name the biggest barriers to treatment in their countries.

The negative attitude of medical staff toward IDUs was stated as a primary barrier to treatment by respondents in 8 of the 13 countries: Belarus, Bulgaria, Czech Republic, Estonia, Hungary, Russia, Romania and Slovakia (no data were available for Poland). For example, in Slovakia, complications from HCV progression should be treated in all people with health insurance, but sometimes doctors refuse to treat people who “look like drug users”. The general opinion of medical professionals in Slovakia is that IDUs would not cooperate and successfully complete the treatment (provided by respondent in country).

An insufficient reimbursement policy and lack of state funded treatment also was mentioned as one of the most common barrier.

Other barriers include, in Bulgaria, the limited number of treatment slots (as a result of the high cost of medications) and slow and delayed diagnostic and administrative procedures. In the Czech Republic, additionally limited collaboration between different specialists, and complications and side-effects of treatment was identified as a barrier. And in Lithuania, centralized purchasing of antiviral drugs, which has resulted in only one drug being available, meaning that when there are contraindications for a particular patient, doctors do not have an alternative to offer, through this system is expected to change in near future including antiviral treatment for HCV into the list of treatments covered by health insurance.

Limited geographical reach was cited as another major barrier to treatment for IDUs in three countries (Estonia, Lithuania and Latvia). In Latvia, treatment is only available at one location in the capital city, Riga. In Lithuania, treatment is provided at five locations in the country’s three largest cities—two in the capital city, Vilnius, two in Kaunas and one in Klaipeda. This situation is mainly due to a limited capability of doctors to provide treatment, indicating the limited availability of experience and education among doctors in smaller cities. This may also be a barrier for treatment, especially among people who cannot afford to travel to other cities on a regular basis.

5.2.8 Access to HCV treatment in prisons

In theory, HCV treatment should be available in prisons in countries such as Bulgaria, Hungary, Lithuania and Poland. In practice, however, it is rarely available and, although data are limited, it appears that very few inmates receive treatment, most often due to lack of funds for treatment and diagnostics. Most countries report that in prisons the symptoms of HCV are often treated (see Table 14).

A variety of limitations and obstacles prevent HCV treatment from being accessible in prisons. For example, in Bulgaria HCV treatment can be provided, but limited diagnostic services in prisons mean that few people with HCV are ever diagnosed. In Lithuania, HCV treatment should have been available in all prisons since 2003. However, liver biopsy must be done to determine the need for treatment, and there are long delays in getting this test. In addition, after biopsy, the patient must sign an agreement stating that if s/he uses drugs the treatment will be discontinued. In Russia, HCV treatment is not generally available in prisons, although on rare occasions a visiting doctor might enable an inmate to receive treatment.

HCV treatment is reportedly available in prisons in Slovenia, where it is well funded by the Ministry of Justice. In Slovakia, inmates are eligible for HCV treatment after six months of abstinence from drugs in prison and approval of the insurance company (all prisoners are automatically insured upon admission to prison). However, in 2004, when four cases of HCV were identified in prisons in Slovakia, one person underwent treatment, two refused treatment, and one was contraindicated for treatment. In 2005, 36 more people tested positive for HCV in Slovakian prisons, and treatment was recommended for 25 of them. Three refused the treatment and the rest were contraindicated in some way (provided by respondent in country).

6. Support for people with hepatitis C

HCV prevention and treatment management are especially challenging among IDUs and people with a history of drug use. Diagnostics and treatment among IDUs can lead to problems with adherence to treatment, management of the treatment schedule, a greater tendency to experience depression, and more and more severe side-effects. Therefore, it is crucial to provide additional support beyond prevention and treatment, such as information, group support, psychological counseling and advocacy for treatment.

Many clinicians, activists and policymakers see support services as optional and of secondary importance to prevention and treatment. Particularly in regions where access to treatment is severely limited and providers and activists are still fighting for basic harm reduction services for IDUs—such as in the new EU Member States and neighboring countries—advice on providing HCV support services may seem idealistic and beyond what is currently possible in the region. However, support services can mean the difference between prevention and treatment efforts that are effective and those that are not.

People living with HCV require a wide range of support services to help them effectively manage and cope with their illness. The kind of support they may need can depend, in part, on their circumstances. For example, it can depend on whether they are current IDUs or former IDUs; whether they contracted HCV through a blood transfusion or another route, in which case they may not want to interact with drug users; and whether they are co-infected with HIV and whether this was the result of drug use, sexual activity or another mode of transmission. In addition, the friends, family and carers of people with HCV often also need support, particularly when they are caring for someone on HCV antiviral therapy who may be both in need of support him- or herself and at the same time particularly difficult to live with.

Equally, people with HCV need different types of support at different times. For example, the support someone needs the day they are diagnosed with HCV will typically be very different from the support someone on antiviral treatment may need, to the extent that putting them together in the same support group could be undesirable. Someone newly diagnosed and already afraid about their future is likely to be further frightened to hear someone on antiviral treatment graphically outline the treatment side-effects. Broadly, there are three identifiable periods with differing needs:

1. just diagnosed;
2. on treatment;
3. living with HCV, which includes making the decision to undergo treatment.

In addition, although it could be considered part of living with HCV, getting access to treatment is worth considering separately, because it may require special support, in particular with advocacy. The following sections highlight support interventions for people at the various stages of HCV management.

6.1 What works in HCV support: guidelines and suggestions

6.1.1 Support when newly diagnosed

HCV diagnosis takes place in a range of settings, such as primary care surgeries, sexual health clinics, drugs service facilities, hospitals and prisons. Wherever it is given, a positive diagnosis can be traumatic, particularly if it is seen as a death sentence. It may be seen as such because it is a life-threatening diagnosis, for example, for someone who is HIV-positive and has had HCV for a long time; or for someone who already has decompensated cirrhosis. It could also be seen as a death sentence because the wrong information is given by medical personnel. Misinformation about the severity of the disease may be compounded by the way it is delivered, especially to active IDUs. Too often, testing is done by someone who either has hepatitis knowledge but no addiction training, such as at a sexual health clinic, or addiction knowledge but no HCV training, such as at a drugs service facility.

People who are being tested need to have an adequate pre-test discussion explaining the consequences of a positive test, followed by a post-test discussion that reiterates the correct facts about HCV, outlines what happens next and signposts ways of accessing support. Because a positive diagnosis can be upsetting, what is said in the post-test discussion may not be well retained, so it should be accompanied by an information leaflet recapitulating what was said.

Once patients have received their medical diagnosis, they may need emotional support while they absorb the information. They also often need further information about the non-medical ramifications of having HCV, for example, who they should tell and how (e.g. should they tell family and friends? what about their employer?); and the likelihood that they may have infected others. These needs are best met by people who have HCV themselves and have been through the same experience of having a positive diagnosis and facing many of the same issues. This is particularly true in countries where HCV infection is heavily stigmatized. Ideally, people would have access to peer support from people in exactly the same circumstances, whether they are current IDUs, former drug users or someone who is co-infected with HIV.

6.1.2 Support while on HCV treatment

Treatment is often difficult: interferon and ribavirin both have significant side-effects, and most people taking them require some form of support. Support is especially important for active drug users and people with a history of drug use, because they tend to experience side-effects more often and more severely, and the consequences of treatment when they are not psychologically ready are likely to be significantly more damaging. Typically, they require four types of support to a greater or lesser degree:

- Support from medical staff, including information on what to expect from treatment, proper explanation of tests and results and, when necessary, reassurance that what they are experiencing is caused by the medicine and not some new frightening illness. They also need access to information on some of the practical issues, for example, what to do if they miss a dose or lose their medicine. Ideally, this support needs to be available every day, not just at a monthly clinic appointment. This is particularly true for people who are HIV/HCV co-infected, who may experience added medical complications.
- Specialist psychiatric support from medical staff. The psychological side-effects of treatment, particularly depression, pose a significant threat to both current and former drug users, who may already have a history of depression or bi-polar disorder. Therefore, they need to

be psychologically assessed prior to treatment, regularly monitored throughout treatment, and offered appropriate pharmacological support, such as anti-depressants. Current drug users may, in fact, find treatment less onerous, because drugs, particularly opiates, may help ameliorate the side-effects, although increased amounts of the drugs may be necessary. Former drug users, especially former opiate users on an abstinence-based program may, by contrast, find treatment more difficult and should be even more closely monitored and offered additional support. The risk is that they will revert to drug use, which will quickly become problematic to the point that they discontinue treatment before it has worked.

- Support from family and friends. The physical side-effects of treatment can be compounded both by the psychological side-effects and the duration of treatment. Often, those on treatment need help not only with physical tasks such as carrying shopping bags, but also with staying motivated. Yet the psychological side-effects—depression, anxiety, obsessive thoughts, mood swings and rage (sometimes leading to uncharacteristic violence)—may alienate family and friends from whom support and understanding is needed. Family and friends may, therefore, also need support.
- Support from others who are either on treatment or have been through it. Knowing that other people have faced the same difficulties and still persevered to the end can be very useful in maintaining motivation. Many people on treatment get worn down by the relentless effort that is required, and at some point think about either missing doses or stopping completely. Peer support is also often needed by those who fail treatment. About half of people who undertake treatment do not achieve a SVR. Despite this, belief that treatment will work is often the prime motivational tool for continuing with it, so failure can be particularly devastating.

6.1.3 Support for people living with HCV

Currently the great majority of people with HCV are faced with the challenge of living daily with their disease, either because they have no access to treatment, it is contraindicated or has not worked, or they choose not to take it. It is also important to remember that even people for whom treatment has worked may find it slow and difficult to recover afterwards, and some may be left with persistent side-effects. Living with HCV raises many issues for which support may be needed:

- **Mental attitude.** Anyone with a chronic disease can be prone to despair, for instance if they see no hope of ever getting the treatment they need. For current IDUs this can have further negative consequences if, for example, they believe there is no point in stopping using drugs because HCV or HCV in combination with HIV will kill them soon anyway. However, chronic disease self-management—taking control of and responsibility for management of one's own illness—has been shown to have significantly improved health outcomes (Lorig, 1999; Lorig, 2001).
- **Treatment decisions.** Even when treatment is accessible, deciding to do it and when to do it is complex. The decision involves such considerations as:
 - the ability to take time off from work or other commitments, such as raising a family;
 - financial implications;
 - possible strain on relationships;
 - chances of success;
 - the urgency of getting treatment as measured by liver damage;
 - the availability of new drugs either with fewer or less severe side-effect profiles or better success rates;

- for women, a further consideration may be the desire to have a child without exposing the child to HCV.
- there are yet more issues for those co-infected with HIV, including the generally increased rate of liver damage and the ability to discontinue ARV treatment.
- **Alternative and/or complementary medicines.** Given the side-effect profile and cost of HCV treatment, many people want information and advice on which complementary medicines to take, and they want to talk to other people about their experiences.
- **General health.** People also need advice and support on improving their health independently of any medicine, for example in improving their diet or their management of stress and energy to try to minimize the damage to their liver or to recover from treatment.
- **Alcohol and other drugs.** People need advice about just how damaging alcohol and other drugs are, and in what quantities, and then sometimes support in cutting down or stopping alcohol use in particular.
- **Discrimination.** People with HCV, particularly drug users, frequently experience discrimination in all areas, not just in accessing treatment. They may need advocacy support with employment or state benefits, for example. (See section 6.2.3.4: Advocacy to fight stigma and discrimination).
- **Telling people.** Who to tell that you have HCV and how to do it is complex, and talking to someone who has experience doing this can be immensely valuable. This support is frequently needed when someone starts a new sexual relationship.
- **Financial.** HCV infection has financial consequences, and people often need information, support and/or advocacy in sorting out issues such as insurance, loans and mortgages.
- **Travel.** Here, too, people need information on which countries may refuse entry (this particularly applies to those co-infected), which inoculations are necessary but also safe, and which medicines are safest for people with liver disease.

6.1.4 Support getting HCV treatment

People generally have difficulty accessing antiviral treatment either because they are considered unsuitable on other than medical grounds—which is often the case for IDUs—or because there are resource constraints. However, the stated reason is not always the real reason, as stigma and discrimination play a role in access to services. In these situations, people typically need help and support in the form of advocacy work with them or on their behalf. There are good reasons for treating HCV, including its infectiousness, the cost of not treating it in both human and financial terms, and the fact that treatment can cure the liver disease it causes, but people refused treatment often need help in using these arguments effectively.

Deciding who should advocate for someone needing treatment depends on who will be most effective. In the United States and most of Western Europe—where there is increasing emphasis on listening to the wishes of patients—patients’ organizations and drug users’ groups are usually the most effective in advocating for treatment for drug users. Elsewhere, other groups such as clinicians may have more power, although advocacy work may be usefully coordinated by patient groups, especially if the efforts could be enhanced by the inclusion of the media and elected representatives at national or local level, or both. Patient groups’ understanding of the wider issues and knowledge of other similar situations can be very useful in engaging both the media and politicians.

Some patients are excluded from treatment for good medical reasons, for example, because IFN and RBV are potent drugs that are contraindicated in a range of conditions. However, treatment

may be refused for other reasons, one of the most common of which is continuing drug use. Active IDUs are, therefore, especially in need of advocacy support to provide the evidence to rebut the myths on which refusal is generally based, such as that they will not be able to adhere to treatment, that they have very poor SVR rates or that they will immediately get re-infected¹. In fact, it can be argued that active IDUs should be treated before anyone else, since in the case of every other infectious disease, priority is given to those who are transmitting the infection. In the case of HCV, IDUs are transmitting the infection most often, so they should have priority (for more information about advocacy, see Box 6: Lobbying for HCV treatment for drug users—The Hepatitis C Trust experience).

6.1.5 Patient self-support

Patient self-support can be broadly divided into four types: physical support, such as groups; phone support; web-based support; and print-based support, such as newsletters.

Physical support. Support groups are the most obvious type of self-support, but setting them up and keeping them running is often a challenge. Aside from the practical requirements of finding a venue, deciding on a structure and letting people know of its existence, someone needs to have the energy and motivation to organize it. These are attributes that people with HCV often lack because of the debilitating symptoms of the disease, especially during treatment. A professional, such as a nurse, is often needed to take on the role of organizer. However, simply turning up may require too much effort for some people with HCV, particularly if the venue is far away or difficult to get to. Again, this especially applies to those on treatment and, possibly, to IDUs. Therefore, attendance can be extremely variable, with few people staying motivated to attend regularly.

A further problem is that those who have contracted HCV in what they consider to be a “blameless” way may not want to share a support group with those who have contracted it through drug use, and equally those who no longer use drugs may not want to be with people who are currently using. Likewise, newly diagnosed people may be frightened away after their first support group by hearing long diatribes about the horrors of treatment. Unfortunately, it is generally the case that there are not enough participants to hold separate groups for each different sub-set of people with HCV.

The Hepatitis C Trust has found that there is a strong (though uneven) presence of Narcotics Anonymous groups in the United Kingdom, and these groups are used informally as a support network for HCV, because so many of the groups’ members have HCV, and there are always some people on treatment at any one time. The first HIV/HCV support group in the UK is due to start up in early 2007 at The Hepatitis C Trust. This has been challenging to set up, because HCV is currently heavily stigmatized in the HIV community, and the HIV gay male community is relatively small and close-knit. A further complication is that HCV is being transmitted sexually between gay men living with HIV.

Another form of physical self-support is provided by what is called the “Chronic Disease Self-Management Program” in the United States, and the “Expert Patients Programme” in the United Kingdom. Based on research at Stanford University (Lorig, 1999; Lorig, 2001) and more recently by the National Health Service in the United Kingdom, this program trains patient tutors

1 Anecdotal evidence given to The Hepatitis C Trust suggests that the length and severity of treatment impresses on current drug users the seriousness of HCV, ensuring that they take precautions to avoid re-infection but also pass that message on to other drug users. In the United Kingdom, as a result of concerted patient and clinician lobbying, current drug users are eligible for treatment.

to deliver to other patients a six-week course that is designed to empower them to take control of the management of their disease. So far in the United Kingdom the program has been somewhat generic, dealing broadly with chronic disease. However, an HCV-specific program is due to be piloted in 2007.

The Hepatitis C Trust also plans to set up a program to train peer educators who have both HCV and a drug-using background, to provide information and support in drug services, both at drop-in centers and residential rehabilitation facilities.

Telephone support. This is a key form of self-support because it can be accessed from anywhere and not just at a fixed time. It is highly interactive and yet allows people to stay anonymous if they wish. However, the people with HCV who staff it need to be trained, both in how to answer calls (e.g. how to deal with aggressive callers) and in providing correct information. The training needs to be continuous, because HCV is a rapidly evolving field with new information coming out all the time. This generally means that telephone support is best run from an office, rather than diverting calls to be answered by helpline staff at home. Recruitment and retention of staff—especially if they are volunteers—can, therefore, be challenging. However, experience shows that working as a helpline volunteer has often been a stepping stone for people with HCV back into full-time employment.

Web-based support. This can take many forms, from information websites to discussion forums and live on-line question-and-answer sessions. Research has shown that some people do not feel ready for interactive support and yet derive support from reading other people's experiences of having HCV or from simply observing other people's discussions (Kerr, 2005).

Print-based support. It might seem that the less physical and interactive self-support is, the less effective it is. However, this is not always the case, because the more interactive the support is the more possibility there is that the personalities of the people involved can interfere. Furthermore, fear of interaction can prevent people accessing the support at all (Kerr et. al., 2005). Therefore, print-based support is still vital.

In general, people feel supported when they feel they are part of a community. A simple way to do this is to distribute a newsletter written by people with HCV for people with HCV. To save costs this can be done as an e-newsletter or distributed as an e-mail. However, the experience at The Hepatitis C Trust has been that people greatly prefer to read a hard copy, especially if it is lengthy (The Hepatitis C Trust newsletter is 40–50 pages per issue).

Box 6: *Lobbying for HCV treatment for drug users— The Hepatitis C Trust experience*

By Charles Gore, The Hepatitis C Trust, United Kingdom

In the United Kingdom, apart from Scotland, the National Institute for Health and Clinical Excellence (NICE) decides which treatments should be prescribed and to whom, and issues guidance that the National Health Service (NHS) must follow. In 2000, NICE issued guidance on the use of alpha IFN and RBV treatment for moderate to severe chronic HCV and said: "Therapy involving either or both of these drugs is not in general recommended for patients who are continuing injecting drugs."

In 2003–4, NICE considered the use of PEG-IFN and RBV for moderate-to-severe chronic HCV and invited The Hepatitis C Trust to give expert opinion from the patient point of view. The first draft of the guidance stated that current IDUs “have high rates of discontinuation in trials and relatively high rates of psychiatric co-morbidities, and thus do not achieve high success rates with interferon therapy”. The Trust objected strongly to this, both on the grounds of its accuracy and because we were concerned that the NHS would use this to deny treatment to active IDUs. Several members of the NICE committee were misinformed about adherence and re-infection rates. With the support of an expert clinician, and to the credit of the NICE committee, the members changed the wording so that the final guidance reads: “Current injecting drug users can have high rates of discontinuation in trials, and thus do not achieve success rates in trials with interferon alpha therapy as high as those obtained by other participants. However, there is evidence that where adherence is achieved, success rates are not significantly different.” While not as favorably worded as the Trust had requested, this was still a major improvement, and NICE further added: “The Committee heard that, although IDUs with HCV might, on average, seek treatment less frequently than other people with HCV, those who do seek treatment have similar adherence rates to other people with HCV. Furthermore, the evidence provided by the experts persuaded the Committee that current information indicated that HCV re-infection rates for people on IFN or PEG-IFN therapy were low in those who continue to inject drugs. Thus, although rates of discontinuation of injecting drug users in trials have been high, the Committee was prepared to accept that in naturalistic settings, the rate of discontinuation would not be so great as to prevent the treatment being cost effective.”

The Trust believed that this guidance clearly allowed current IDUs to be treated. However, in its advocacy work it continued to come across cases where active IDUs were being denied treatment and the NICE guidance was being used to justify this. So, when NICE considered extending the guidance to cover mild chronic HCV in 2005–6 and again asked the Trust to provide input, it was argued that this new guidance should be clearer. Once again NICE issued new guidance, which states: “The Committee was persuaded by the experts that the previous guidance on treating people with moderate chronic hepatitis C who continue to inject drugs and/or misuse alcohol and people co-infected with HIV should be extended to members of all such groups who have mild disease ... with respect to those continuing to use injecting drugs, in naturalistic settings, the rate of discontinuation of treatment would not be so great as to prevent the treatment being cost effective. In addition alcohol consumption is not in itself an absolute contraindication to therapy, but it should be emphasised as an important contributory factor to the development of liver disease and should be taken into account in advice and information given by the clinical team.”

Although NICE guidance must, in theory, be followed, in practice it is easy for clinicians to find reasons not to treat IDUs. Thus a clinician could, for example, cite psychiatric co-morbidities as a reason for refusing treatment, when in fact the real reason is that s/he believes the IDU will waste his/her time by missing appointments or will lower the clinic’s treatment success rate by not adhering to treatment. Therefore, at the same time as

providing evidence to NICE, the Trust also began subtly educating clinicians. For example, it held a discussion in Parliament on where best to deliver treatment. This consisted of presentations of examples of good practice, including pilot schemes for treating IDUs, followed by a debate. A report called *Expanding the Options* was then written and widely circulated to clinicians and Ministers. Furthermore, in advocacy work on behalf of IDUs who have difficulty getting treated, the Trust tries not to force reluctant clinicians into accepting that they have to treat, but rather to educate them on the benefits of so doing.

In 2003–2004, the Trust organized a series of workshops with the goal of improving understanding of the way PEG-IFN and RBV treatment for HCV raises particular issues for people with an addictive substance-using background. The workshops, intended primarily for Hepatitis Nurse Specialists and Drug Action Team nurses, were designed to examine methods of offering extra support to patients from an addictive substance-using background and also of identifying those patients whose psychiatric state indicated that treatment should be delayed. The aim in each case was to increase adherence to the treatment regime, improve treatment outcomes and prevent relapse. As a result, a consensus statement was developed on how to improve care and support for this group.

Little by little, there is evidence of not just an acceptance that IDUs must be treated, but a growing willingness to do so. Unfortunately, at the same time, the United Kingdom is facing increasingly restrictive capacity restraints, and it is almost inevitable that, in any form of rationing, someone who was infected through a blood transfusion prior to screening in 1991 is more likely to get treated than an IDU, who may have been infected relatively recently, if only because of the perceived length of infection. The Trust is lobbying very hard at the local level, where spending decisions are now made, for increased resources to prevent this sort of rationing.

6.2 HCV support and self-support services in the new EU Member States and neighboring countries

There are few support services for people with HCV in the new EU Member States and neighboring countries. Many activists and clinicians in the region focus their energy and minimal resources on prevention and removing barriers to treatment for IDUs. Yet support services can greatly enhance the effectiveness of prevention efforts and treatment management. This section highlights the information that is available about support services in the region.

6.2.1 Support when newly diagnosed

As discussed in Section 4, pre- and post-test counseling can help people to avoid the panic or depression that might accompany an HCV diagnosis, by helping them understand their positive test results. There are numerous examples from the region of people who are diagnosed with HCV and do not receive adequate counseling, which leads them to assume their diagnosis is a death sentence. For IDUs, this might mean that they increase rather than decrease practicing

risk behaviors such as injecting, which of course can exacerbate their illness. In many cases, a positive diagnosis does not mean that treatment is needed immediately. Adequate counseling can help people understand the importance of decreasing risk behaviors and taking other measures to manage their illness.

In the region, only Slovenia reported that pre- and post-test counseling are regularly provided at its Centers for the Prevention and Treatment of Drug Addiction and Clinic for Infectious Diseases. In most other countries, pre- and post-test counseling are either not provided at all, or are provided sporadically. In Belarus, post-test counseling after a positive diagnosis is sometimes provided.

While most countries provide HCV testing in **prisons** on a very limited basis, most do not provide pre- or post-test counseling. The only exceptions are Belarus, where post-test counseling is usually provided, and Lithuania which provides both pre- and post-test counseling to inmates.

No further assessment of support provided (support to people diagnosed with HCV by patient organizations, availability of telephone support, etc.) was made in the framework of the survey.

6.2.2 Support for people on treatment and people living with HCV

In a number of countries, support is provided by liver patient organizations or associations; for example in Hungary, **peer education and psychological support** for people undergoing HCV treatment is currently being put in place by the Hungarian Liver Patient Association, in Lithuania by the Liver Disease Patients and Doctors Association. Slovenia also reports that peer education and support for HCV treatment is available. Overall, however, most countries do not offer specific peer education and support for IDUs in treatment. More commonly, peer education and support for prevention of HCV, rather than for treatment, is available in the region. This is the case in Bulgaria, the Czech Republic, Estonia, Hungary and Slovenia, and on a limited basis in Lithuania and Russia (no data were available for Latvia and Ukraine). However, this may be due to limited availability of HCV treatment for IDUs.

Side-effect management counseling is provided in nine countries in the region, usually by the treating doctor. **Drug and alcohol use counseling** is provided in about half of the countries in this study. And **mental health care**, on the other hand, is only reported to be provided in Bulgaria, the Czech Republic and Slovenia. In Belarus, no specialized mental health care is provided, but information about mental health issues may be included along with information about side-effects and treatment.

6.2.3 Support for getting antiviral treatment

6.2.3.1 Support from health care professionals

Stigma and discrimination against drug users on the part of clinicians and doctors who provide HCV treatment is confirmed by this survey to be pervasive in the region. In fact, self-support organizations are often hindered in their efforts by the lack of involvement of medical professionals. Yet, as experience from the region shows, the most successful advocacy efforts are often those that are supported or endorsed by health care specialists. There are examples of clinicians and specialists in addiction treatment in the Czech Republic and Slovenia who made a successful effort to involve IDUs and OST clients in HCV treatment. In the Czech Republic, a primary health care clinic operates with the cooperation of specialists in infectious diseases and addiction treatment specialists, which is proving to be an effective way to increase access

to treatment at least for the clients of OST. In Slovenia, guidelines for providing HCV treatment were drafted jointly by specialists in infectious diseases and addiction treatment specialists at the Centers for the Prevention and Treatment of Drug Addiction (see Table 13). As a result, Slovenia's treatment guidelines include access to treatment for drug users and patients of OST programs, and helped to educate specialists in infectious diseases on working with drug users and addiction specialists to better understand HCV.

6.2.3.2 Support from drug users' groups

Due to obvious limitations, such as a lack of funding and human resources, drug users' groups often have to fight for their survival and the sustainability of basic services such as harm reduction, drug and HIV treatment services. This limits their capacity to incorporate other issues into their work, such as HCV. Where drug users are highly stigmatized and discriminated against—which is the case in most countries of the region—it is difficult for drug users' groups to advocate for the right to HCV treatment, especially where HCV treatment is difficult to get, even for non-drug users. The criminalization of drug use further compounds the difficulties of representing drug users' interests and rights. Throughout the new EU Member States and neighboring countries, drug users' groups are only just beginning to mobilize around the issue of HCV, primarily focusing on access to treatment and care.

Box 7: *Advocacy work by drug users' organization in Bulgaria*

By Rumén Donski and Milena Naydenova, NGO HOPE-SOFIA, Bulgaria

One of the few drug users' organizations in the region to be directly addressing HCV is HOPE-SOFIA. With the increasing awareness in Bulgaria of HIV and AIDS on World AIDS Day, the NGO brought attention to HCV and the lack of access to treatment, particularly for drug users. There are estimates that at least a quarter of a million people in Bulgaria have HCV, and most people find out about their status by chance during visits to their doctor. The low level of awareness about HCV means that this diagnosis is often particularly traumatic.

Despite the high incidence of HCV in Bulgaria, free HCV treatment was discontinued in 2006, even for people with health insurance (although, up to that point, the health insurance system only paid for treatment for about 50 people each year). However in 2007, the Government has committed to cover the treatment course for 60 people, which, considering the scale of the disease, is grossly inadequate. With the required year-long treatment for HCV costing around EUR 20 000, this means that the majority of people with HCV will not be able to get treatment. Moreover, according to HOPE-SOFIA, only a few people with a history of drug use have ever been given HCV treatment, and in those cases it occurred only because there was donated medication available (though much of the medication was out of date). Instead of helping some of these people, the treatment actually harmed them, because they did not get a full course of free medication. Those who could not afford to pay for the remainder of the medication often became resistant, which made their illness much harder to treat.

HOPE-SOFIA held a press conference about the lack of HCV prevention, treatment and care for drug users and also tried to represent drug users' interests and rights in a public debate on national television. However, their position was not included in the debate because, it was argued, discussing drug users' needs would draw attention away from the overall issue of a lack of accessible diagnostics, treatment and support for non-drug users with HCV. Despite the fact that HCV is highly prevalent among IDUs, the generally negative attitudes towards drug users meant that the debate about HCV was incomplete, at best.

Throughout 2007, HOPE-SOFIA will take part in public debates along with patients' organizations, professionals and representatives from the Ministry of Health and the National Health Insurance System. It will do advocacy work to persuade decision-makers to substantially increase the number of people who can receive free HCV treatment each year, and to stop differentiating between different types of drug users and based on ethnicity (e.g. Roma). The organization will urge policymakers to use health insurance status as the only criterion for getting free treatment, since Bulgarian legislation states that having health insurance gives the right to free treatment.

Since the cost of drug addiction treatment is not covered by the health insurance system in Bulgaria, even if drug users have health insurance, they must pay for both addiction treatment and HCV treatment. As these are the two most common health issues for which drug users need treatment, health insurance for drug users is of limited use. HOPE-SOFIA's advocacy work is also aimed at improving conditions such as this that limit drug users' access to health care. The organization is also building partnerships with the Bulgarian Helsinki Committee, an international human rights organization, to take action against the refusal for HCV treatment of people who use drugs and have health insurance.

6.2.3.3 Support from liver patient organizations

In most countries of the region, there are either liver patient organizations or associations representing people with HCV, such as in Hungary, Latvia, Lithuania and Romania. These groups provide information and support and also work to ensure the availability and quality of HCV treatment. Generally, however, they do not focus on the special needs of IDUs or at the time of survey had not yet worked with IDUs.

In many countries, drug users are viewed as "guilty" of contracting HCV, while those who contract it, for example, through blood transfusion, are seen as "innocent" and therefore a priority for treatment. This is not helped by the fact that most HCV guidelines and practices in the region forbid treatment for drug users. The requirement in national guidelines or the recommendation from doctors that IDUs abstain from using drugs for at least six months before receiving HCV treatment puts up another barrier to getting treatment.

The limited number of drug users and OST clients who are receiving HCV treatment in the region can be attributed partly to the fact that drug user and liver patient organizations have not yet built effective partnerships. Moreover, there are few drug users who need treatment support at

the present time, since so few are actually receiving treatment; rather, they require support on how to live with HCV without treatment.

As presented in Box 7: Advocacy work by HOPE-SOFIA, stigma and discrimination pose great challenges to self-support organizations that advocate for HCV treatment for drug users, and sadly this is the case throughout the region. Likewise, the lack of interest among non-drug users with HCV to interact with IDUs, and the lack of involvement or support of medical staff, is often due to or exacerbated by stigma and discrimination.

7. Conclusions and recommendations for action

In terms of HCV, IDUs are both the most at-risk population and the group with the highest prevalence—in some cases as much as 60–90%. Therefore, interventions to effectively address the growing concern about HCV must be targeted to the particular needs of IDUs, and must ensure that IDUs receive appropriate services.

This survey confirmed HCV, especially among injecting drug users is a neglected problem. In all 13 countries assessed there is a lack of low threshold testing and prevention and support measures designed specifically for IDUs, which, means that this group is consistently denied its rights to health care, while rates of HCV in the population continue to rise.

IDUs also have very limited or no access to life-saving HCV treatment.

Although virtually all 13 countries of the region have guidelines for HCV treatment, none of them rely on recent scientific evidence or international guidelines, which recommend not excluding IDUs from treatment but rather making decisions on a case-by-case basis. Through adoption of guidelines identifying access for IDUs would be a step forward, there are other barriers in access to treatment. Stigma and discrimination against drug use especially on behalf of health care professionals mean that those with the greatest need for HCV support, treatment and care are often denied these services. Besides, policy and advocacy efforts do not adequately address this issue and significantly more effort is needed in order to bring the issue up on the Public Health policy agenda.

The survey also confirms that an EU strategy and Europe-wide guidelines on hepatitis (as also outlined by the European Liver Patient Association report “*Health care access and public policy for the prevention and care of viral hepatitis in Europe*”) would help to improve and unify diagnostics, treatment and care practices across European countries.

As this report summarizes, there are measures that can prevent further transmission of HCV, and IDUs can be treated as successfully as non-drug users. Therefore, there is no sound argument for denying prevention, treatment and care to IDUs. Protection of the rights and interests of those who are most at risk (IDUs), as well as their involvement in development of policies and guidelines that affect their health and rights, is crucial for HCV prevention and management. It is also important for more successful management of HIV, since co-infection among IDUs is common and ART is more complicated among people with HCV co-infection.

This report supports the principle that all people, including IDUs, have equal rights to health care, accurate information, treatment and support. Therefore, relying on international experiences and results of this survey, the report makes the following recommendations to policymakers, health-care specialists, service providers, IDUs and people living with HCV.

7.1 Recommendations for policy-makers

- Policy-makers should acknowledge the need for, and express a greater level of commitment to, HCV prevention and treatment, and develop programs and strategies addressing HCV and liver diseases. Due to the high prevalence of HCV among drug users in the region, the issue should also be appropriately covered in drug strategies and programs.
- People living with HCV—as well as IDUs—should be involved in the development, implementation and evaluation of policies and strategies related to drug use issues and liver diseases.
- Clear and realistic mechanisms should be developed to provide reimbursement for HCV diagnostics and treatment in cooperation with insurance and pharmaceutical companies, taking into account national economic and social conditions.
- More political and financial support is needed from national and local authorities for cost-effective drug-related harm reduction measures in the community and in prisons.
- Policymakers should support the dissemination of good practice from their countries to neighboring countries and support international collaboration for health care and low threshold service providers and patient organizations.
- Repressive legislation on drug use and drug users should be revised and should reflect a non-stigmatizing approach based on public health interests 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. The distinction between drug users and drug traffickers is essential, as repression of drug users often restricts their willingness to obtain health services, and increases populations in prisons and pre-trial detention institutions, where preventive services are limited, and care is often interrupted or delayed.

7.2 Recommendations for intergovernmental and international agencies (including the EU and the United Nations)

- In cooperation with national governments and civil society representatives, recommendations and/or a pan-European strategy on hepatitis need to be adopted with clear accountability mechanisms at international, regional and national levels. In addition, the integration of HCV issues into HIV and AIDS, drug-use and prison health care agendas is essential for coordinated, efficient and cost-effective action.
- Intergovernmental organizations like the EU (European Centre for Communicable Disease Control, European Monitoring Center for Drugs and Drug Addiction), WHO and other relevant United Nations agencies should collaborate with national governments, service providers and epidemiologists to establish more accurate, specific and sustainable databases to track incidence, prevalence and trends in HCV. Data collection and analysis should also be used to assess risk behaviors and promote access to evidence-based services for drug users in the community and in prisons.

7.3 Recommendations to donors (especially in the EU and those providing support to the EU neighborhood)

- Donors and foreign development agencies supporting harm reduction, HIV prevention and other services targeted at IDUs and prisoners should include an HCV component in their programs to form a comprehensive response to challenges posed by drug use, and at the same time to encourage funding recipients to include HCV-related activities in their services.

7.4 Recommendations to health care authorities

- 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 (developing new guidelines or adopting existing European guidelines). Guidelines should be based on results of recent medical research and should reflect international good practices that recommend including drug users in treatment based on clinical criteria and deciding on treatment eligibility on a case-by-case basis.
- Health care institutions and liver patient organizations should work together with low threshold service providers and representatives from communities affected by HCV and IDU to develop systems of cooperation to ensure the accessibility of confirmatory testing, diagnostics and qualitative evaluation of health conditions, in order to establish comprehensive responses to HCV and increase access to treatment, care and support for IDUs.
- A course on addiction treatment should be included in graduate and post-graduate education for specialists in infectious diseases and for liver specialists.
- HBV and HAV vaccination should be made widely available and should be free of charge and accessible for IDUs as a high-risk group, especially through low threshold services and in prisons.

7.5 Recommendations for low threshold and other health service providers

- Drug-related harm and risk reduction programs need to be diversified and expanded to reach at least 60% coverage. Services should include NEPs and distribution of other injecting equipment; distribution of condoms; free and voluntary HCV testing with pre- and post- counseling; HAV and HBV vaccination; and information and skills building on safer injection and drug use. HIV testing should always be offered to clients with HCV, and HCV testing should be offered to PLWH.
- IDUs should be involved in activities implemented by service providers, especially in outreach activities, peer education, service planning and evaluation.
- Strategies should be developed to reach young, experimenting and occasional injectors in and out of schools through primary and other prevention, including outreach.

- Program monitoring and evaluation should be done to assess programs' efficiency and impact, with the goal of increasing the effectiveness of HCV prevention and management services over time.
- Local, regional and international best practice examples of HCV prevention, testing and treatment for IDUs should be disseminated to health care authorities and policymakers.

7.6 Recommendations for prison administrations

- Prevention services in prisons should be equivalent to those provided in the community and should include education and counseling on HCV, provision of sterile injecting equipment and other measures to address HCV risk-related practices, such as drug use, tattooing, shaving, piercing and anal sex. 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 to reduce the risk of HCV.
- Prisons should develop and implement treatment programs for drug-dependent prisoners, including the use of OST.
- Voluntary testing and counseling on HCV should be widely available in prisons. Voluntary and informed testing should be promoted through counseling to prisoners on admission and upon release.
- Prison medical staff should receive training on issues related to HCV, drug use and human rights and should be educated on how to deliver test results to patients, ensuring data protection and the confidentiality of prisoners. HCV testing and treatment, together with HAV and HBV vaccination, should be viewed as part of health care policy in prisons.
- There should be sustainable funding for treatment of HCV in prison settings as well as for diagnostics, which can help ensure wider access to treatment.

7.7 Recommendations for researchers

- Researchers, scientists and research organizations should cooperate with service providers and health care authorities and jointly seek additional research funding, using national and international resources and programs, such as the EU Community Program for Research and Development, to track HCV incidence and determine the prevalence among IDUs and the impact of HCV on public health, economics, public finance and other areas.
- Cost-effectiveness analysis in Central and Eastern Europe should be conducted to compare (1) early treatment vs. late treatment in IDUs and (2) treatment vs. non-treatment in IDUs, taking into consideration different national health insurance or treatment schemes and epidemiologic trends.
- Closer collaboration is needed with service providers to assess the impact of drug policy on the HCV epidemic and service provision.
- Innovative prevention and treatment strategies need to be developed for HCV and drug dependency (including vaccines, new HCV treatment medications with lower toxicity, fewer side-effects and greater efficacy, and drug treatment methods).

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Appendices

Table 1: Population and estimated number of IDUs in the new EU Member States and neighboring countries

Country	Population (millions)*	Estimated number of IDUs	IDUs as % of total population	Source	Date
Belarus	9.82	41 000–51 000	0.42–0.52	WHO Regional Office for Europe	2004
Bulgaria	7.76	4 000–12 000	0.05–0.15	UN Reference group on HIV prevention among injecting drug users	2003
Czech Republic	10.22	27 000	0.25	2004 Report for the EMCDDA by Reitox National Focal Point	2004
Estonia	1.35	10 000–30 000	0.74–2.22	UN Reference group on HIV prevention among injecting drug users	2003
Hungary	10.11	15 000–25 000	0.15–0.25	UN Reference group on HIV prevention among injecting drug users and Rapid Assessment and Response of Injecting Drug Use in Hungary; <i>Addictologia Hungarica</i> 3-4 (2003): 305-345	2003
Latvia	2.31	9 000–12 000	0.39–0.52	UN Reference group on HIV prevention among injecting drug users	2003
Lithuania	3.44	5 000–11 000	0.15–0.32	WHO Regional Office for Europe	2004
Poland	38.18	77 000–116 000	0.20–0.30	UN Reference group on HIV prevention among injecting drug users	2003
Romania	21.68	90 000–112 000	0.42–0.52	UN Reference group on HIV prevention among injecting drug users	2003
Russia	143.85	1 455 000–2 500 000	1.01–1.74	WHO Regional Office for Europe	2005
Slovakia	5.38	11 000–16 000	0.20–0.30	UN Reference group on HIV prevention among injecting drug users	2003
Slovenia	2.00	5 000	0.25	WHO Regional Office for Europe	2004
Ukraine	47.45	397 000	0.84	UNODC HIV/AIDS Unit, September 2005 (midpoint estimate)	2005
TOTAL	303.55	2 146 000–3 314 000	0.71–1.09		

*Source: World Development Indicators 2006, World Bank

Table 2: HIV prevalence among IDUs in different settings in the new EU Member States and neighboring countries

Country	Geographical scope/Coverage	Year	Setting/population	Sample size	HIV+ (%)
Belarus	National	2003	DTC, hospital	3589	3.7
	• Minsk	2002	NSP, STR	400	23
Bulgaria	• Sofia	2004	DTC, NEP; serum	1203	0.7
Czech Republic	National	2004	PHL, STI, ANT, OHC, PRI, HTC, DTC, LTF, STR; serum, saliva; IDUnk	1609	0
	National	2004	DTC	511	2.7
Estonia	• Tallinn	2004	LTF; dried blood spots	350	54.3
Hungary	National	2003-04	DTC, STR, PHL; serum, saliva	448	0
	• Budapest	1999	DTC, STR	179	2.2
Latvia	National	2002	OHC, ARR	185	14.6
	• Riga and Tukums	2004	NEP, STR, HIV counseling center and outreach workers	205	22
Lithuania	National	2003	DTC, NEP, OHC; serum	1112	2.4
Poland	National	2002	DTC, LTF, STR; serum	2626	6.8
	• Warsaw	2004	DTC, LTF, STR, 5 sites; serum	200	16
Romania		2004	DTC; serum	87	1.1
Russian Federation	National	2002		331 112	3.1
	• St-Petersburg	2001	NEP	252	35.7
	• Togliatti	2001	Community	418	56
Slovenia		2004	NEP, DTC; saliva, serum	476	0.4
Slovakia	• Bratislava	2003	DTC	970	0
Ukraine	National	2002	-	21 472	12.1
	• Donetsk	2003	NEP, STR	252	38.1
	• Odesa	2002	NEP, STR	259	58.3

DTC—Drug Treatment Centers; NEP—Needle and Syringe Exchange Programs; LTF—Low Threshold Facilities; PHL—Public Health Laboratories; STI—STI Clinics; ANT—Antenatal Clinics; OHC—Other Hospital or Clinics; PRI—Prisons; HTC—HIV Testing Centers; STR—Street. IDUnk—IDU not known, prevalence may be too low.

Sources:

For Belarus, Russian Federation, Slovenia, Ukraine—EuroHIV end year report 2003

For other countries—EMCDDA Annual report 2006. Available online at: <http://ar2006.emcdda.europa.eu/>

Table 3: HCV prevalence among IDUs in different settings in the new EU Member States and neighboring countries

Country	Geographical scope	Year	Setting/ Population	Sample size	HCV+ (%)	Source
Belarus	Svetlogorsk region	1996-2001		1792	32	Provided to CEEHRN by respondent in country
Bulgaria	Sofia		NEP, DTC	773	73.9	Vassilev Z et al. (2006). Needle exchange use, sexual risk behavior, and the prevalence of HIV, hepatitis B virus, and hepatitis C virus infections among Bulgarian injection drug users. <i>International Journal of STD & AIDS</i> , 2006 Sep;17(9):621-6
Czech Republic	Karvina region	1998-2001	LTF	308	21.1	Mravčik V et al. (2002). Séroprevalence virových hepatitid typu B a C u injekčních uživatelů drog – projekt IKTERUS [Seroprevalence HBV and HCV in IDUs – IKTERUS Project]. <i>Adiktologie</i> , 2002; 2: 13–35.
	Prague	2000-2002	OST	154	59.1	Wilczek H et al. (2003) [Prevalence of serological markers of viral hepatitis B and hepatitis C in drug-dependent individuals treated at the Drop Methadone Center in Prague]. <i>Cas Lek Cesk</i> , 2003; 142: 240–243.
	Hradec Kralove	1998-2002	DTC	170	22.4	Klusonova H et al. (2004). [Viral hepatitis in users of addictive drugs in the Czech Republic]. <i>Epidemiol Mikrobiol Imunol</i> , 2004; 53: 47–54.
	9 regions	Sep 2002 - Dec 2003	LTF (not on OST or DTC clients)	760	34.97	Zabransky T et al. (2005). Hepatitis C virus infection among injecting drug users in the Czech Republic - prevalence and Associated Factors. <i>European Addiction Research</i> , 403, 2005
Estonia	Tallinn	Jul 2002 -Feb 2003	ACP	63	90.5	Provided to CEEHRN by respondent in country
	Ida Viruma	Jul 2002 -Feb 2004	ACP	37	89.2	Provided to CEEHRN by respondent in country
Hungary		2004	Community	93	13.9	National Center for Epidemiology, 2005
		1995 - 1998	Community; injecting and non-injecting drug users	256	24 - IDU 1.4 – drug users	Osztrogonacz H et al. (2000). Prevalence of chronic viral hepatitis in drug users. <i>Orv Hetil</i> , 2000 Apr 2; 141(14):715-8

Country	Geographical scope	Year	Setting/ Population	Sample size	HCV+ (%)	Source
Lithuania	Vilnius	Jun 2005 -Nov 2005	mobile NEP	681	82	Provided to CEEHRN by respondent in country
	Klaipeda	2001	ACP with NEP	13	100	Provided to CEEHRN by respondent in country
	Klaipeda	2003	ACP with NEP	29	93	Provided by respondent in country
Poland	Regions of Warsaw, Silesia and Lubuskie	2003	street, LTF,DTC	423	55-68	National Institute of Hygiene
Romania	Bucharest	Jan 2005- Nov 2005	LTF	108	44	Provided by respondent in country
	Bucharest	2004	OST	87 (out of 152 clients)	80.45	National Anti-Drug Agency Romania and Public Health Institute
	Bucharest	2004	OST	86 (out of 121 clients)	47.7	National Anti-Drug Agency Romania and Public Health Institute
Russia	St. Petersburg	2000	mobile NEP	2504	66.5	Provided by respondent in country
		2001	mobile NEP	1005	77.6	Provided by respondent in country
		2003	mobile NEP	144	72.2	Provided by respondent in country
	St. Petersburg	2004	ACP	89	85.4	Provided by respondent in country
	St. Petersburg	2005	ACP	342	96.8	Provided by respondent in country
	Togliatti	2001	community	411	87	Rhodes T et al. (2005). Hepatitis C virus infection, HIV co-infection, and associated risk among injecting drug users in Togliatti, Russia. <i>International Journal of STD & AIDS</i> , 2005; 16: 749–754.
	Moscow, Volgograd and Barnaul (Siberia)	2003	community	1473	54-70	Rhodes T et al. (2006). Prevalence of HIV, hepatitis C and syphilis among injecting drug users in Russia: a multi-city study. <i>Addiction</i> , 101, 252–266, 2006
Slovakia	Bratislava	2004	IDUs applying for drug treatment	72	45.8	2005 Report for the EMCDDA by Reitox National Focal Point

Country	Geographical scope	Year	Setting/ Population	Sample size	HCV+ (%)	Source
Slovenia	Maribor		OST	40	40	Baklan Z et al. (2004). Prevalence of HIV, hepatitis B, C and G virus infections among injecting drug users on methadone maintenance treatment in Maribor. <i>Wien Klin Wochenschr.</i> 2004;116 Suppl 2:5-7
Ukraine	Odesa	2002	LTF		78.8	Provided by respondent in country
	Vinnytsya		community	315	74.4	Soldyshev R et al. (2006). <i>Prevalence of hepatitis C among injecting drug users in Vinnitsa, Ukraine.</i> XVI International AIDS Conference, Toronto, Canada. August 13-18 2006 (abstract CDC0224).
	Kharkiv	2004	LTF	450	60.9	Provided by respondent in country

ACP—anonymous consultation point, DTC—drug treatment centers, NEP—needle and syringe exchange program, LTF—low threshold facilities, OST program—substitution treatment program.

Table 4: Number of HIV and AIDS patients with acute/chronic HCV in the new EU Member States and neighboring countries (as of end 2005)

Country	"Reported number of PLWH" (=Cumulative minus the registered deaths)	Number of HIV and AIDS patients seen for care ¹ in 2005	Number of HIV and AIDS patients with acute/chronic hepatitis C (among HIV and AIDS patients seen for care)
Belarus	7 014	5 688	1 552 (27%)
Bulgaria	598	245	22 (9%)
Czech Republic	827	780	260 (33%)
Estonia	5 063	1 800	(app 80%)
Hungary	1 285	641	16 (2%)
Latvia	3 332	2 251	1 364 (61%)
Lithuania	1 100	397	525 (47%) ²
Poland	9 801	5 000-5 400	800-1 200 (16-22%)(est.)
Romania	16 258	7 623	228 (3%) ⁴
Russian Federation	334 158	135 340 ³	71 000 (52%) ⁵
Slovenia	281	161	11 (7%)
Ukraine	88 628	62 888	(77%-80%) ³

¹ Seen for care is defined as patients coming for medical check-up at least once a year

² Lithuania has provided the cumulative number of PLWH diagnosed with HCV

³ Data from Form No. 61 of State Federal Statistic Surveillance for 2005

⁴ Still under evaluation for chronic hepatitis C

⁵ Estimated among those who were seen for care in medical settings in 2005

Source: WHO Regional Office for Europe (2006). Sexually transmitted infections/HIV/AIDS program. WHO/Europe annual survey on HIV/AIDS and HAART. Copenhagen, WHO 2006.

Table 5: HCV incidence in prisons in selected countries of the new EU Member States

Country	Coverage	Dates	Population	Sample size	HCV (%)	Source
Czech Republic	Hradec Kralove	1998-2002	Drug users in prison	144	18.1	Klusonova H et al. (2004). [Viral hepatitis in users of addictive drugs in the Czech Republic]. <i>Epidemiol Mikrobiol Imunol</i> , 2004; 53: 47–54.
Czech Republic		2002	Drug users in prison	1319	52	[Directorate-general of the Czech prison services]. [Results of the seroprevalence examinations in the Czech prisons]. [<i>Czech Prison Services</i>], 2003.
Estonia	Tallinn		IDU, prisoners	122	97.5	Provided to CEEHRN by respondent in country
Estonia		1996	Prisoners	55	81.8	Provided to CEEHRN by respondent in country
Estonia		1999	Prisoners	68	97.1	Provided to CEEHRN by respondent in country
Estonia		2000	Prisoners	114	97.4	Provided to CEEHRN by respondent in country

Table 6: Availability of testing protocols and low threshold testing in the new EU Member States and neighboring countries

Country	Protocols for hepatitis testing?	Free HCV testing for IDUs	HCV testing at NEPs	HCV testing on OST	Use of rapid tests	Is HCV testing available in prisons?*
Belarus	No	Testing recommended by doctor (when suspected due to symptoms or in case of reported «risk behavior»)	No	Not applicable	No	On admission tests for HIV and syphilis offered, but not HCV. HCV testing offered to PLWHA, or when suspected due to symptoms.
Bulgaria	No	Available	Available	Available	No	Testing not provided upon admission and/or release. Testing for HCV, HBV and HAV when suspected due to symptoms
Czech Republic	Yes	At low threshold facilities, upon entrance to drug treatment.	Available	Available	Yes	On admission (not all prisons). Mandatory for all suspected, diagnosed and self-reported drug users; when suspected due to symptoms
Estonia	Yes	Limited, sometimes through local initiatives. Usually available at low threshold facilities, offering HIV testing	Limited	No	Rapid tests used when admitted to Center for Addictive Disorders	Testing not provided upon admission and/or release. Suggested when suspected due to symptom. Special actions - voluntary testing is done among IDUs for relevant research
Hungary	Yes	Limited	Limited	Available	Only during special testing campaigns	Testing not provided upon admission and/or release. Suggested when suspected due to symptoms. Tested for HBV, HCV and HIV when donating blood
Latvia	Yes	Limited	No data	No data	No data	Testing not provided upon admission and/or release.

Country	Protocols for hepatitis testing?	Free HCV testing for IDUs	HCV testing at NEPs	HCV testing on OST	Use of rapid tests	Is HCV testing available in prisons?*
Lithuania	No	Limited. Available in Vilnius at AIDS Center for IDUs referred from Vilnius Center for Addictive Disorders	Limited. Performed when additional grants are provided. In 2005 mobile needle exchange program tested clients for HIV, HBV and HCV in capital Vilnius	In Vilnius, clients of OST programs are referred to AIDS Center for testing once a year, if suspected of infection, can be tested more regularly	Rapid tests used for testing at mobile NEP	Testing not provided upon admission and/or release. Suggested when suspected due to symptoms. Available on request, medically indicated to all people with HIV
Poland	No	When referred by a GP, and in some detoxification centers	No	No	No	Provided in a limited number of prisons on admission; Suggested when suspected due to symptoms.
Romania	No	Limited. Pregnant women can be tested at the Romanian Angel Appeal testing centers	No	Available	Yes	Testing not provided upon admission and/or release. Suggested when suspected due to symptoms and when donating blood (HBV, HCV, HIV testing)
Russia	No	Available with referral from GPs; provided in some low threshold facilities	Limited	Not applicable	No	Testing not provided upon admission and/or release. Usually done if a prisoner is admitted to a medical facility in prison and shows symptoms of HCV
Slovakia	Yes	Available with referral from a GP or at the Center for the Treatment of Drug Dependencies (ID and health insurance required)	Limited. Since mid-2006 provided by NGO Odyseus, in mobile needle exchange unit in Bratislava	Only people registered at the Centre for the Treatment of Drug Dependencies are routinely tested for HCV	No	On admission provided in limited number of prisons. Suggested for all suspected, diagnosed and self-reported drug users; provided upon request

Country	Protocols for hepatitis testing?	Free HCV testing for IDUs	HCV testing at NEPs	HCV testing on OST	Use of rapid tests	Is HCV testing available in prisons?*
Slovenia	Yes	At the Centers for the Prevention and Treatment of Drug Addiction and at the Clinic for Infectious Diseases	Available	Available to all people on drug treatment including OST at least 2 times a year, in case of reported risk behavior	Yes	Suggested when suspected due to symptoms. Provided to PLWHA/tested positive for HIV in prison
Ukraine	Yes	No data	No data	No data	Rapid tests are registered in the country, but are not used yet	Testing not provided upon admission and/or release. Limited, state prison department does not purchase tests at all

Source: CEEHRN survey on HCV among IDUs, 2006 – 2007

* Information about availability of testing on admission and upon release in 8 new EU member states (the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia, Slovenia) obtained through ENDIPP and is published in Weilandt C, Eckert J, Huisman A. (2005) Data collection to develop an inventory of social and health policies, measures and actions concerning drug users in prison in the recently incorporated Member States to the EU (CT.04.P2.329). European Monitoring Centre for Drugs and Drug Addiction, European Network on Drugs and Infections Prevention in Prison, German Medical Association (WIAD).

Note: Availability of testing at needle exchange and OST programs does not indicate the scale of availability of tests, which is usually limited due to the difference in scale of harm reduction services in different countries of the region, and due to the fact that not all NEPs or OST programs have the resources to carry out tests.

For example, in Hungary, where HCV testing is available in NEPs and OST programs, in 2004, only at 21% of low threshold facilities HCV testing was available. Source: Márványkövi Ferenc, Rácz József (2005) Alacsony-köszöbű, droghasználókat ellátó szolgáltatások jellemzői Magyarországon 2004-ben, *Addictologia Hungarica*, L'Harmattan Könyvkiadó és Interdiszciplináris Addiktológiai Fórum, Budapest, 2005.

Table 7: Availability of NEPs and other prevention interventions in communities and prisons in the new EU Member States and neighboring countries

Country	Availability of NEPs: fixed, mobile, peer distribution, pharmacy based	Other injecting equipment distribution at low threshold facilities?	Condoms distribution at low threshold facilities	Trainings on safer injecting at low threshold facilities	Availability of NEPs in prisons	Availability of disinfectants (bleach) in prisons	Condoms distribution in prisons	Trainings on safer injecting in prisons
Belarus	Fixed, mobile	Yes - disinfecting tissues provided at some NEPs, other low threshold facilities	Yes	Only printed information handed out at NEPs	A pilot program since 2003 ended by the end of 2006	Disinfectants available upon request	Yes - in all prisons (funding ensured by GFATM program), in specialized health units + provided by volunteers	In prison where needle program was established information related to safer use is provided
Bulgaria	Fixed, mobile, peer distribution, in pharmacies	Limited	Yes	Yes	No	No	No data	No
Czech Republic	Fixed, mobile, peer distribution, in pharmacies	No data	Yes	Yes	No	No	Available in shops in some prison	Yes
Estonia	Fixed, mobile; 27 government-funded programs; others financed by municipalities	Limited - disinfecting tissues and water (as part of local initiatives)	Yes	No	No	Yes. No guidelines or counseling how to use properly provided	Yes - in specialized health units, in specialized places, through outreach programs	Yes
Hungary	Fixed, mobile, peer distribution, in pharmacies	In 2004 only 1 NEP provided all types of injecting equipment: tourniquet, spray, sterile water, ascorbic acid, vein care ointment, spoon, filter, water container*	Yes. In 2004 38% of low threshold facilities gave out condoms*	Limited	No	No	Available in shops in some prison	No
Latvia	Fixed, mobile	Yes	Yes	No	No	No	Available in prison shops	No

Country	Availability of NEPs: fixed, mobile, peer distribution, pharmacy based	Other injecting equipment distribution at low threshold facilities?	Condoms distribution at low threshold facilities	Trainings on safer injecting at low threshold facilities	Availability of NEPs in prisons	Availability of disinfectants (bleach) in prisons	Condoms distribution in prisons	Trainings on safer injecting in prisons
Lithuania	Fixed, mobile	No	Yes	No data	No	In some prisons. Information/guidelines how to use are also provided	Yes. Free-of-charge (only for long time visits)	No
Poland	Fixed, mobile and peer distribution	Yes	Yes	No	No	No	Yes - distributed in limited number of prisons	No data
Romania	Fixed, mobile	Disinfectants only	Yes	No	No	No	In some prisons available upon release or home leave	No
Russia	Fixed, mobile and peer distribution	Limited	Yes	No	No	No	Limited; usually if prisons has additional grant funding. Condoms usually are provided for long time meetings.	No
Slovakia	Fixed, mobile (most common), peer distribution and some pharmacies sell without a prescription	Yes	Yes	No	No	No	Available in prison shops	No
Slovenia	Fixed, mobile and in pharmacies	Yes, at some NEPs cookers, water, spoons, swabs distributed	Yes	Yes, at drop-in centers (about 5-6 locations)	No	Yes. Information/guidelines how to use also provided	Available for free in some prisons	No
Ukraine	No data	No data	No data	No data	Yes	No data	No data	No data

Source: CEEHRN survey on HCV among IDUs, 2006 – 2007

* Márványkövi Ferenc, Rácz József (2005) Alacsony-köszöbű, droghasználókat ellátó szolgáltatások jellemzői Magyarországon 2004-ben, Addictologia Hungarica, L'Harmattan Könyvkiadó és Interdiszciplináris Addiktológiai Fórum, Budapest, 2005.

Table 8: Availability of OST in communities and prisons in the new EU Member States and neighboring countries

Country	Starting year	Who pays for OST?	Is OST legal in prisons?	Is OST actually provided in prisons?	Criteria for admission to OST program in prisons
Belarus	Not provided	Not applicable	Not applicable	Not applicable	Not applicable
Bulgaria	1995	State, patients	Legal for maintenance	No	Not applicable
Czech Republic	1997 methadone, 2001 buprenorphine	State (for methadone, via annual grant); covered by insurance, which is universal in Czech Rep: social/health insurance pays for service/staff while patient pays for the buprenorphine	Legal for maintenance (pilot project in 2 prison with 20 beds each; targeting males only)	Yes	Being on OST before entering prison
Estonia	1997	State, social/health insurance, GFATM	Legal	No	Being on OST before entering prison, the same as in the community
Hungary	1994 (1992 first semi-legal project)	Social/health insurance	Illegal	No	Not applicable
Latvia	1996	State, patients	Illegal	No	Not applicable
Lithuania	1995	State, social/health insurance, patient	Illegal	No	Not applicable
Poland	1995	Social/health insurance	Legal for maintenance, legal for detoxification	Yes	The same as in the community, must have reserved place in community MMP after discharge from prison
Romania	1999	State, social/health insurance	Legal for maintenance, legal for detoxification	No (methodological guidelines are expected to be drafted (mainly concerning methadone regime inside penitentiaries))	Not applicable
Slovakia	1997	Health insurance, Slovak Antidrug Found co-founds methadone OST through project agreement	Legal for maintenance	No	Not applicable

Country	Starting year	Who pays for OST?	Is OST legal in prisons?	Is OST actually provided in prisons?	Criteria for admission to OST program in prisons
Slovenia	1995	Social/health insurance	Legal for maintenance	Yes	The same as in the community
Ukraine	2003	GFATM or other international project	Not available	No - there is no regulating documents for this	Not applicable

Source: CEEHRN survey on OST, 2006

Table 9: Availability of HAV and HBV vaccination for IDUs in communities and prisons in the new EU Member States and neighboring countries

Country	HAV vaccination targeting drug users in community	HBV vaccination targeting users in community	HAV vaccination targeting drug users in prisons	HBV vaccination targeting drug users in prisons
Belarus	Possible vaccination at cost (30–40 EUR per vaccination)	Possible to get vaccinated in some health care centers (depending on availability of vaccine and motivation of doctor)	No	No
Bulgaria	No	Vaccination at cost	No	Yes
Czech Republic	Provided in some low threshold facilities; vaccination at cost possible	Provided in some low threshold facilities	Yes	Yes. For risk groups, including IDUs
Estonia	No	Vaccination at cost	No	Yes. For convicts and risk groups sentenced to more than 7 months
Hungary	No	One low threshold program provided vaccination in 2004	No	Available on request
Latvia	No	No	No	No
Lithuania	No	No	No	Limited availability in some prisons
Poland	No	No	No	No
Romania	Free vaccination provided by an outreach program for sex workers and IDUs; funds are from international donors (GFATM) and available only in Bucharest	Free vaccination provided by an outreach program for sex workers and IDUs; funds are from international donors (GFATM) and available only in Bucharest	No	No
Russia	No	Limited in some cities, for example in St. Petersburg	No	No
Slovakia	No	Free HBV vaccination is provided upon registration at the Center for the Treatment of Drug Dependencies	No	Vaccination at cost can be provided on request
Slovenia	For risk groups (including IDUs) and on request	For risk groups (including IDUs) and on request	For risk groups and on request	For risk groups and on request.
Ukraine	No	No	No	No

Source: CEEHRN survey on HCV among IDUs, 2006 – 2007

Table 10: Adherence and SVR rates: Results from clinical trials

Author and date	No. and population	SVR	Other comments
Fried et al., 2002	1121; no current IDUs	44% in treatment arm receiving standard IFN and RBV	Registration trial
Manns et al., 2001	1530; no current IDUs	47% in treatment arm receiving standard IFN and RBV	Registration trial
Robaey et al., 2006	Total no. 406; 98 current or former IDUs	IDUs (including methadone maintenance): 46.6% Non-IDUs: 34.6% (not significant after controlling for HCV genotype) Regimen: standard IFN and RBV	24% of IDUs were using drugs during HCV treatment, yet there was no significant difference in compliance or SVR between current/former IDUs vs. non-users; participants were randomized to daily interferon for 8 weeks vs. thrice weekly interferon
Sylvestre, 2005a	76 IDUs on methadone maintenance; the interval of abstinence from illicit drug use varied from 0-18 years	28% Treated with standard IFN and RBV	59% used illicit drugs during HCV treatment; 20% drank alcohol during HCV treatment; 59% had a pre-existing psychiatric condition
Matthews et al., 2005	12 IDUs	50% Treated with standard or PEG- IFN and RBV	Eight of 12 completed >80% of HCV treatment
Cournot et al., 2004	Total no. 425; 116 IDUs	IDUs: 28% Non-IDUs: 21% Treated with standard IFN monotherapy or standard IFN and RBV, depending on protocol at time of treatment initiation	Methadone and buprenorphine also provided
Van Theil et al., 2003	Total no. 120; 60 current or former IDUs	IDUs: 33% Non-IDUs: 37% Regimen was IFN monotherapy (5 million units/day)	Daily interferon injections for at least a year; methadone also provided
Backmund et al., 2001	No. 50 from detoxification program	Overall: 36% Relapsed, returned to drug treatment: 53% No relapse during HCV treatment: 40% Relapsed, no further drug treatment: 24% Regimen was standard IFN or IFN and RBV, depending on protocol at time of treatment initiation	HCV treatment was not discontinued during relapse to active drug use; methadone provided No cases of re-infection

Table 11: HCV treatment guidelines: International practices and who should be treated

Source and date	Recommendation
<p>American Association for the Study of Liver Diseases</p> <p>AASLD Practice Guideline Diagnosis, Management and Treatment of Hepatitis C, 2004</p> <p>Online: http://www.aasld.org/eweb/docs/hepatitisc.pdf#search=%22AASLD%20hepatitis%20C%20Treatment%20Guidelines%22</p>	<p>“Treatment decisions should be individualized, based on the severity of liver disease, the potential of serious side effects, the likelihood of treatment response, and the presence of comorbid conditions.”</p> <p>Characteristics of Persons For Whom Therapy Should be Individualized:</p> <p>“Current users of illicit drugs or alcohol but willing to participate in a substance abuse program (such as a methadone program) or alcohol support program.”</p>
<p>Short Statement of the First European Consensus Conference on the Treatment of Chronic Hepatitis B and C in HIV Co-Infected Patients, March 2005</p> <p>Online: http://www.jhep-elsevier.com/article/PIIS016882780500142X/fulltext#section4</p>	<p>“Active drug use should not be an absolute exclusion criteria since full benefits of HBV and HCV therapy are not compromised when active drug users are successfully retained in treatment. Patients who require treatment should be offered opiate substitution therapy, including heroin maintenance programs, where medically available. If the patient is not ready to stop drug use, any assessment for initiation of HBV or HCV treatment should be made on a case-by-case basis.</p> <p>Substitution therapy as a step towards cessation should be considered. Help provided (e.g. through needle- and syringe-exchange programs) reduces the risk of further re-infection, including parenteral viral transmission.”</p>
<p>Management of Hepatitis C and HIV Coinfection: Clinical protocol for the WHO European Region (2006)</p> <p>Online: http://www.euro.who.int/Document/SHA/HEP_C.pdf</p>	<p>«Efforts must also be made, via multidisciplinary health care services, to increase the applicability and availability of treatment, especially in more vulnerable populations, including but not limited to migrants, IDUs, prisoners, people with psychiatric illnesses and people who consume too much alcohol.» Treatment of patients on substitution therapy should not be deferred and initiation of HCV treatment in active drug users should be considered on a case-by-case basis (also stated in Protocol 5, HIV/AIDS treatment and care for injecting drug users.)</p>

Table 12: SVR to HCV treatment among HIV/HCV co-infected persons (regimen: 48 weeks of PEG IFN and RBV)

Study and source	SVR, overall	SVR, genotype 1	SVR, genotypes 2 and 3
RIBAVIC Carrat et al., 2004	27%	17% (Includes genotype 4)	44% (Includes genotype 5)
ACTG 5071 Chung et al., 2004	27%	14%	73%
APRICOT Torriani et al., 2004	40%	29%	62%

Table 13: HCV treatment guidelines and access to treatment for IDUs in the new EU Member States and neighboring countries

Country	HCV treatment guidelines	Abstinence required	Access to treatment for people on OST	Access to treatment for active IDUs	Guidelines on HIV/HCV co-infection treatment
Belarus	2002 by Minister of Health	Yes. Abstinence term not mentioned	Not mentioned	No. Active drug use is contraindication to treatment	No
Bulgaria	2002 by The Association of Gastroenterology	Yes. Drug abstinence for 6 months required	Not mentioned	No. Active drug use is contraindication to treatment	Yes
Czech Republic	By the Czech Society of Hepatology	Yes. Abstinence term not mentioned	Not mentioned	No. Active drug use is contraindication to treatment	Yes
Estonia	2006 by Society of gastroenterologists and Society of specialists in infectious diseases	Yes. Abstinence term not mentioned	Not mentioned	No. Active drug use is contraindication to treatment	Yes
Hungary	2005 guidelines (expanded by the end of 2006) by Hepatology Section of the Gastroenterological Professional College New guidelines are pending for approval	Yes. Abstinence for 6–12 months required	Not mentioned	No. Active drug use is contraindication to treatment	No
Latvia	Latvian Centre of Infectology approved by the State Medicines Pricing and Reimbursement Agency in 2006	Yes	Not mentioned	No	Yes
Lithuania	2003 by Ministry of Health (updated 2005)	Abstinence term not mentioned	Not mentioned	No. Active drug use is contraindication to treatment	Yes
Poland	No data	No data available	No data available	No data available	No data available

Country	HCV treatment guidelines	Abstinence required	Access to treatment for people on OST	Access to treatment for active IDUs	Guidelines on HIV/HCV co-infection treatment
Romania	1998 by Ministry of Health	Abstinence term not mentioned	Yes	No. Active drug use is contraindication to treatment	Yes
Russia	2006 by Ministry of Health and Social Development		Not mentioned	The order sets the standards of treatment and does not identify inclusion/exclusion groups	No
Slovakia	2004 by Ministry of Health	Yes. Drug abstinence for at least 6 months required	Yes - people stabilized on substitution treatment program can be eligible	No. Active drug use is contraindication to treatment	No data available
Slovenia	2006 by Coordination of Centers for the Prevention and Treatment of Drug Addiction at the Ministry of Health of the Republic of Slovenia	Yes	Yes	Yes. Treatment recommended in cooperation with drug treatment providers for all candidates (active, past or on ST)	No data available
Ukraine	Draft, not adopted yet		Draft guidelines mandate treatment for all HIV+ IDUs before starting antiviral therapy, though OST not mentioned	Not mentioned as contraindication in draft guidelines	No

Source: CEEHRN survey on HCV among IDUs, 2006 – 2007

Table 14: Availability of and reimbursement of HCV diagnostic tests and treatment in the new EU Member States and neighboring countries

Country	Tests used for diagnostics	Reimbursement	Available treatment	Treatment price	Reimbursement	Treatment in prisons	Source of funding for antiviral treatment
Belarus	Confirmatory antibody test, RNA and genotype test, liver biopsy applied if fibrosis or extended liver damage suspected; before starting treatment for people with HCV genotype 1	Antibody and qualitative RNA tests free of charge if referred by GP; quantitative RNA and genotype tests free in exceptional cases* - not covered by health insurance.	IFN + RBV, interferon monotherapy	2 000 - 2500 EUR year long course (price of cheapest drugs registered in Belarus)	Not covered by health insurance. State can cover treatment of IFN monotherapy in number of cases (for children in some regions). Partial coverage by the state - up to 3 first months of treatment, after SVR evaluation a person has to pay for treatment	Antiviral treatment is not provided. Most often symptoms are treated.	
Bulgaria	Confirmatory antibody test, RNA, genotype test/liver biopsy available	Cost of all these tests covered by health insurance	PEG-IFN + RBV, IFN+RBV, IFN monotherapy	20 000 EUR for a 52 weeks course	In 2007 treatment will be reimbursed to 50 people by the State Waiting list for those expected to be put on treatment is available	Most often only symptoms are treated. In theory, antiviral treatment can be provided as in community in case patient has health insurance, however limited in practice due to limited diagnostics in prisons	
Czech Republic	Confirmatory antibody test, RNA and genotype test, liver biopsy; liver biopsy to assess severity of disease, typically part of pre-treatment evaluation	All tests widely used and covered by insurance, whether as component of treatment or just diagnostic tool; available to all citizens	PEG-IFN+RBV	For genotype 1 (approx. 80% of patients), 22 800 EUR per treatment course; for genotype 2 (approx. 20%), 11 300 EUR per treatment course	State/health insurance. Free treatment is available for majority of people with health insurance	Access to antiviral treatment in prisons limited	Insurance

Country	Tests used for diagnostics	Reimbursement	Available treatment	Treatment price	Reimbursement	Treatment in prisons	Source of funding for antiviral treatment
Estonia	Confirmatory antibody test, RNA and genotype test, liver biopsy for people with chronic HCV and before treatment	Cost of all these tests covered by health insurance	PEG-IFN+RBV; IFN mono-therapy.		State/health insurance. Full price covered by the state for people with health insurance	Due to limited funds - practically not available. Most often symptoms are treated	Ministry of Justice.
Hungary	Confirmatory antibody test, RNA and genotype test, liver biopsy most often used before starting treatment	Cost of all these tests covered by health insurance	PEG-IFN + RBV; IFN + RBV, IFN mono-therapy.	Approx. 19 440 EUR	State/health insurance. Full price covered by the state for people with health insurance	In theory should be available in all prisons. Due to limited funds - limited.	prison health care budget for inmates
Latvia	Confirmatory antibody test, RNA and genotype test, liver biopsy	If patient is referred to specialist in infectious diseases/ hepatology by GP, expenses covered by the State	PEG-IFN+RBV, IFN+RBV		State/patient. State covers 75 % of standard treatment with IFN+RBV (through the Health Compulsory Insurance State Agency, a person has to pay remaining 25 %. 75 % of PEG IFN+RBV treatment planned to be covered by the State in 2006 for 80 patients, receiving treatment.	Antiviral treatment is not provide	

Country	Tests used for diagnostics	Reimbursement	Available treatment	Treatment price	Reimbursement	Treatment in prisons	Source of funding for antiviral treatment
Lithuania	Confirmatory antibody test, RNA and genotype test; liver biopsy applied if there no contra-indications	Covered by State Sick Fund through centralized purchase of tests and equipment.	PEG-IFN+RBV; IFN+RBV; IFN mono-therapy.		Treatment price is covered from State Sick-Fund, through centralized purchase of medicines (then 85% of drugs are provided by one company, 15% by other companies producing antiviral drugs. There is a waiting list for those for whom treatment is indicated	In theory should be available in all prisons since 2003. Complicated to start antiviral treatment because liver biopsy should be done and it is done not in prisons. Following tests a person has to sign an agreement, which states that if patient will use drugs, the treatment will be cancelled.	Ministry of Internal Affairs. Limited funding and the source is not permanent, previously funding came from Penitentiary institutions' health centers and National HIV/AIDS Program, this year from STD program
Poland	No data	No data	PEG-IFN + RBV		State/health insurance	Has to be provided in all prisons, however most people needing it is not treated	
Romania	Confirmatory antibody test, RNA and genotype test	No data	IFN+RBV	From 4 800 to 12 000 per treatment course, depending length of course	State/health insurance. Fully covered by state for people with health insurance through the HCV national program	Antiviral treatment is not provide	

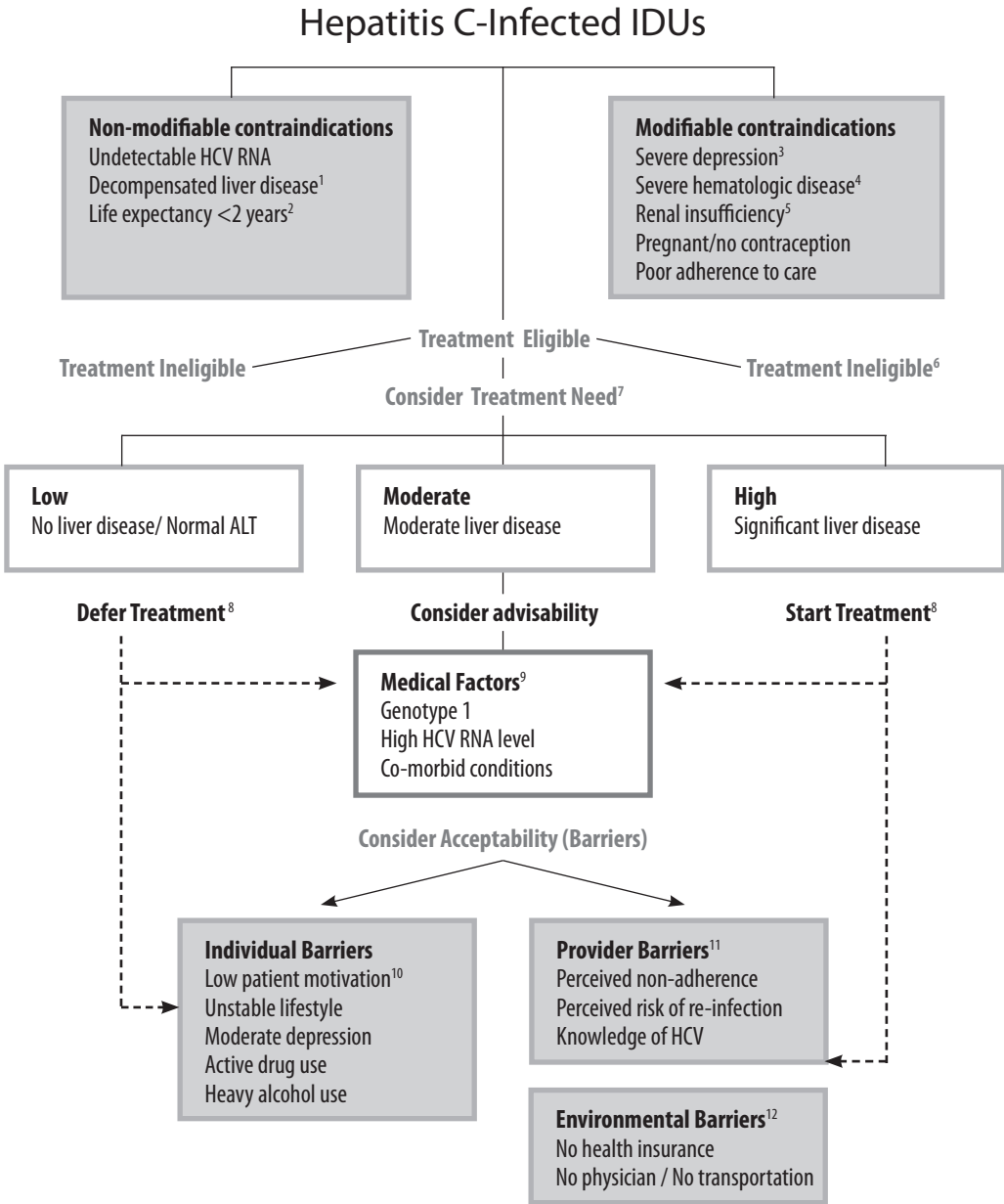
Country	Tests used for diagnostics	Reimbursement	Available treatment	Treatment price	Reimbursement	Treatment in prisons	Source of funding for antiviral treatment
Russia	Confirmatory antibody test, RNA and genotype test; liver biopsy limited except among military conscripts	Antibody test is free-of-charge for people with health insurance; a person pays for all other tests	PEG-IFN + RBV; IFN + RBV	PEG-IFN+RBV (48 weeks) 22 244 EUR; IFN+RBV (54 weeks) 2 561 EUR	Not covered by health insurance. Free treatment can be provided to people with disablement. This means PLWHA with HCV (registered in AIDS Centre) can receive free treatment in Moscow and is covered by municipality.	In general antiviral treatment is not provided. Some exceptional examples of treatment, appointed by visiting doctors	
Slovakia	Confirmatory test, RNA, genotype test, insurance company requires liver biopsy necessary for diagnosis	Diagnostics partially paid by insurance companies and partly by pharmaceutical companies. In 2006: fully paid by pharmaceutical companies	PEG-IFN+RBV	24 weeks: 7216 EUR; 48 weeks: 14 433 EUR	State/health insurance. Treatment can be fully covered for people with history of drug use if they demonstrate that they have abstained from drug use for at least 6 months, confirmed by a specialist and supported by toxicological evidence (health insurance required)	Yes. The same procedures as outside prison are applied — after 6 month abstinence in the prison, they can begin the treatment, after approval of the insurance company. All prisoners automatically are insured on admission to prison	Insurance companies
Slovenia	Anti-HCV and HCV-RNA, genotype test, liver biopsy	Cost of all these tests covered by health insurance	PEG-IFN+RBV		State/health insurance.	Yes	Ministry of Justice
Ukraine	HCV-RNA, genotype test, liver biopsy	Paid for by the patient	PEG-IFN+RBV		Patients	Antiviral treatment is not provided	Not applicable

Comments:

*Belarus: Free quantitative RNA and genotype tests available if hospital decides to cover them from internal resources (free genotype test in children's hospital in Minsk; RNA test in infectious disease hospital in Gomelsk). In reality, genotype of infection in most IDUs unknown, liver biopsy usually is not carried out.

Source: CEEHRN survey on HCV among IDUs, 2006 – 2007

Figure 1: Determination of HCV treatment eligibility, advisability and acceptability*



¹ Child-Turcotte-Pugh score >6.

² Examples include individuals with severe congestive heart failure or metastatic cancer.

³ This refers to severe depression with suicidal ideation.

⁴ One that cannot be medically corrected; neutrophil count <1000 cells/mm³, hemoglobin <10.5 g/dl, or platelet count <50,000/mm³.

⁵ Defined as serum creatinine >1.5 times the upper limit of normal.

⁶ Because these contraindications are potentially modifiable, individuals have the potential to shift in and out of eligibility.

- ⁷ These are not absolutes. Treatment decisions need to take additional factors into account.
- ⁸ Treatment need is determined on the basis of liver biopsy [no liver disease is stage 0 fibrosis (modified Ishak), moderate or mild disease is stage 1-2, significant liver disease is \geq stage 3 fibrosis but not end-stage liver disease].
- ⁹ Medical factors are all likely to decrease the likelihood of treatment response/success, but none would preclude treatment.
- ¹⁰ Individual barriers are all likely to decrease the acceptability of treatment to the patient, and may negatively impact adherence and treatment success.
- ¹¹ Provider barriers will decrease the likelihood that a provider will prescribe HCV treatment to an IDU.
- ¹² Environmental barriers will decrease access to therapy for IDU.

Source: Mehta S, Thomas D, Sulkowski M et al. (2005). A framework for understanding factors that affect access and utilization of treatment for hepatitis C virus infection among HCV-mono-infected and HIV/HCV-co-infected injection drug users. *AIDS*. 2005 Oct;19 Suppl 3:S179-S189.

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