

EURASIAN HARM REDUCTION NETWORK  
CORRELATION PROJECT

# Hepatitis C

**transmission  
and injecting  
drug use: harm reduction  
responses**



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De Regenboog



Groep



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June 2010

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# Abbreviations

ACMD	Advisory Council on Misuse of Drugs
ACS	Amsterdam Cohort Study
AIDS	Auto immunodeficiency syndrome
ARUD	Arbeitsgemeinschaft für risikoarmen Umgang mit Drogen (Association for Risk Reduction in the Use of Drugs)
BBA	Be Blood Aware
BBV	Blood borne virus
CEECA	Central and Eastern Europe and Central Asia
DCR	Drugs Consumption Room
EECA	Eastern Europe and Central Asia
EHRN	Eurasian Harm Reduction Network
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
EU	European Union
GP	General Practitioner
HAV	Hepatitis A virus
HBV	Hepatitis B virus
HCV	Hepatitis C virus
HCV RNA	Hepatitis C virus-ribonucleic acid
HIV	Human immunodeficiency virus
IDU	Injecting drug user (active or former)
IHRA	International Harm Reduction Association
NHS	National Health Service
ÖGABS	Austrian Association for the Medically Assisted Treatment of Addiction
ÖÄK	Österreichische Ärztekammer (Austrian Medical Chamber)
OSI	Open Society Institute
OST	Opioid substitution therapy
PIEDs	Performance and image enhancing drugs
PNEX	Pharmacy Needle Exchange
QUZ	Interdisciplinary Quality Circles
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly
UNODC	United Nations Office on Drugs and Crime
WHO	World Health Organization



# Executive Summary

Transmitted through the sharing of needles, syringes and, unlike HIV, other injecting-related equipment, hepatitis C is the most common infectious disease among people who inject drugs.<sup>1</sup> On average 60% of injecting drug users (IDUs) are estimated to have hepatitis C in Europe and in several countries the vast majority, over 90%, of people who inject drugs are believed to be living with hepatitis C.<sup>2</sup> While the HIV epidemic is stabilizing overall across the EU, hepatitis C is increasingly prevalent and disproportionately affects drug users.<sup>3</sup>

This report outlines interventions for tackling hepatitis C in IDU populations in Europe and the surrounding area. These approaches are detailed in the context of the major common challenges faced across the region in addressing hepatitis C in IDU populations:

- Insufficient political will and leadership;
- Low levels of understanding of hepatitis C;
- Marginalization and stigmatization of drug using communities and of hepatitis C;
- A lack of standardized and well monitored disease surveillance;
- Inadequate access to hepatitis C prevention, diagnosis, treatment and care services for IDU populations;
- The high cost, long-term nature and side-effects associated with hepatitis C treatment; and
- Insufficient cooperation between specialists working with risk groups.

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1 Eurasian Harm Reduction Network (2007b)

2 Cook and Kanaef (2008)

3 European Monitoring Centre for Drugs and Drug Addiction (2009)

This publication includes examples of interventions focused on awareness, prevention, treatment and care. They illustrate a range of approaches to tackling hepatitis C among IDUs, particularly in the context of the major common challenges facing the region today. Based on the insights of these interventions as well as the issues that each is working to address, the Correlation Network concludes that while there are many barriers to delivering hepatitis C prevention, diagnosis, care and support services to injecting drug users, these interventions demonstrate that through effective service provision these can be reduced and, in many cases, removed. Models of how this can be achieved are increasingly numerous and varied, and much can be learned from, and achieved through, working together. The Correlation Network recommends that this is approached at both regional and national level, by governments, civil society, and by people with direct experience of hepatitis C and injecting drug use. In particular, the Correlation Network recommends that:

- Governments and policy-makers should develop national hepatitis C frameworks to ensure that this received the requisite attention for all members of society;
- Governments and policy-makers should develop national treatment standards and protocols where these are not in place, working in partnership with health care professionals, drug treatment specialists and affected communities;
- International and intergovernmental organizations and donor agencies should assure equal access to hepatitis C treatment for all groups including socially marginalized groups such as drug users;
- International organizations and agencies should significantly improve the surveillance and monitoring of the burden of disease associated with hepatitis C;
- WHO, in light of the resolution at the 63<sup>rd</sup> World health Assembly, should demonstrate leadership for global strategies to reduce pricing for hepatitis C treatment and provide assistance for the development of national protocols on treatment quality and access and hepatitis policy framework;
- Healthcare professionals should increase cooperation and knowledge sharing in building a comprehensive approach to hepatitis C;
- Healthcare professionals should rely only on scientifically proven evidence when determining patients' treatment and care;

- Healthcare professionals include affected communities into decision making, advocacy work and service provision;
- Civil society organizations should advocate for the development of the national programs on hepatitis C treatment, and call for reviews of national legislation and the development of national treatment guidelines;
- Civil society organizations' should use their expertise and experience to inform government policy-making and effective partnerships will need to be developed and maintained to inform this work wherever possible.



## Section

# Introduction and Overview

## 1.1. Hepatitis C and injecting drug use in Europe

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Although precise prevalence data is often unavailable, the World Health Organization (WHO) estimates that 130 – 170 million people across the world are currently living with chronic hepatitis C and a further 2 million are infected with the hepatitis C virus each year.<sup>1</sup> Other estimates put the figures even higher, indicating 140 - 200 million people living with hepatitis C<sup>2</sup> and 4 million new infections occurring each year.<sup>3</sup> Up to 90% of these infections occur due to injecting drugs.<sup>4</sup>

Transmitted through the sharing of needles, syringes and, unlike HIV, other injecting-related equipment, hepatitis C is the most common infectious disease among people who inject drugs.<sup>5</sup> Hepatitis C prevalence among IDUs has been found at rates of over 50% in forty-nine countries or territories across the world.<sup>6</sup> In several countries, including EU countries such as Estonia, Lithuania and Luxembourg the vast majority of people who inject drugs are believed to be living with hepatitis C.<sup>7</sup> While the HIV epidemic is stabilizing overall across the EU, hepatitis C is increasingly prevalent and disproportionately affects drug users.<sup>8</sup>

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1 World Health Organization (2009)

2 Global Burden of Hepatitis C Working Group (2004)

3 Hoover (2009)

4 Hellard et al. (2009)

5 Eurasian Harm Reduction Network (2007b)

6 Aceijas and Rhodes (2007)

7 Cook and Kanaef (2008)

8 European Monitoring Centre for Drugs and Drug Addiction (2009)

The estimated prevalence of hepatitis C among IDU populations in Europe in 2006-7 ranged from approximately 18% to approximately 95%, with half of countries reporting levels in excess of 40%.<sup>9</sup> Even in countries with low HIV prevalence, less than 1%, among IDUs hepatitis C levels vary from 20-25% (Czech Republic, Hungary, Slovenia) to 40-75% (Greece, Croatia).<sup>10</sup>

As symptoms of chronic hepatitis C infection often do not appear for several years, many people are not aware that they have the virus. A recent study across several European countries found that only 10%-40% of people with hepatitis C in Europe are likely to be aware of their infection.<sup>11</sup> 18% of countries in the WHO European region have no free testing provision for any citizens.<sup>12</sup> When chronic hepatitis C is left untreated its impact can be very severe and today it is the leading cause of liver cancer and liver transplants in Europe.<sup>13</sup> Still there is no government funding for treatment in 25% of countries in the WHO European region.<sup>14</sup> Liver disease resulting from hepatitis C is estimated to cause 350,000 deaths worldwide each year.<sup>15</sup>

Recent studies by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) also show a wide range of prevalence levels among injecting drug users under 25 years and those injecting for less than 2 years, suggesting that many injectors contract the virus early in their injecting career and there is therefore only a small window to initiate effective HCV prevention measures.<sup>16</sup> Moreover, there is increasing evidence to indicate that hepatitis C is more difficult to treat successfully in longer-term cases, and therefore that identifying and treating the disease early improves treatment outcomes.<sup>17</sup> Early engagement of IDUs with awareness and testing interventions is therefore likely to be particularly beneficial.

An increasingly clear challenge, especially in Eastern Europe where there is an extensive HIV epidemic, is addressing HIV-HCV coinfection. Coinfection reduces the likelihood of

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9 European Monitoring Centre for Drugs and Drug Addiction (2009)

10 European Monitoring Centre for Drugs and Drug Addiction (2009)

11 Merkinaite et al. (2008)

12 Reid (2010)

13 Hoover (2009)

14 Reid (2010)

15 World Health Organization (2009).

16 European Monitoring Centre for Drugs and Drug Addiction (2009)

17 Hellard et al. (2009)

recovery from acute HCV, reduces the effectiveness of existing hepatitis C treatment, and accelerates the progression of hepatitis C to liver disease.<sup>18</sup> End-stage liver disease caused by hepatitis C coinfection has become one of the leading causes of death among people living with HIV and AIDS in Europe; a stark change in the epidemiology of HIV/AIDS-related deaths in the region.<sup>19</sup> Approximately 10 million people are living with chronic hepatitis C in former Soviet Union countries.<sup>20</sup> In Russia an estimated 90% of the country's 2 million IDUs have hepatitis C while in Ukraine between 70 and 90% of estimated 400,000 IDUs have hepatitis C.<sup>21</sup> In both countries up to 95% of people with HIV are coinfecting with hepatitis C as the majority have acquired these viruses through injecting drugs.<sup>22</sup>

The considerable and increasing burden of hepatitis C across Europe is rarely reflected in awareness or attention to the issue. Many persistent challenges exist to implementing effective prevention, diagnosis, treatment and care systems, particularly for IDU populations. Although many of these are specific to individual countries, there are also a number of issues common across the region. These include:

- A widespread lack of awareness and understanding of hepatitis, its causes and consequences, among governments and policy-makers, and as a result insufficient attention, political will and leadership at international, regional and national levels;
- A lack of standardized and well monitored disease surveillance for hepatitis C. This is often in addition to a lack of monitoring of injecting drug use;
- Widespread marginalization of drug using communities and the services they need, as well as stigmatization of this population and of hepatitis C;
- Low levels of understanding of hepatitis C, including its transmission dynamics, risk factors and, in particular, prevention measures for high risk populations such as IDUs;
- Inadequate access to hepatitis C prevention, diagnosis, treatment and care services for IDU populations;

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18 Eurasian Harm Reduction Network (2007)

19 Bica et al. (2001).

20 Hoover (2009)

21 International Harm Reduction Association (2008)

22 Aceijas and Rhodes (2007)

- Existing treatment, where it is available, is high cost and requires specialist facilities, long-term patient engagement and can have severe side effects. This increases the likelihood of non-compliance and the reluctance of people with hepatitis C to undergo treatment;
- An insufficient level of knowledge of treatment standards, and of cooperation between specialists, including primary care, infectious disease and drug treatment specialists, resulting in hepatitis C infected persons failing to complete the diagnostic, referral, treatment and care pathway.



## 1.2. Key issues and challenges

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### 1.2.1. Political will and leadership

Injecting drug use is rarely a prominent issue on national, or regional or international, agendas. This is particularly the case in the public health context, and conditions such as hepatitis C which are largely perceived to be limited to the IDU population rarely obtain the priority that would be afforded to a similar disease that affected less marginalized groups. Insufficient political will and leadership is therefore a very significant problem across almost all EU Countries.

Although the great majority of governments in Europe assert that they consider viral hepatitis an urgent public health issue,<sup>23</sup> studies of national policy and services in Central and Eastern parts of the region have found that strategies for addressing hepatitis nationally, in community settings and/or in prisons, both of which significantly impact upon the degree to which IDUs are able to access services, are rare.<sup>24</sup>

Some progress is being made, however. At the international level, in May 2010 a resolution on viral hepatitis (hepatitis A to E) was adopted at the 63rd session of the World Health Assembly. This calls on the WHO to develop a comprehensive approach to the prevention and control of viral hepatitis, providing leadership as well as potential technical support to governments where it is needed. Additionally in 2007 the European Parliament adopted a written declaration on hepatitis C. This calls on the European Commission and Council to (1) recognize hepatitis C as an urgent public health issue; (2) identify priority actions in programs of future Council presidencies; and (3) adopt a Council recommendation on hepatitis C screening, ensuring early diagnosis and wider access to treatment and care. While the recommendations are yet to be implemented, this declaration represented the first official acknowledgement of the issue by policymakers at the European level.

Some national governments have also made significant strides in this area. Scotland, most prominently, has developed a comprehensive national strategy in recognition of hepatitis C as "one of the most serious and significant public health risks of our

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23 Reid, (2010)

24 Reid, (2010); Eurasian Harm Reduction Network (2007B)

generation.”<sup>25</sup> 24,000 people are estimated to be active injecting drug users in Scotland<sup>26</sup> and a total of 50,000 of the 5m population are believed to have hepatitis C.<sup>27</sup> Scotland’s Hepatitis C Action Plan, which has been implemented in 2 phases since 2006, offers a framework for enhanced and equitable service provision across the HCV care pathway. Initially focused on prevention and improving disease surveillance mechanisms to fully understand the problem, the second phase is now also working towards improving and increasing treatment and care services.<sup>28</sup>

Few countries, however, have developed this level of comprehensive response. This is likely to significantly impact upon prevention, diagnosis, and treatment and care service provision and funding as well as the coordination and integration of IDU, hepatitis C and related services.

### **1.2.2. Prevention, diagnosis, treatment and care**

In addition to a need for greater attention at policy and planning level, a number of additional challenges and issues to addressing hepatitis C in IDUs are commonly faced. These exist across prevention, diagnosis and care services and are closely interlinked with each other. They are also related to, and often stem from, the lack of national-level attention afforded to hepatitis C and to wider harms associated with injecting drug use.

There are many challenges to delivering interventions for IDUs as these populations are often reluctant to engage with services. Often this is linked to the stigma and discrimination associated with both drug use and hepatitis C. Persistent stigma and discrimination of drug users and policies criminalizing them has been found to increase marginalization of these people from society, discouraging them from seeking treatment and from accessing harm reduction services.<sup>29</sup> Engagement of the degree required for successful hepatitis C treatment is often difficult to maintain over the long term and additional problems faced, such as unstable financial and housing situations and mental health problems, further exacerbate the challenges common to all with hepatitis C.

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25 Chisolm (2004)

26 2006 data. Hay (2009)

27 Scottish Government (2008)

28 Scottish Government (2008)

29 See Reuter (2009); UNODC (2008); Stuijke et al. (2009)

In many areas the monitoring and disease surveillance that should both motivate and inform increased action in this area, as well as drug use and other related issues, are insufficient or wholly unavailable. No prevalence estimates for hepatitis C are available for 17% of WHO European region countries and 35% do not include chronic hepatitis in disease surveillance systems.<sup>30</sup> Awareness of hepatitis C is therefore low, among policy makers and practitioners as well as the general public and often among those at highest risk.

While effective treatment for HCV does exist the current cost of treatment is very high. Prevention measures could mitigate the need for this expenditure considerably. Awareness raising work, a key component of this, has been funded by less than half of European governments, however, despite insufficient knowledge and awareness of blood borne viruses in most populations.<sup>31</sup>

No government funding for testing or treatment is available in any low or lower middle income country in the WHO European Region, and no provision for free testing exists in almost one in five of these.<sup>32</sup> Screening IDUs for infection and offering combination antiviral therapy has, however, been shown to be cost effective, improve quality of life and extend life expectancy.<sup>33</sup>

It is estimated that over two thirds of the average treatment costs can be compensated for through avoiding the costs of liver disease and related complications.<sup>34</sup> However, the lack of generic alternatives to pegylated interferon means that a standard 48-week course of treatment for HCV infection is extremely costly even in EU countries. This totals 13,000 EUR in Germany, 14,000 EUR in Estonia and more in Eastern Europe.<sup>35</sup> One study examining future costs of treating drug-related HCV, HBV and HIV infections in 10 EU countries has estimated the cost at EUR 1.89 billion per year, with HCV accounting for almost 40% of this expenditure.<sup>36</sup>

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30 Reid (2010)

31 Reid (2010)

32 Reid (2010)

33 Jager et al. (2004)

34 Jager et al. (2004)

35 Hoover (2009).

36 The countries are Belgium, Denmark, France, Germany, Greece, Italy, the Netherlands, Portugal, Spain, the UK. Jager et al (2004)

Additionally, even where treatment is available access is often proscribed or restricted for active IDUs and some also extend this to people in opioid substitution therapy (OST). A number of countries require abstinence for 6 months to 1 year (Bulgaria, Hungary, and Slovakia) or 1-2 years (Finland).

Particularly where people face comorbidities such as injecting drug use and mental and physical health problems it is very challenging to maintain the degree of engagement needed to address hepatitis C. In many instances these difficulties are exacerbated by a lack of coordination and collaboration across services. Comprehensive understanding of hepatitis C is often lacking in healthcare providers, most importantly those who work with IDUs. People undergoing OST or accessing needle exchanges may therefore not be advised or referred to be tested for hepatitis, for example. This, as is the case in many other contexts, misses a valuable opportunity for awareness raising and health promotion.

### 1.3. Responding to hepatitis C: examples of good practice

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The examples included in this report were gathered through civil society organizations operating across the European Union (EU) and beyond. Following a large scale call for abstracts in January 2010, members of the Correlation Network initially evaluated each submission according to a set of pre-defined criteria: originality, cost effectiveness, user engagement, and its replicability and scalability within the European context.

Following the first selection, members of the Correlation Network then reconsidered the shortlisted abstracts in the context of the major common challenges faced in addressing hepatitis C among injecting drug users across all countries in the region as identified by the network and outlined in section 1.2.1 and 1.2.2: insufficient political will and leadership; low levels of understanding of hepatitis C; marginalization and stigmatization of drug using communities and of hepatitis C; a lack of standardized and well monitored disease surveillance; inadequate access to hepatitis C prevention, diagnosis, treatment and care services for IDU populations; the high cost, long-term nature and side-effects associated with hepatitis C treatment; and insufficient cooperation between specialists working with risk groups.

This publication includes examples of interventions focused on awareness, prevention, treatment and care. While there is sufficient scientific data on the effectiveness of treatment, including among people who may be injecting drugs,<sup>37</sup> there is significantly less evidence of what works in prevention. This is largely due to: (1) the highly infectious nature of the virus (2) the possibility of re-infection, and (3) the likelihood that most harm reduction services will have contact with drug users who already have hepatitis.

In consequence, while outcomes data have been included where available, the interventions described in this report were not selected as being the 'most effective' approaches. There is not yet a sufficient evidence base to measure this in a meaningful or comparable way. Many of the interventions discussed in this report are also similar to other interventions underway across the region, each tailored to the unique context of the community or country. The interventions discussed are therefore intended not as blueprints for service design but to illustrate the diverse ways in which prevention, diagnosis, treatment and care can be managed and delivered from grassroots work to policy level across Europe.

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37 Cournot et al. (2004); Sylvestre (2005); Matthews et al. (2005); Robaey et al. (2006)

Across the European region, many diverse interventions have been developed for reducing hepatitis C and related harms in IDU populations. In the context of this report IDU, or injecting drug user, refers both to people who continue to inject (active IDUs) and former IDUs unless otherwise specified. This publication sets out eight examples of these, each of which focuses upon a different stage and approach to tackling this issue. They are intended to provide an insight for those involved in developing policies and interventions to reduce the incidence of hepatitis C and to support IDUs who are already infected to access testing, treatment and care.

Each example describes the context in which the intervention is delivered, and how this related to wider regional challenges. A short conclusion at the end of each case highlights the main points and contribution such an intervention is likely to make to tackling hepatitis C in IDU populations. Following this, at the end of the report we conclude the overarching themes common to all of the interventions discussed and recommend actions through which HCV prevention, diagnosis, treatment and care of among IDUs might be improved.







## Section 2

# Hepatitis C prevention and diagnosis

### 2.1. Increasing public awareness of blood borne viruses in the United Kingdom

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According to the UK Health Protection Agency 2009 report on hepatitis C, approximately 142,000 people aged 15-59 were living with chronic hepatitis C in England and Wales in 2003, in addition to 39,000 in Scotland and 4,000 in Northern Ireland. The predominant risk factor for HCV infection in all four countries is injecting drug use.

Evidence from across Europe has shown that hepatitis C is often contracted within a year or less of a person beginning to inject drugs.<sup>38</sup> Additionally, due to the highly infectious nature of the virus, in many instances hepatitis C is contracted by people who are not regular injection drug users but have injected only a few times.<sup>39</sup>

Be Blood Aware is a campaign to raise awareness among the general public as well as certain target groups about hepatitis and HIV. The campaign was developed following a series of surveys and workshops undertaken by the UK Hepatitis C Resource Centre which is run by Mainliners, a UK-based civil society organization that works across England, Scotland, Wales and Northern Ireland.

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38 European Monitoring Centre for Drugs and Drug Addiction (2009).

39 European Monitoring Centre for Drugs and Drug Addiction (2009).

The results of pre-project research had signaled a profound and widespread need for a more targeted approach to the delivery of essential information about blood borne viruses, particularly to groups considered at risk of infection. This was especially evident among young people aged 16–24 who, while they may have some understanding of the consequences of the risks of sexual behavior as it pertained to HIV or other sexually transmitted infections, rarely had any knowledge of hepatitis C. The campaign was therefore intended to reduce risk behavior through educating people about the risks they may be exposed to before this occurs.

The Be Blood Aware campaign was designed to approach blood borne viruses from the 'blood' angle. It seeks to emphasize that because the route of transmission – blood – is common to all, many people may needlessly be putting themselves at risk. While, for example, awareness of the risks of sharing needles is relatively widespread those associated with sharing injecting-related equipment, with tattooing in unlicensed premises, or with sharing notes for snorting drugs are much less well known. People may therefore be inadvertently exposing themselves to hepatitis C and other blood borne viruses.

Be Blood Aware was designed for use as a simple and concise direct intervention tool. This focuses on three areas: assessing the individual's baseline knowledge of blood borne viruses; highlighting all major risk activities; and, as appropriate to each context, devising ways in which different risk factors can be avoided or minimized.

A particular strength of this tool is its adaptability; it relies on short-term, direct relationships between the person delivering the intervention and the person participating in it, allowing an opportunity to explore risk factors particular to that individual and to develop personalized ways to address these. Over 1,200 people participated in the Be Blood Aware tool in 2008/2009 at a wide range of occasions including education and health events and music festivals.

The program helps break down the myths, stigma and inaccuracies surrounding hepatitis C among groups who are likely to be particularly vulnerable to misinformation. By offering practical, face-to-face advice, it helps personalize the risk factors that each individual faces.

With the emphasis on awareness for all, through a focus on blood, this intervention builds people's knowledge and understanding of hepatitis C and other blood borne viruses. It also promotes testing and counseling based on individual factors, and provides accurate

information on HCV to reduce the stigmatization of the virus itself and associated risk behaviors.

The flexibility of this approach has also enabled it to be replicated and delivered by former participants, offering an excellent opportunity for peer education and support. With training, younger people have delivered it directly and have assisted with adapting the campaign to social media sites such as Facebook.

The high incidence of hepatitis C in recently initiated injecting drug users means that early intervention is paramount to reducing infection rates. Disseminating prevention messages prior to exposure to major risk factors can therefore greatly contribute towards reducing the spread of HCV and other blood borne viruses. In addition, bringing the issue to the attention of the general public assists in tackling the stigma and discrimination that is often associated with these viruses. Doing this through a peer to peer model can also both reduce the resources, human and financial, required for implementation and sustainability of this type of intervention and reinforce the weight and legitimacy of prevention messages.

**For further information see Mainliners website:**

[www.mainliners.org.uk](http://www.mainliners.org.uk)



## 2.2. Increasing detection of viral hepatitis in Germany

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As opioid substitution therapy (OST) requires regular and close contact between patient and doctor, this can provide an excellent opportunity to engage people with wider medical services including hepatitis A and B vaccination, hepatitis C testing and, if required, treatment. However, in many instances this is not undertaken and, as is the case overall with surveillance of viral hepatitis, data relating to whether, when and where this is undertaken is often not available.

Across Europe at least 60% of people with HCV are believed to be unaware of their infection, and in Germany the rate is especially high, estimated at 90%.<sup>40</sup> A total of 6,195 cases of hepatitis C, equating to an incidence of 7.5 per 100,000 people, were reported in Germany in 2008.<sup>41</sup> As is seen across Europe, the predominant risk factor for hepatitis C in Germany is injecting drug use and this was reported in 36% of these cases. More than 50% of IDUs are believed to be infected with hepatitis C in the country.<sup>42</sup>

While the majority of young people in Germany are immunized against hepatitis B, older groups, and at least one third of younger people, remain at risk of infection.<sup>43</sup> An estimated 9% of all injecting drug users in Germany are infected with hepatitis B.<sup>44</sup> Coinfection of hepatitis C with either hepatitis A or hepatitis B poses significant additional challenges to treatment and can lead to more severe liver disease and a higher likelihood of progression to liver cancer.

The Deutsche AIDS-Hilfe e.V. (German AIDS Foundation), working with drug and HIV/AIDS organizations and self-help groups, began gathering data on testing for viral hepatitis and vaccination for hepatitis A and B among people in OST in 2008. The project was initiated in response to anecdotal evidence suggesting that prevention, including vaccination, as well as testing and treatment work was often not being undertaken in OST services, and to the absence of surveillance of this at that time.

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40 Merkinaite et al. (2008)

41 Reitox National Focal Point (2009)

42 Reitox National Focal Point (2009)

43 Ringwalda et al. (2006)

44 Reitox National Focal Point (2009)

The aim of the study was to obtain information on the implementation of HCV testing and on vaccination rates for HAV and HBV among drug users in the framework of substitution therapy. Over a period of one year 534 people were surveyed in 18 cities across Germany using a standardized questionnaire which examined access to hepatitis testing and vaccination.

57% of respondents indicated that they had not been tested for hepatitis C at any time during substitution therapy. For a further 15% the interval between tests had been at least two years. Only 26% of respondents reported that they had been tested every 6 to 12 months. Approximately two thirds of respondents reported not having been vaccinated for hepatitis B and over 70% had not been vaccinated for hepatitis A.

These results concurred with anecdotal evidence gathered from patients and practitioners that overall access to testing and treatment among people receiving substitution therapy was low. The results of the survey also helped to establish that the majority of contact for people in OST was with assistants, while that with physicians was often relatively limited. Patients in this context often lacked self-confidence and also rarely had sufficient knowledge of hepatitis A, B and C; most were therefore unlikely to request tests or vaccinations.

The results indicated a clear gap in service provision and a resulting missed opportunity to disseminate information, prevent further infection and initiate treatment if required. Much of this appeared to result from a lack of awareness among practitioners of the high prevalence rates of hepatitis A, B, and C among drug users and the ways in which engagement with substitution services may provide an opportune platform for detection, prevention and treatment.

In light of the results of the study several programs have been developed to raise awareness among addiction specialists, as well as those being treated, of the need for ongoing hepatitis testing and for hepatitis A and B vaccination. Posters and fliers providing information on hepatitis and HIV/AIDS have been distributed to more than 700 addiction specialists and a series of further tools have been developed to inform practitioners and patients of the issue and to maintain this awareness over the long term.

Despite increasing availability of testing in many parts of the EU most people who have hepatitis C are unaware that they are infected.<sup>45</sup> In light of the high prevalence of viral hepatitis among injecting drug users, services used by active and former IDUs provide an important opportunity to engage those most at risk, to raise awareness and promote testing, HBV vaccination, and treatment. This requires improved awareness of viral hepatitis among professionals working in OST services, a willingness and ability among these practitioners to engage with this issue, and improved integration of OST with wider healthcare services.

The research carried out by The Deutsche AIDS-Hilfe e.V. illustrates the extent to which there is scope to better integrate hepatitis services in OST. Using this to inform future activity also ensures that work is focused where it is most needed and can be most effective, as well as providing the evidence base from which practitioners can be engaged.

**For further information see the Deutsche AIDS-Hilfe website:**

[www.aidshilfe.de](http://www.aidshilfe.de)

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45 Merkinaite et al, (2008)

### 2.3. Education and peer support in Scotland, United Kingdom

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Research across many countries, including Scotland, has shown that IDUs will modify their behavior to mitigate risks such as HIV and HCV when provided with effective and appropriate information.<sup>46</sup> The source of this information and the way in which it is disseminated are central to its effectiveness.<sup>47</sup> Evidence also points to the influential role that active injectors play in others' initiation, despite often feeling uncomfortable in that position.<sup>48</sup> Further studies have found that increasing injectors' awareness of their role in initiation and assisting them in developing the skills to not 'encourage' new injectors can be effective in reducing the numbers who start to inject.<sup>49</sup>

90% of people who have hepatitis C in Scotland have injected drugs and an estimated 1,000 to 1,500 IDUs become infected with hepatitis C each year.<sup>50</sup> Aberdeen City has among the highest rates of injecting drug use in Scotland, which largely exists within a long-term, embedded IDU population.<sup>51</sup> Rates of hepatitis C these drug using populations tend to be considerably higher than in newer IDU populations, and the risk associated with the re-use of injecting equipment is therefore particularly great.<sup>52</sup> Moreover, within these populations hepatitis C is often contracted within one to two years of people starting to inject drugs.<sup>53</sup>

The Break the Cycle project, based in Aberdeen, Scotland, began in 2007 as part of Scotland's Hepatitis C Action Plan Phase 1. Funded by the local National Health Service, the project was delivered by Drugs Action, an independent drug service in the North East of Scotland and the main needle exchange provider in Aberdeen. The project is delivered through the city centre needle exchange, four needle exchange outreach sites and through Quay Service, a drop in centre for women sex workers offering needle exchange provision, condoms, harm reduction advice, sexual health advice and access to other services.

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46 Des Jarlais et al. (1995)

47 Des Jarlais et al. (1995)

48 Strang et al. (1992)

49 Hunt et al (1998)

50 Scottish Government (2008)

51 Hay et al. (2009)

52 Advisory Council on the Misuse of Drugs (2009)

53 European Monitoring Centre for Drugs and Drug Addiction (2009)

The project targets active injecting drug users, and uses a questionnaire-based assessment tool alongside additional materials such as posters, cards and briefing papers to raise awareness of their role in initiating people into injecting.

The project aims to inform, develop and maintain the understanding of active IDUs about their role in the initiation of new drug users. Each session is designed to raise awareness of issues around initiation with injecting users, discuss how best to manage initiation requests and increase competence in refusing these. They also provide an opportunity to disseminate harm reduction information, raise awareness of possible risks for the initiated and initiator and reinforce the idea that talking about and injecting in front of non-injectors may influence their behavior.

The topic is routinely raised with people accessing the services to maintain knowledge and awareness over the long term. Meetings with specialist staff are also provided to discuss harm reduction strategies, including alternatives to injecting, with existing IDUs. In turn, this information 'filters down' to new IDUs as behaviors and messages become better embedded within the existing IDU population.

This design provides a mechanism through which to disseminate essential information about the risks of starting to inject to those who have not yet begun injecting and, ultimately, reduce initiation. In the event that people do begin to inject it also works to improve awareness of the risks and of how these can be mitigated.

Follow-up sessions with participants on a one to one basis are held to evaluate the effectiveness of the intervention. 52 people have participated in individual follow-up sessions and 16 group meetings have also been held. The results suggest that participants are less likely to speak about injecting or to inject in front of non-injectors after taking part in the program.

A number of participants involved in the evaluation asserted that they had not previously been aware of the impact of their behavior on others' injecting practices. Participants were able to identify more risks to both the initiator and initiated. Awareness of new injectors' risk of contracting blood borne viruses increased by 36% from initial assessment to the follow-up. 79% stated that in light of these risks they were less likely to initiate someone else and 42% that they were more likely to actively refuse an initiation request than before taking part in the program.



In addition, 67% of those involved in the Break the Cycle campaign had passed the information obtained through their participation on to other IDUs. Opportunities to develop this project to include a greater degree of peer to peer work in awareness raising are to be evaluated in 2010.

Break the cycle interventions have been used in a variety of different contexts in countries across the world, and can offer an effective and sustainable mechanism through which to deliver essential harm reduction messages. Particularly in the case of hepatitis C in IDUs, where infection can occur very soon after a person begins injecting, few interventions can be delivered at an early enough stage to reduce the risk of infection. Through highlighting active injectors' role they also offer a clear way to communicate the risks and responsibilities of injecting in a very practical sense, and to ensure that this information is passed between drug users in environments where formal interventions are unlikely to be present.

**For further information see Drugs Action website:**

[www.drugsaction.co.uk](http://www.drugsaction.co.uk)

**Scottish Drugs Forum Website:**

[www.sdf.org.uk](http://www.sdf.org.uk)

## 2.4. Preventing transmission of HCV among IDUs in Germany

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Since the 1990s a series of pilot projects, health promotion campaigns and surveys have indicated that a new approach is required to reach those at risk of hepatitis C in Germany. Foremost among these are injecting drug users. There is a clear need to improve knowledge of, and develop specific programs for, IDUs. Prevalence of hepatitis C among injecting drug users is very high: at least 60% in comparison to 0.4-0.7% among the general population.<sup>54</sup> An estimated 36% of newly diagnosed cases of HCV are believed to have been acquired through unsafe sharing of injecting equipment.<sup>55</sup>

The German Federal Statistical Office Robert Koch Institute provides annual data on diagnosed HCV antibody status in the German population. The findings published in the 2008 report indicated that further work was needed to reinforce earlier campaigns and to provide a new point of contact for injecting drug users. With funding from the Federal Department of Health and the Berlin Department of Health, an early intervention program was developed by a local nongovernmental organization, Fixpunkt, in October 2008.

The program aims to educate active IDUs on the ways in which the risk of hepatitis C transmission can be reduced through adopting safer methods of drug use such as smoking or sniffing. The program does not advocate drug use, although neither is prevention one of the aims; the focus is on minimizing associated risks where drug use is already taking place.

Whilst the primary aim of the project is to reduce transmission of HCV it is also hoped that knowledge and awareness of HAV and HBV vaccination, infection status and prevention will also be improved. This project works with active drug users and aims to reach people before or soon after they begin injecting. Information promoting the service is provided through multiple organizations linked to drug addiction and care. Flyers are also left at syringe distribution machines across the city.

The method of contact is through the drug consumption room (DCR) and mobile vans. A space to inject safely is provided in a drug consumption van which aims to provide a low risk setting for existing drug users. People are free to participate or to decline, and

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54 Retoix National Focal Point (2009)

55 Retoix National Focal Point (2009)

those that participate sign an agreement. The DCR is at a fixed address whilst the two vans go to three different locations in Berlin at fixed times.

In these settings information and guidance is given by qualified and specially trained nurses relating to hygiene, skin disinfection, and the use of sterile materials. Participants are also given information on how to dispose of equipment safely after drug use and how to disinfect items within the room such as tables and lighters. All drug users have to follow these rules irrespective of their method of drug use.

The program provides an opportunity to engage people accessing the DCR for the first time and therefore to educate them early, before they place themselves at serious risk. In addition, complementary interventions work with all drug users to educate them about the risks of hepatitis C infection and to provide testing.

Between February and December 2009 165 clients accessed the project (137 men, 28 women) among whom the average age was 29 (range: 19-61). Initial results are encouraging and the potential replication of the program was being evaluated by other organizations in Berlin, Dortmund and Frankfurt at the time of publication. Plans for new projects were also being developed, including training for people initiating injecting, prophylactic impetus and a break the cycle campaign.

In many countries there is often an apparent reluctance to providing services which may be perceived as condoning, or even advocating, drug use. Interventions which focus on minimizing risk are, however, essential to developing awareness of hepatitis C, as well as other blood borne viruses and injecting risks. Very often people accessing treatment and similar services have already contracted HCV and other blood borne viruses.

These measures are especially important for some of the hardest to reach groups who may be reluctant to actively seek services but may be willing to use those that engage them in an environment with which they are familiar. These may also, in the longer term, provide a gateway to both new and entrenched drug users accessing other important services.

**For further information see Fixpunkt website:**

[www.fixpunkt.org](http://www.fixpunkt.org)

## 2.5. Reaching additional risk groups: non-opiate injectors in Scotland, United Kingdom

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Research examining the cost effectiveness of needle exchange programs for HCV prevention in Europe is generally limited. An Australia-based study, however, estimated that 21,000 cases of HCV were avoided and approximately 738 million Australian dollars saved in lifetime treatment costs through needle exchange programs between 1991 and 2000.<sup>56</sup> Ensuring all those who require these services are able to access them is therefore paramount to effective HCV prevention.

40% of people who have hepatitis C in Scotland reside in the Greater Glasgow and Clyde area.<sup>57</sup> Rates of injecting drug use overall there are also disproportionately high; approximately 3.2% of the population are active injecting drug users, significantly higher than the Scotland (1.6%) and UK (0.6%) averages.<sup>58</sup> The IDU population in Glasgow is long-established and, at 60%, the city has one of the highest levels of hepatitis C among IDUs in the United Kingdom.<sup>59</sup>

Glasgow Addiction Services, an integrated Health and Social Care Partnership organization, estimated that between 2.5 and 4.1 million clean syringes would need to be distributed each year for all injections to be administered using a previously unused syringe.<sup>60</sup> Based on one injection per day per IDU, this is likely to be a highly conservative estimate and the reality may be up to five times this level. It still, however, indicates a shortfall of at least 1.5 million needles when compared to the number currently distributed through needle exchanges.

Scotland's Hepatitis C Action Plans have provided a comprehensive framework for tackling the virus since 2006. The Action Plans specifically recognize that IDUs are not one single, homogeneous group all of whom can be engaged through the same mechanisms, and as such that tailored interventions are likely to be necessary if the needs of all those who inject in Scotland are to be met.

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56 Commonwealth Department of Health and Ageing (2002)

57 Scottish Government (2008)

58 Advisory Council on the Misuse of Drugs (2009)

59 Advisory Council on the Misuse of Drugs (2009)

60 Unpublished data submitted to study

The Glasgow Drugs Crisis Centre provides Scotland's only needle exchange that is open 24 hours a day, 365 days a year. Through ongoing monitoring of the people attending the centre they had observed increasing numbers of injectors not of opiates but of performance and image enhancing drugs (PIEDs) such as steroids. Between one quarter and one half of people accessing the service reported injecting PIEDs. Rates of exchanges distributed to people injecting PIEDs at general pharmacy needle exchanges in the area were, however, largely stable at less than 2%.

This group was therefore identified as at particular risk as they appeared less likely to consider themselves 'injecting drug users' and not to be accessing most mainstream awareness and harm reduction services. A wider need to improve knowledge about injecting practices among people who inject PIEDs had also been highlighted in a 2009 UK Advisory Council on the Misuse of Drugs report on tackling hepatitis C.<sup>61</sup>

In February 2009 Glasgow Addiction Services launched an awareness raising program specifically targeted at users of PIEDs at the Glasgow Drugs Crisis Centre. Initially piloted for six months, posters were developed and displayed in gyms, health clubs, health food shops and GP surgeries advertising a dedicated weekly clinic for people who currently or formerly injected PIEDs.

The clinic provided advice on hepatitis A, B and C, including information about accessing testing and about vaccination against hepatitis A and B. A compact set of sterile syringes and injecting related equipment, tailored to the needs of PIED injectors, was also provided. People attending the clinic were encouraged to use traditional needle exchange services outside of clinic hours. Pharmacy staff were given specific training on working with this population to ensure they could offer appropriate advice, information and support.

Evaluation of the pilot program found that 72% of PIED injectors had changed their injecting behavior and 64% demonstrated improved knowledge and awareness of blood borne viruses as a direct result of attending the clinic. In addition, 29% stopped injecting altogether and used the diet and exercise regimes promoted by the clinic. The percentage who had attended a pharmacy needle exchange rose considerably, from 30% to 65%.

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61 Advisory Council on the Misuse of Drugs (2009)

Based on the evaluation, a number of new additions to the clinic, including offering hepatitis C testing onsite, were being considered for introduction from 2010. At the time of study Glasgow Addiction Services were working with other services considering offering this type of intervention.

While opiate users constitute the majority of injecting drug users across Europe, recognizing other injectors who may be at risk is essential to providing comprehensive HCV awareness and prevention. The work undertaken in Scotland explicitly addresses the need to consider the diversity within injecting populations, and indeed opiate injectors cannot be considered a single, homogeneous group that can all be engaged through a narrow range of services. Where attention is paid to this diversity, great strides can clearly be made in raising awareness and reducing the likely of infection with hepatitis C and other blood borne viruses to all populations that may be at risk.

**For further information see Glasgow Addiction Services Website:**

**[www.glasgow.gov.uk/en/Residents/Care\\_Support/drugs\\_alcohol](http://www.glasgow.gov.uk/en/Residents/Care_Support/drugs_alcohol)**









## Section 3

# Hepatitis C treatment, care and support

### 3.1. Reaching most at risk groups: prison-based HCV interventions in Scotland, United Kingdom

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**Across Europe, as well as globally, higher than national average rates of hepatitis C (and hepatitis B and HIV) are consistently found in prison populations. This has been attributed to higher levels of injecting drug use, as well as tattooing and unsafe sexual activity, occurring both in prisons and among individuals more likely to be incarcerated.<sup>62</sup>**

In Scotland 50,000 people are estimated to have hepatitis C,<sup>63</sup> 3,700 of whom will be incarcerated each year.<sup>64</sup> Prison settings are therefore likely to pose a high risk for transmission of hepatitis C as well as potentially offering an opportunity for delivering interventions for prevention, diagnosis, treatment and care of hepatitis C.

The most recent national data for the prison population, collected from 1994 to 1996, indicate a hepatitis C prevalence rate of 20%. Half of those who tested positive were active injectors and 3% had never injected drugs. More than half of injectors reported having injected drugs in prison and of these 80% reported sharing injecting-related equipment.<sup>65</sup>

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62 See, for example, Gore et al. (1999); Dolan et al. (2007); Esteban (2008)

63 Scottish Government, The (2008)

64 Scottish Prison Service (unpublished)

65 Gore et al. (1999)

Since 2003 self-reported data on injecting in prisons have been collected through the Scottish Prisoner Survey. This has shown relatively consistent injecting rates, with approximately 8% of the prison population overall reporting having ever injected in prison and 3% having done so during the month prior to survey completion<sup>66</sup>. To address this and associated risks, the Scottish Prison Service has implemented a series of interventions, initially to increase the rates of prisoners in OST programs and to reduce risks associated with injecting, and subsequently, under the Phase II Action Plan 2008, to develop the prevention, treatment and care services available in prison settings.

While OST was available in prisons before 2000 it was not widely used. Since that time it has been formally managed across the prison service and take-up of treatment has steadily increased. Over five years the number of people accessing methadone treatment has almost doubled, from 845 people, 14% of the total prison population, in December 2004 to 1,605 people (20%) in August 2009.<sup>67</sup>

To address the risks of drug injecting where this is ongoing a pilot harm reduction intervention was initiated in 2005. This made a 'kit' containing all injecting-related equipment with the exception of syringes available to all prisoners. The kit includes water for injection, citric acid, a spoon, filter, and pre- and post-injection swabs as well as information materials on hepatitis C and safer injecting. People accessing the kits also offered a meeting on safer injecting with an addictions nurse. This program was extended to all Scottish prisons in 2008, although challenges remain, particularly as prisoners accessing the kits often have concerns about making their drug use public to prison staff.

The 2008 Scottish Prisoner Survey found that 31% of prisoners reported having been tested for hepatitis C whilst in prison, and 81% reported to be willing to be tested if available.<sup>68</sup> The second phase of Scotland's Hepatitis C Action Plan, which was launched in 2008 and focuses on developing and improving prevention, diagnosis and care services includes three actions specifically addressing hepatitis C in prisons.

A memorandum of understanding to 'promote the treatment of hepatitis C infected patients in Scotland' was agreed by the Scottish National Health Service (NHS) and the Scottish Prison Service in 2008. Traditionally prison health services have been provided and managed separately to mainstream services. This agreement has built upon existing

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66 Scottish Prison Service (2009)

67 Unpublished data submitted to study

68 Scottish Prisoners Service (2008)

prison medical provision, bringing in NHS services in order to increase the availability of testing, treatment and care within prisons.

Local NHS boards provide tailored services to all Scottish prisons, and each is designed and implemented with prison staff to complement those services already provided. Most testing and diagnostics is carried out in prison settings, making testing and treatment more easily accessible. Where previously hospital attendance was required very few prisoners completed biopsies or started treatment, and where this did occur completion rates were very low. Specialist hepatitis C services are now available in all Scottish prisons, and increased treatment rates are expected to be evident from 2010 (data were not available at time of study).

By 2009 6% of all cases of hepatitis C in Scotland had been diagnosed in prison settings.<sup>69</sup> In recognition of the high rates of hepatitis C among the prison population, the Scottish Prison Service and NHS Scotland intend for prisoners to represent 10% of all people newly accessing treatment by 2011.

Most injecting drug users will come into contact with prison services at some time in their lives and prisons also pose a particularly high risk environment for transmission of hepatitis C, HIV and other blood borne viruses. Prison settings therefore provide both opportunity and need to deliver awareness, prevention, treatment and care through a range of interventions.

In some instances this may also be the case for interventions that require longer-term settings such as opioid substitution therapy and hepatitis C treatment. Increasing the capacity of prison services to understand the need for, and to deliver, these services will be essential to tackling hepatitis C among IDUs and reducing the large numbers of people across Europe who are currently unaware that they have hepatitis C. Integrating prison health with national health services also offers better potential for long-term OST and HCV treatment to be maintained where an individual enters, moves or leaves prison.

**For further information see Scottish Prison Services website:**

[www.sps.gov.uk](http://www.sps.gov.uk) 

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69 Unpublished data submitted to study

### 3.2. Comprehensive treatment, care and post-treatment support in the Netherlands

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Although existing evidence indicates that active injecting and non-injecting drug users can be successfully treated for hepatitis C, the Netherlands is one of only a few countries across Europe to do this.<sup>70</sup> As has been observed in many countries with similar policies, however, this is not routinely provided and practitioners can be reluctant to treat active drug users.<sup>71</sup> This reluctance often stems from concerns relating to the likelihood of re-infection as well as ongoing alcohol abuse, mental health and other problems which may adversely impact on treatment compliance and success.<sup>72</sup> While these issues clearly create additional challenges to providing treatment, most research has found that where treatment is provided in an appropriate way outcomes for (I)DUs are similar to those for the wider population.<sup>73</sup>

Approximately 60,000 people are estimated to have chronic hepatitis C in the Netherlands, 0.37% of the total population. Only 5,000 to 10,000 of these people, however, are aware of their status.<sup>74</sup> While, as is the case in much of Europe, HCV prevalence rates among injecting drug users in the Netherlands are high, the epidemiology differs in that incidence is believed to be decreasing. Harm reduction programs, combining needle exchange programs and methadone distribution, together with hepatitis C treatment to active drug users and injecting drug users may contribute to this trend. Still, uptake of hepatitis C treatment among active (I)DUs remains low.

The Amsterdam Cohort Studies (ACS) has been monitoring long-term trends in drug use since 1985 through a continuously recruiting program. Screening of the ACS study population, including retrospective screening from blood samples stored since the program began, found an 84.5% prevalence rate for HCV antibodies at study entry among participants who have ever injected drugs, with 30.9% co-infected with HIV. Prevalence of hepatitis C was 4.4 times that of HIV among this group.

While HIV treatment in existing primary care facilities was believed to be effectively meeting the needs of people with HIV, hepatitis C treatment saw much lower uptake and

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70 Hellard et al (2009)

71 Hellard et al (2009)

72 Hellard et al (2009)

73 Hellard et al (2009)

74 Eurasian Harm Reduction Network (2007a)

completion rates. In this context a pilot testing and treatment program was established for HCV-infected ACS participants, with treatment provided largely outside hospital settings. The ACS program involves professionals from a range of disciplines, offering wider mental and physical health services as well as OST and harm reduction interventions. All patients who test positive for hepatitis C are also offered further psychiatric and medical screening, and all are assessed for their suitability for hepatitis C treatment.

The central criteria for treatment are the degree of stability in a person's life and the support networks - professional and familial - that they have access to. Most importantly, those initiating treatment must have stable housing and be well engaged with services. Participants are active (injecting) drug users, and treatment has mostly been provided to people with co-existing psychiatric and alcohol misuse problems. Where people with chronic HCV infection are initially not believed to be suitable for treatment they are offered support in addressing any areas of concern until they are able to undergo treatment.

The approach is focused on tailoring services and support to the needs of the patient. Medication is provided at the most convenient point of access for the patient, such as through local methadone clinics where needle exchange programs are used and where methadone is collected. Of the 70 active (I)DUs to have initiated treatment only 4 have chosen to discontinue it. 65% of people treated between January 2005 and April 2010 with sufficient follow-up time attained a sustained virologic response, a similar rate to that seen in mainstream hospital populations. Healthcare workers observe that individuals who have been treated may (at least temporarily) achieve greater stability and rehabilitation in their lifestyle, which may result from the support provided and the intensive, long-term engagement required for successful hepatitis C treatment. Data on this are collected for analysis; the results were not available at the time of this study.

Many challenges exist to treating active, and often former, IDUs for hepatitis C. These are often confounded by reservations among policy-makers and practitioners as to the feasibility and benefits of treatment for these people. The successes of this program, however, show that effective treatment is possible even where people continue to inject drugs. Furthermore, approaching this as one part of a more holistic intervention to address the range of needs common among IDUs both increases the likelihood of successful hepatitis C treatment and can bring wider benefits including the reduction or cessation of drug injecting itself.

**For further information see ACS website:**

[www.amsterdamcohortstudies.org](http://www.amsterdamcohortstudies.org)

### 3.3. Multidisciplinary services for injecting drug users in Switzerland

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Successful detection and treatment of hepatitis C in IDUs requires effective links between a wide range of professionals, as well as between these professionals and others involved in post-treatment care.

Liver specialists, infectious disease specialists, general practitioners, prison doctors, nurses, mental health professionals and addiction specialists all play decisive role in successfully addressing the range of issues that are often involved when working with IDUs with hepatitis C.

Traditionally in Switzerland substitution treatment providers offer few other services, however, and where additional support is provided this is usually restricted to psychiatric care. This is believed to have contributed to a low uptake of HCV screening and hepatitis C treatment among IDUs.

The ARUD (Arbeitsgemeinschaft für risikoarmen Umgang mit Drogen; Association for risk reduction in the use of drugs) project was established in 1991 in Zurich. At that time injecting drug users were largely not marginalized from mainstream society, which assisted in engaging this population. Initially solely a methadone program providing substitution therapy, the project has developed into an integrated program providing wider treatment, care and support for IDUs.

Today four outpatient clinics in the Zurich area care for 1,000 patients, 70% of whom are dependent on heroin. HCV, as well as HIV, has been found to be highly prevalent among people accessing these services. Hepatitis C in IDUs in the area has been found at 70% prevalence of HCV antibody, indicating that the individual has been exposed to the hepatitis C virus, and 42% prevalence of active infection. In addition, 10% of the IDU population is living with HIV. As a consequence of these high prevalence rates complete antiviral care for HCV and HIV was included within the program, as well as a comprehensive range of other services such as needle exchange, follow-up treatment, social work and psychiatric care.

Every patient entering the program is offered testing for HIV, viral hepatitis and syphilis. This is provided on an opt-out basis and take-up of testing is approximately 90%; the remaining 10% either decline or attend for too short a period of time to be tested.

Offering all of these programs through a single service in a single location encourages people to consider all aspects of their health and well-being, not solely OST and/or hepatitis C treatment. In addition, staff are able to monitor referrals to other specialists and professionals, making sure that these are consistently followed-up and that patients attend their appointments. Strong communication links with patients are established and appointment reminders are provided either as phone calls or as SMS text messages. In addition, links have been made with specialists at a university hospital for the most complicated cases in order to ensure that all those who come to the centre receive the complete care that they need.

To date one third of patients who have been diagnosed with chronic hepatitis C have received interferon treatment, and the completion rate is 62%. The central success of this project is in enabling patients to access additional care at the same time as OST and hepatitis C treatment. This is not possible in other settings as staff in most services do not have such frequent contact with patients or an interdisciplinary team. The strong relationships built between staff and patients, as well as the links with additional care, provide the support and comprehensive service access that IDUs with hepatitis C often need to successfully complete treatment.

**For further information see ARUD website:**

[www.arud.ch](http://www.arud.ch) 





## Section: 4

# Building comprehensive responses

### 4.1. Training networks for professionals in Austria

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**Up to 63% of injecting drug users in Austria are estimated to have hepatitis C.<sup>75</sup> As is the case across Europe, people who inject drugs often face a range of additional physical, psychological and social problems beyond drug use. Detection of hepatitis C, as well as the duration and side-effects of treatment, are particularly challenging when faced with one or more comorbidities. Moreover, the interactions of these problems with the treatment of addiction must be taken into account and, in practice, can represent a major challenge for the physician providing opioid substitution therapy.**

Interdisciplinary collaboration is necessary to fully address the complex range of needs faced by IDUs with hepatitis C and therefore to achieve effective assessment, preparation, treatment and care. OST is a major dimension of this. In 2009 approximately 11,000 of the 33,000 IDUs in Austria were receiving substitution therapy, 7,176 (65%) of whom resided in Vienna. Particular attention to the issue was therefore required in and around the city.<sup>76</sup>

In the majority of cases in Vienna, both the establishment of need for (75.9%), as well as the provision of (85%), substitution therapy is carried out by physicians with their own

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75 2007 data. European Monitoring Centre for Drugs and Drug Addiction. Country Overview: Austria.

76 Unpublished data submitted to study.

practice, largely by general practitioners (GPs).<sup>77</sup> GPs provide testing for hepatitis C and referrals to specialist clinics for treatment where and when appropriate. The integration of these physicians into the care network was identified as essential for the effective provision of testing and treatment of patients with hepatitis C.

The Austrian Association for the Medically-Assisted Treatment of Addiction (ÖGABS) and the Viennese Medical Chamber initiated Interdisciplinary Quality Circles (QUZ) in late 2006. The QUZ were developed by Dr. Hans Haltmayer, Medical Director of the low threshold outpatient clinic "Ganslwirt" and Prof. Dr. Michael Gschwantler, a leading hepatologist. They provide practice-oriented, interdisciplinary training for practitioners involved in the treatment of IDUs and HCV, including GPs, psychiatrists, doctors at drug addiction institutions, public health officers, social workers, and representatives from self-help groups. Hepatologists from specialist hospitals and university hospitals have also joined the network. Beyond training, the QUZ also enable participants to build professional links, improving their understanding of the role that each plays and building more effective communication mechanisms between them.

The QUZ training provides qualifications for the advanced diploma program from the Austrian Medical Chamber (ÖÄK) and for the ÖÄK diploma for substitution therapy. The goal of the QUZ is to raise awareness among practitioners and, through them, patients, as well as developing knowledge about preliminary care, diagnostic procedures and treatment of drug addicts with viral hepatitis and building networks across the disciplines involved. Eighteen events, involving over 300 participants, have been held to date.

In Austria people with chronic hepatitis C can be treated while they are receiving OST, as can people who continue to inject drugs if they are not doing so in a high risk way. Most commonly, referrals involve those receiving OST and former drug users. Practitioners have found that patients with chronic hepatitis C who are undergoing OST are particularly suitable for antiviral therapy as they are in constant medical care, used to the regular intake of medicines and the majority are living in a stable social environment. Aside from medical contraindications, there are no limitations for antiviral treatment in patients undergoing OST. With appropriate preparation and care the prognosis for this group is comparable to that of the wider population.

Those involved in the training network have found that personal contact between caregivers, especially treating physicians, greatly assists the treatment process. This

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<sup>77</sup> Unpublished data submitted to study.

facilitates the exchange of information about the treatment itself as well as the wider dimensions of the referral and treatment process. It also ensures the patient is provided with accurate and appropriate information, for example about contacts, business hours of outpatient clinics, or the documentation they require. This is particularly important for patients who are likely to find engaging with a range of services, and the stresses often involved in this, difficult to manage.

The Vienna interdisciplinary network and training program makes it possible to reach a large number of doctors providing maintenance treatment within their own practice and to link them to the diagnostic procedures and treatment of IDUs with hepatitis C. This has proven to be highly beneficial both for the practitioners involved and for the patients that they work with. Since the first network began in Vienna QUZ have also been established in Innsbruck (Tyrol), Linz (Upper Austria) and Wiener Neustadt (Lower Austria).

Successfully treating drug addiction, like hepatitis C, requires long-term engagement and, often, addressing a range of other issues. Building networks across the many disciplines involved in the prevention, diagnosis, treatment and care of IDUs with hepatitis C can therefore have a very positive impact both for the practitioners involved and for the patients that they are treating. Making professional development and training the basis of these also increases the value they offer to practitioners as well as improving capacities across disciplines to successfully address hepatitis C among people who inject drugs.

**For further information see:**

[www.oegabs.at](http://www.oegabs.at)



## 4.2. Mobilizing advocacy for Hepatitis C in Eastern Europe and Central Asia

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Eastern Europe and Central Asia (EECA) is in the process of reforming and rebuilding its health systems as part of the post-Soviet economic, social and political transition that began in the late 1980s. These countries face many varied health challenges in the context of very limited domestic resources and, as in much of the transitional and developing world, attention to hepatitis C in EECA is insufficient at national, regional and international levels.

Over the past twenty years the region of Central and Eastern Europe and Central Asia (CEECA) has experienced an unprecedented growth in drug use and, related to this, one of the fastest-growing HIV/AIDS and other blood borne virus epidemics in the world. CEECA is currently home to 3.7 million people who inject drugs, almost one-quarter of all IDUs worldwide.<sup>78</sup> In EECA one in four injectors is believed to have HIV.<sup>79</sup> The quality of health-related, and particularly harm reduction, services however is often poor and service coverage is inadequate. Harm reduction coverage falls well below the 60% recommended by UNODC for HIV prevention, and not more than 10% of those in need have access to needle and syringe programs in the CEECA region.<sup>80</sup>

Where prevalence data exist these indicate that HCV is a major public health problem for many groups in EECA, particularly among IDUs, people living with HIV, prisoners and very probably certain healthcare professionals. Due to the highly infectious nature of HCV the region faces extremely high prevalence rates. Providing access to HCV information, treatment and care is therefore a major priority for harm reduction and advocacy groups.

The Eurasian Harm Reduction Network (EHRN) and the Open Society Institute (OSI) began a series of hepatitis C-related interventions in 2006. Focused on the needs of IDUs and other vulnerable populations, these aim to build civil society groups' and professionals' capacity to develop mechanisms for catalyzing government action in improving access to treatment and investment in hepatitis C services. Over the long term these also

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78 Mathers et al. (2008)

79 Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization

80 Mathers (2010)

aimed to develop civil society and professionals' capacity to address the inaccessibility of treatment and low interest in investing in HCV services.

In 2006, EHRN organized a multi-stakeholder HCV consultation for Central and Eastern Europe. Through these they conducted the first regional assessments of HCV prevalence and mapping prevention, testing, diagnostics, treatment, care and support services. Examples of good practice in integrated drug treatment, HIV and hepatitis C treatment services were introduced, and the potential role of harm reduction in responding to the HCV epidemic among drug users in the region was examined. The consultation found a high prevalence of HCV among IDUs and a widespread lack of harm reduction interventions. Treatment guidelines were found to often be restrictive toward drug users, requiring a period of abstinence or, in some countries, prohibiting HCV treatment for people in OST. A widespread lack of political commitment, awareness and capacity to effectively address hepatitis C at the national and regional level was also observed.

In line with its mission, EHRN initially focused on policies affecting people who use drugs and services for HCV prevention, treatment and care. However, as the research and consultation progressed one issue in the Eastern European countries involved provoked particular concern: almost no or very limited availability of hepatitis C diagnostics and treatment that did not require out of pocket payment by the patient.

In 2009, the first Eastern European and Central Asian consultation on hepatitis C diagnostics and treatment was jointly organized by EHRN and OSI. It brought together community groups and health professionals from Georgia, Kyrgyzstan, Russia, and Ukraine to review the current gold standard in diagnostics and treatment as well as examine new medicines in development. The high cost was identified as the most significant barrier to hepatitis C diagnostics and treatment. Cost reduction strategies were discussed and a need for greater knowledge of aspects related to patents on medicines was identified, in response, OSI organized and delivered regional training on the relationship between intellectual property and access to medicines.

In late 2009 and 2010, further support for national hepatitis C advocacy groups was provided in order to identify national level priorities for HCV action and, in some instances, to begin defining these priorities with the participation of broader civil society groups. This was also an opportunity to build coalitions and better document the situation in each country. Key highlights and activities included:

**Georgia:**

A literature review initially assisted to mobilize interest from stakeholders, as HCV prevalence has been found as high as 6.7% in the adult population. Numerous actors – from young economists and professionals in facilitating political dialogue to harm reduction and drug user activists – reviewed the situation and defined requisite next steps for building national commitments and implementing a concrete strategy for reducing the price of diagnostics and initiating a national program. This builds on recent positive development in the country to ensure treatment access for HIV/HCV coinfecting people. Georgia had become the first country to obtain funding for HCV treatment from the major global HIV donor, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM).

**Russia:**

National consultation brought together activists from HIV and HCV advocacy groups which identified several objectives in Russia for improving disease surveillance and monitoring systems, and examining pricing and procurement mechanisms and opportunities to reduce the cost of treatment. Current funding for hepatitis C treatment is allocated from the HIV budget only after HIV costs have been met. As is the case elsewhere, close integration with HIV/AIDS services, particularly in developing treatment availability (including opportunities to finance hepatitis C treatment through the GFATM), was identified as central to this strategy and was highlighted at the Eastern Europe and Central Asia AIDS Conference 2009 at the session organized by EHRN and the Andrey Rylkov Foundation.

**Kyrgyzstan:**

National resources in this Central Asian Republic are very scarce for health care in general and access to hepatitis C services is lower than in most other countries in the region. An alliance of patient associations, human rights lawyers and harm reduction services was formed to develop a comprehensive national research platform on the prevalence of hepatitis C, service provision, patient advocacy, HCV-related discrimination and stigma, awareness of prevention and on diagnostics and treatment accessibility. This was designed as a tool to provide the baseline knowledge required to develop an effective national strategy. In development at the time of writing, this will inform one short-term and one long-term framework to guide an interdisciplinary coalition of civil society organizations.

These interventions have served to raise awareness of HCV across EECA countries, and to engage practitioners in all related disciplines in prioritizing the need to tackle HCV. The regional awareness work and technical support helped to engage national groups and achieve a common understanding that HCV is an important advocacy area. A central element in initiating national processes was acknowledging that advocacy is a long-term process which may not have specific results in the short term and requires commitment from organizations and people, coordination, and prioritizing among many challenges and areas for improvement.

Although undertaking this through long-term, country-specific action is of particular importance, increased government and health sector attention to this issue became evident at a relatively early stage, particularly in Ukraine and Georgia. The interventions, especially those undertaken at the regional level, have also assisted in developing understanding of international agendas and processes around hepatitis C in a region which is often isolated from international discourse due to language barriers and the legacy of post-Soviet health systems. Identifying regional as well as national concerns, most prominently in relation to treatment costs and availability, gives these countries a stronger voice to influence the global agenda for hepatitis C and injecting drug use while also ensuring that future developments and programs are tailored to national and local contexts.

Furthermore, obtaining funding for national groups to undertake advocacy work and providing them technical support to do so is of utmost importance. The national work remains at an early stage, though is beginning to develop and show inspiring progress which will require ongoing support.

**For further information see EHRN website:**

[www.harm-reduction.org/hepatitis-c](http://www.harm-reduction.org/hepatitis-c)

**and OSI and Soros Foundations Network website:**

[www.soros.org/initiatives/health/focus/access](http://www.soros.org/initiatives/health/focus/access)





## Section: 5 Conclusion and recommendations

This publication focuses on distinct interventions which largely exist as stand-alone projects, operating as a result of need but often not as part of a coordinated framework to tackle hepatitis C in an integrated and unified way. All of the areas illustrated here are essential dimensions of achieving an effective overall strategy for tackling hepatitis C. Collectively these interventions demonstrate diverse strengths and original approaches to addressing a massive public health problem amongst a difficult to engage group.

**The central message evident throughout this report is that, while many excellent and innovative examples exist across the region, a more unified approach and increased understanding of hepatitis C and injecting drug use is essential to improving current insufficient service provision and effectiveness.**

Insufficient attention to hepatitis C, and indeed to the more general challenges faced by many active and former injecting drug users, is evident across the majority of countries in Europe. The results of this are broad and affect every dimension of the treatment pathway and long-term outcomes for IDUs affected by hepatitis C.

Another clear and unifying factor is massive under-diagnosis, which likely both stems from and results in the lack of attention paid to this issue by policy makers and health service planners. Civil society therefore has a fundamental role to play in raising awareness of hepatitis C and in developing effective service provision.

The simplicity of many of these interventions means that they are easy to replicate and to tailor to specific national and local needs. They are also cost effective and can be delivered with limited resources, which in turn eases concerns about sustainability and development. Many of the examples selected have already begun to be replicated in

other cities and countries and this success strengthens the validity of these interventions in informing further work.

Many challenges exist to working with IDUs, but the examples here show the effectiveness of making access easier. Delivering a range of assistance through a single service or actively taking the intervention to the community in prisons, for example, or through a safe, mobile place for drug use can be highly effective. This is especially important in prevention when the opportunity to educate people who inject before the, often very early, point at which they are exposed to the virus occurs.

Many people's lives are unnecessarily put at risk through hepatitis C every day, be this through unsafe injecting, through a lack of awareness, or through a lack of access to diagnosis, treatment and care services. With so many people unaware that they are infected with hepatitis C, it is paramount that all opportunities to test high risk groups are utilized when and where these arise. The examples of research, professional networks and integrated services first underline how this can be better understood and then, by identifying missed opportunities for testing and disseminating information, how interventions can be developed to address these problems.

The interventions show that an open dialogue with drug users is an important part of reducing risk and preventing future infections. By engaging drug users in prevention work it is possible to help people apply safer methods of injecting. Recognising the diversity within IDU populations and that drug users are not seen as passive recipients, but as active participants, in interventions consistently yields results. Peer to peer prevention work in particular can be a simple and effective approach and can have a positive impact where other prevention work might not have a place. Moreover, this often offers benefits for the person delivering the intervention as well as the person engaged.

The examples in this report illustrate the importance of maintaining a broad perspective in who we regard 'at risk'. Drug practices change, the people who use drugs change and the reasons for drug use changes. It is important that drug prevention changes as well and therefore the people targeted need to be reviewed. New and emerging groups at risk need to be identified before the numbers of people contracting hepatitis C and other viruses are too great. Policy-makers need to be made aware of the importance of addressing this, and new approaches must continue to be developed to counteract and target the new groups at risk.

In summary, while there are many challenges and barriers to delivering hepatitis C prevention, diagnosis, care and support services to injecting drug users, these interventions demonstrate that through effective, tailored service provision these can be reduced and, in many cases, removed.

### **Recommendations for governments and policymakers:**

- Develop national hepatitis C frameworks to ensure that this issue receives the requisite attention for all members of society;
- Develop national treatment standards and protocols where these are not in place, working in partnership with health care professionals, drug treatment specialists and affected communities;
- Ensure training to healthcare professionals is provided at the highest standard.

### **Recommendations for international organizations:**

- All international and intergovernmental organizations and donor agencies should ensure equal access to hepatitis C treatment for all groups including socially marginalized groups such as drug users;
- International organizations and agencies (such as WHO, EMCDDA) should significantly improve surveillance and monitoring of disease burdens, tackling progression and outcomes of treatment, non treatment, and effective prevention measures;
- In the light of adoption of Viral Hepatitis Resolution by the World Health Assembly, we call for increased focus on hepatitis C by the WHO, including:
  - Leadership for global strategies to reduce the cost of hepatitis C treatment and include pegylated interferon and ribavirin, the two medications comprising the current standard treatment, into its Model List of Essential Medicines as necessary steps to catalyzing and assisting effective national-level responses to hepatitis C and injecting drug use;
  - Provide recommendations and assistance for the development of national protocols on treatment quality and access and national hepatitis policy frameworks.

### **Recommendations for health-care professionals:**

- Increase cooperation and knowledge sharing among different health care providers, including infectious diseases specialists, drug treatment and harm reduction service providers, and liver patient organizations, in building a comprehensive approach to hepatitis C;
- Rely only on scientifically proven evidence when determining patients' treatment and care, not discriminating or withdrawing treatment from anyone;
- Include affected communities in decision making, advocacy work and service provision.

### **Recommendations for civil society:**

- Civil society organizations should advocate for the development of national programs on hepatitis C treatment, and call for reviews of national legislation and the development of national treatment guidelines;
- In light of the considerable role played by these organizations in both drug addiction and hepatitis C interventions, these organizations' expertise and experience is central to effective government policy-making and effective partnerships and will need to be developed and maintained to inform this work wherever possible.



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The Eurasian Harm Reduction Network (EHRN) is a regional network with a mission to promote humane, evidence-based harm reduction approaches to drug use, with the aim of improving health and protecting human rights at the individual, community, and societal level.

EHRN seeks to help implement non-discriminating policies for drug users and other vulnerable people in the EHRN territory (Central and Eastern Europe and Central Asia), and to improve and expand the use of evidence-based interventions and services that target them.

As a partner organization for Correlation II project EHRN seeks to promote effective and qualified prevention and management of HCV among drug users and help build the capacities of harm reduction, drug services, practitioners and potential advocates hepatitis C counselling and treatment and living with HCV.



The overall aim of Correlation II is to tackle health inequalities in Europe and to improve prevention, care and treatment services, targeting blood-borne infectious diseases (BBID), in particular Hepatitis C and HIV/AIDS among vulnerable and high risk populations (e.g. drug users and young people at risk).

Target groups are service providers, including peer educators, notably those working in drug services, harm reduction facilities or health services for young people at risk; policy makers, notably those involved in policy development on drugs and BBID.

The project approaches the issue from different angles and with interventions, which have been identified as effective, such as outreach/early intervention, e-health and peer support.

