SELECT BARRIERS TO HARM-REDUCTION SERVICES FOR IDUs IN EASTERN EUROPE

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SUMMARY

Background: In eastern Europe, the high prevalence rates of HIV and the hepatitis C virus (HCV) are concentrated among injecting drug users (IDUs). Harm reduction programmes such as needle and syringe programmes and opioid substitution therapy (OST) have been shown to be effective in preventing these infections. However, structural barriers can limit their effectiveness by hindering access.

Methods: Through use of a semi-structured online survey sent to 65 professionals in the region, this study explores the prevalences of age restrictions, user fees or a lack of confidentiality for these programmes as well as HIV/HCV testing programmes.

Results: Twenty respondents reported that age restrictions were not widespread in the 11 reporting countries, apart from for OST. User fees were found to be very common in HCV testing and varied for other services. It was stated to be common to inform parents of young IDUs who receive HIV services, but not to inform public authorities when IDUs enter harm reduction programmes.

Conclusion: Where access to services is limited or confidentiality is compromised, as reported in this pilot study, it is crucial that health-care guidelines and national legislation are reformed to ensure access to these evidence-based interventions.

Key words: harm reduction, health policy, hepatitis, HIV, eastern Europe, central Asia

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INTRODUCTION

The HIV epidemic struck eastern Europe, including central Asia, in the 1990s, leading in 1999 to 2001 to the fastest-growing increase in reported new HIV cases the world had ever seen (1, 2). In 2007, the estimated number of people living with HIV (PLHIV) in eastern Europe and central Asia reached 1.6 (1.2–2.1) million, with an estimated 150,000 (70,000–290,000) new infections the same year (3). Despite national differences, the far most common transmission route in these countries is the use of contaminated needles and syringes. In 2006, injecting drug use was the reported cause for 79% of all new HIV diagnoses with a known transmission route in eastern Europe (4).

The hepatitis C virus (HCV) constitutes another serious – although often overlooked – threat in the region. Some 70–90% of all injecting drug users (IDUs) in Estonia, Lithuania, the Russian Federation and Ukraine are estimated to be infected with HCV (5). HIV/HCV coinfection is a major problem among IDUs (6), and today, now that more PLHIV are receiving antiretroviral therapy, HIV deaths are increasingly due to the hepatic complications of HCV, such as cirrhosis or hepatocellular carcinoma.

The HIV situation in these countries is alarming, and focussing on IDUs is thus of paramount importance. Nevertheless, significant barriers prevent most of this risk group from accessing preventive evidence-based services. Some of the obstacles are rooted in the health system that emerged after the breakdown of the Soviet Union (7, 8). Today, vertically organized programmes still dominate the health-prevention and health-promotion services of the former Soviet republics. As a result, they have been ill prepared to solve the complex health problems, including coinfection with tuberculosis, hepatitis and sexually transmitted infections, that confront PLHIV (9, 10).

Evidence-based HIV and HCV Prevention among IDUs

Experience from western European countries shows that harm-reduction programmes can halt the spread of HIV and HCV among IDUs (11). Needle-exchange programmes (NEPs), opioid substitution therapy (OST) and HIV and HCV testing are all harm-reduction programmes that have proven effective in preventing the spread of HIV (12–16) and, to a lesser extent, HCV. An important principle of harm reduction is that no one should be denied access to health services just because they are practising an illegal or disapproved of behaviour (17). The harm-reduction approach represents an alternative to criminalizing risk behaviours – an approach that sets realistic goals for people who will not or cannot stop their use of injectable opiates (18).

Despite clear evidence of their effectiveness and promotion by doctors, researchers and leading bilateral and multilateral organizations, harm reduction programmes continue to be controversial in many countries of Europe, but in particular eastern Europe. Consequently, IDUs often face formidable obstacles, as discussed below, in trying to access these preventive services, and their

coverage in the region is currently low (19), though increasing. In the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia, from 2004, 52 European and central Asian countries agreed to scale up IDU access to interventions such as NEP, OST and HIV testing (20). These commitments, mostly unfulfilled (4), to improve access built on an implicit notion that they would increase the scope and utilization of such programmes, reducing the spread of HIV and HCV among IDUs.

This pilot study investigates select potential barriers, age restrictions, user fees and lack of confidentiality, to HIV and HCV-prevention programmes in the region, to understand how best to improve access to prevention programmes for HIV and HCV.

The prevalence of age restrictions on harm reduction services has not been explored in depth even though the age of initiation for injecting seems to be decreasing in central and eastern Europe, where most IDUs start injecting in their teens or early twenties (21). While data stratified by age in general is lacking for IDUs with HIV or HCV in the region, the proportion of people living with HIV that are IDUs is almost 60% in eastern Europe [1] (22). No regional data is available for HIV prevalence among IDUs, but some country specific numbers exist. For example, in Estonia the estimated HIV prevalence among IDUs in 2005 was 63.3% (23).

User fees and lack of confidentiality are both structural barriers that have been explored in different settings providing evidence that these factors also constitute barriers to accessing health care services. User fees for health care services can greatly affect their accessibility and utilization (24). Studies show that fees and lack of health care insurance hinder access (25–28), that significantly more people use health care services when it is free (29) and that young IDUs with health care insurance are significantly more likely to utilize health care services than those without (30).

Connections between a country's health care system and its judicial system can influence the utilization of health services (31). Registration for drug use treatment (26) and the simple fear of breaches in confidentiality (32) are two significant barriers in IDU access to harm reduction and other health services. They also have consequences for getting jobs and general feelings of discrimination (26).

METHODS

To map the occurrence of the three aforementioned structural barriers to harm reduction programmes in the region, a survey was conducted online from March to April 2008. The semi-structured questionnaire consisted primarily of questions with closed answer categories. We pilot-tested the survey with three experts in the field to ensure the clarity of the questions.

On 17 March 2008, we sent out the questionnaire to a total of 65 potential respondents working in the region for either WHO, UNICEF, ministries of health (experts with knowledge of either HIV, HCV or IDUs) or the non-governmental organization the Eurasian Harm Reduction Network (EHRN) in the 15 countries of the former Soviet Union. Reminders were sent out twice in the following two months.

Where several people from the same country completed the questionnaire, we compared the replies in order to compile a composite result for the country. In cases of inconsistent or contradictory responses, we prioritized those that were most common or most detailed, respectively.

RESULTS

We received completed questionnaires from 26 respondents representing a total of 12 countries. Six responses were not relevant for this study as they merely gave information on the respondent but not on the main questions, leaving us with 20 eligible surveys from 11 countries: Armenia (2 surveys), Belarus (2), Estonia (1), Georgia (1), Kazakhstan (1), Kyrgyzstan (2), Lithuania (1), the Republic of Moldova (2), the Russian Federation (2), Tajikistan (2) and Ukraine (4). The results below are based solely on these survey responses.

Age Restrictions

Out of the 11 responding countries, three (Kazakhstan, Lithuania and the Republic of Moldova) report age restrictions for access to NEP (see Table 1).

Seven countries provided OST to drug users, and five of these had age restrictions (Estonia, Georgia, Lithuania, the Republic of Moldova and Ukraine). This makes OST the programme for which age restrictions were most commonly reported. Lithuania had the lowest reported age limit at 15, while Georgia represented the highest reported one, at 25. Generally, 18 was the most common age limit for OST.

Two (Kazakhstan and Ukraine) out of the 11 reporting countries had age restrictions for being HIV tested.

Out of the 11 countries, nine had no age restrictions for having an HCV test. Respondents from the two remaining countries did not know whether this applied in their countries as well. There was a general lack of knowledge about access to HCV testing programmes in the responses.

User Fees

Of the 11 countries from which our findings are based, NEP is provided for free in eight countries (Belarus, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Lithuania, Moldova and Tajikistan). Three countries (Armenia, the Russian Federation and Ukraine) offer NEP free of charge officially, but respondents indicated that user fees are sometimes to be found in practice (Table 2).

OST was only available in seven of the 11 countries. In five of these, OST was officially without charges (Belarus, Estonia, Georgia, Kyrgyzstan and Lithuania). There were indications of user fees for access to OST to some degree in Moldova and Ukraine.

In seven countries out of 11, HIV testing was provided for free (Belarus, Estonia, Kazakhstan, Kyrgyzstan, Lithuania, Moldova and the Russian Federation). However, there were indications of user fees for getting an HIV test in Armenia, Georgia, Tajikistan and Ukraine.

Only Estonia and Kazakhstan provided HCV testing without any indications of user fees. Nine out of 11 countries (82%) had user fees for HCV testing to some extent. In five out of these nine

[1] Excluding the Russian Federation

Table 1. *Age restrictions for eastern European harm reduction services*

Country	Needle exchange	OST	HIV test	HCV test
Armenia	Presumably none	—	None	Not known
Belarus	None	Contradictory replies. Possibly none, but indications that pilot OST programmes restricted to 18+ years	None	None
Estonia	None	Yes, to 18–19+. Stated in national regulations and guidelines	None	None
Georgia	None	Yes, officially restricted to 21+/25+, exceptions made for HIV+ and pregnant. Stated in national guidelines	None	None
Kazakhstan	Yes, not officially, but in practice	Not known	Yes, not officially, but in practice	Not known
Kyrgyzstan	None	None	None	None
Lithuania	Yes, officially restricted to 18+. Stated in legislation. Indications suggest exceptions are made in practice	Yes, officially to 15+ years. Stated in legislation	None	None
Moldova	Yes, presumably in practice to 18+ but not officially. Stated in regulations	Yes, presumably to 18+. Stated in regulations	None	None
Russian Federation	Presumably none	—	None	Presumably none
Tajikistan	None	—	None	None
Ukraine	Presumably none	Yes, restricted to 18 years; unclear if restriction is official or only in practice	Contradictory replies. Presumably not officially restricted, but in practice to 18+ years	None

— = no response.

Table 2. *User fees for eastern European harm-reduction services*

Country	Needle exchange	OST	HIV test	HCV test
Armenia	Free, as stated in health ministry decree; indications suggest user fee in practice	—	Free, as stated in health ministry decree; indications suggest user fee in practice	User fee, presumably
Belarus	Free, as stated in legislation	Free, as stated in legislation	Free, as stated in legislation	Free; indications suggest user fee in practice
Estonia	Free, according to official documents	Free, according to official documents	Free, according to official documents	Officially free,
Georgia	Officially free	Officially free	Officially free, but not stated in legislation; indications suggest user fee in practice	Officially free, but not stated in legislation, indications suggest user fee in practice
Kazakhstan	Officially free	—	Officially free	Officially free
Kyrgyzstan	Free, as stated in legislation	Free, as stated in legislation	Free, as stated in legislation	User fee
Lithuania	Free, as stated in legislation	Free, as stated in legislation	Officially free	Officially free, but indications suggest user fee in practice
Moldova	Free, as stated in legislation	Contradictory replies. Officially free, as stated in legislation, but indications of user fee in practice	Free, as stated in legislation	User fee
Russian Federation	Contradictory replies. Indications suggest free at a some distribution points	—	Free, as stated in legislation	Officially free, but indications suggest user fee in practice
Tajikistan	Officially free	—	Officially free; indications suggest user fee in practice	Contradictory replies. Presumably free at some distribution points. Not stated in legislation
Ukraine	Officially free; indications suggest user fee in practice	Free, as stated in legislation, but indications suggest user fee in practice	Free, as stated in legislation, but indications suggest user fee in practice	Contradictory replies. Officially free, as presumably stated in legislation, but strong indications of user fee in practice

— = no response.

countries (Belarus, Georgia, Lithuania, the Russian Federation and Ukraine), HCV testing was free of charge officially, although user fees in practice were reported.

Confidentiality with Respect to Parents

In connection to informing parents of young IDUs, the majority of the respondents did either not answer questions on this or answered that they did not know (see Table 3).

Our findings showed a high degree of uncertainty with regard to confidentiality when receiving needles and syringes through NEP. In three countries (the Russian Federation, Tajikistan and Ukraine) it was reported that it was not common practice to inform parents of young IDUs participating in NEP. In contrast, it was common practice in Armenia and "presumably" Moldova when the IDU was under the age of 16 and 18, respectively.

We lack information from nine countries on whether it was common practice to inform parents of young people receiving OST. In Moldova, there were indications that it was normal practice to inform parents of IDUs younger than 18, as well as in Ukraine – although it was at the same time reported that no one under the age of 18 receives OST in Ukraine.

In five countries (Armenia, Kazakhstan, Moldova, Tajikistan and Ukraine) parents were informed when minors are tested for HIV.

In both Moldova and Tajikistan parents were usually informed when young people receive an HCV test. Only Ukraine reported that this was common practice. However, we lack information on eight countries on this issue.

Confidentiality with Respect to Public Agencies

Most countries did not provide full information about providing information to public agencies, such as social services or law enforcement, on IDUs' participation in any of the four programmes we have looked into (See Table 4).

It was not common practice in all 11 countries to inform public agencies when young people participate in NEP.

Providing information to public agencies on participation in OST programmes was not common practice in Georgia and Kyrgyzstan, while it was reported as common in Moldova and Ukraine. For the remaining seven countries we lack information.

It was not common practice to contact public agencies when young people were tested for HIV, although respondents from two countries reported that they do not know.

It was reported that it was not common practice to inform public agencies in any of the countries investigated when people were tested for HCV.

In nine out of 11 countries it was reported that the confidentiality of personal information was secured, e.g. HIV status, in legislation.

DISCUSSION

The occurrence of structural barriers as demonstrated by age restrictions, user fees and lack of confidentiality in the programmes we examined has not been investigated before in any similar study in the region. We found that age restrictions, user fees and a lack of confidentiality, in terms of sharing information with parents, were common when accessing harm-reduction programmes in Armenia, Kazakhstan, Moldova, Tajikistan and Ukraine. By contrast, such obstacles were reported as exceptional in Belarus, Estonia and especially Kyrgyzstan. It is important to note, however, that the number of implemented programmes varies from country to country, and an absence of such barriers may conceal an overall lack of programmes in the country.

Limitations

Our findings are from 11 of the 15 countries of the former Soviet Union (Azerbaijan, Latvia, Turkmenistan and Uzbekistan did not respond) and can thus not be generalised to the region as a whole. It is also important to note that because all the respondents were working in public health at the time of the survey, they may have had a vested interest in emphasizing problems with ac-

Table 3. *Common practice to inform parents of clients using eastern European harm-reduction services*

Country	Needle exchange	OST	HIV test	HCV test
Armenia	Yes, for clients <16 years	—	Yes, for clients <16	—
Belarus	—	—	—	—
Estonia	Not known	Not known	Not known	Not known
Georgia	Not known	Not known	Not known	Not known
Kazakhstan	Not known	—	Yes	Not known
Kyrgyzstan	Not known	Not known	Not known	Not known
Lithuania	—	—	—	—
Moldova	Contradictory replies. Presumably yes for clients <18 years	Contradictory replies. Presumably yes for clients <18	Contradictory replies. Presumably yes for clients <18	Contradictory replies. Presumably yes for clients <18
Russian Federation	No	—	Not known	Not known
Tajikistan	No	—	Yes, for "minors", "adolescents"	Yes, for "all adolescents"
Ukraine	No	No, but no IDUs <18 receive OST	Yes, for clients <18 years	No

— = no response.

Table 4. *Common practice to inform public agencies about clients using eastern European harm-reduction services*

Country	Needle exchange	OST	HIV test	HCV test	HAART
Armenia	Presumably not	—	No	Not known	No
Belarus	—	—	—	—	—
Estonia	Not known	Not known	Not known	Not known	Not known
Georgia	No	No	No	No	No
Kazakhstan	Not known	—	Not known	Not known	Not known
Kyrgyzstan	No	No	No	No	No
Lithuania	—	—	—	—	—
Moldova	No	Yes	No	No	No
Russian Federation	No	—	No	No	No
Tajikistan	No	—	Contradictory replies	Contradictory replies	Contradictory replies
Ukraine	No	Inconsistent replies; presumably common practice	Inconsistent replies; presumably not	Inconsistent replies; presumably not	Yes

— = no response.

cess to harm reduction programmes and described a less nuanced picture than a more heterogeneous group of respondents would have. At the same time, as they often worked for governmental or government-funded programmes, the reverse may also be true: that they underemphasised the problems associated with harm reduction and HIV/HCV testing programmes. In general, a larger and more diversified pool of respondents would have been desirable in order to provide clearer, representative results. Due to individual cultural and linguistic assumptions, some responses may not have reflected the questions' intended meaning. In order to process the key results for each country, a simplification of the data may have taken place and again, as pointed out above, additional respondents coupled with an additional stage of the study, in which experts discuss the results and the laws and practices are examined in detail, would have greatly improved the data validity.

Age Restrictions

Of the five types of harm reduction programmes our survey addressed, age restrictions were most commonly reported for OST, suggesting widespread resistance towards offering the treatment to minors despite strong evidence supporting the efficacy of this intervention (13).

The respondents noted cases for which official exceptions are made. In Georgia, pregnant women and PLHIV have access to OST irrespective of age. In Ukraine, exceptions are made for IDUs with addictions of several years' duration or with comorbidities, which may be interpreted as a practice of individual assessment. The fact that exceptions are made suggests a certain degree of flexibility in health care system interactions with juvenile IDUs. However, when access is not ensured officially, the users will not be guaranteed access to services.

User Fees

There were eight countries where NEPs were reported as being free of charge. In Armenia, for example, the law requires needles and syringes to be distributed for free, but the survey respondents indicated that some distribution points have user fees, which indicates a failure of enforcement of this policy. Taken into account that OST is an expensive intervention (33), the financial design of an OST programme is critical. In general, user fees often determine IDU uptake of a given service. For instance, respondents from several countries described the cost of an HCV test as considerable for IDUs, which significantly limits how many IDUs are tested (5).

Sharing Client Information with Parents

The respondents that replied to these questions reported that confidentiality, in the few cases where the respondent actually was familiar with the confidentiality situation, is often lacking when it comes to informing parents. However, our survey revealed much uncertainty among respondents with regard to confidentiality and participation in NEPs, as respondents from six countries either did not know or did not reply to this question.

There was even less information on whether parents of IDUs on OST are notified; only the Moldovan and Ukrainian respondents described the situation in their countries, and their multiple respondents were contradictory. This lack of knowledge among public health experts make it impossible for us to assess the state of OST confidentiality in the region.

Sharing Client Information with Public Agencies

According to our respondents, it is not common for harm reduction programmes to share individual client information with public authorities. Note that we did not take legislation on drug use into account, which can have a substantial effect on whether such information-sharing, particularly with law enforcement agencies takes place.

In nine of the 11 countries we studied, respondents said that the confidentiality of personal information such as HIV status is protected by legislation or decrees. However, in practice we were informed that the laws are not always followed.

Public Health Implications of Restricted Access

The three barriers examined have implications for the use of health care services targeting IDUs in the region, as well as for HIV and HCV prevention efforts. Every country in eastern Europe has signed international declarations committing it to improve IDU access to HIV prevention programmes (20, 34). According to our respondents, barriers to access still remain in all 11 countries, while the coverage of harm reduction programmes investigated in this study is far from optimal.

External donors often have a great influence on whether a particular harm-reduction programme is available or not because they provide much of the funding (11). This point was illustrated by the Moldovan respondent who stated that the supply of HCV tests was limited because donors were not as involved in HCV prevention as HIV prevention. In addition, this study revealed that some public health experts in the region display a considerable lack of knowledge about hepatitis C testing. This finding reflects a general lack of international focus on the HCV epidemic, something that may be remedied by the new annual World Hepatitis Day and by the creation of the World Hepatitis Alliance (35), which is expanding into eastern Europe. A future challenge lies in extending the knowledge on both HCV and evidence based harm reduction services and their significant impact on preventing HIV and HCV transmission.

The Future Reforms of Harm Reduction Policies

A new United Nations report provides technical guidance to countries on setting national targets for scaling up towards universal access to HIV/AIDS prevention, treatment and care for IDUs (36). In addition, the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) has provided basic operational guidance on medical services including testing with regards to HIV and HCV as well as other infectious diseases in IDUs (37).

Multilateral organizations, non-governmental organizations and public health professionals recommend that vulnerable groups including IDUs should be involved in designing these programmes to minimize obstacles to access (4, 16, 38). Such programmes have been criticized for rarely involving IDUs in their development and implementation (38), which is one reason that client needs are not being met.

Removing structural barriers is critical in making access to health care services universal. However, it is important to remember that the decision to use health care services should always be up to the individual. The Universal Declaration on Human Rights (http://www.un.org/Overview/rights.html) and its following convention The International Covenant on Civil and Political Rights (http://www.hrweb.org/legal/cpr.html) (as well as the European Convention on Human Rights (http://conventions.coe.int/Treaty/en/Treaties/Html/005.htm)) all protect the right to liberty, privacy and the freedom of expression, which are all recognized human rights.

CONCLUSIONS

This study reports the findings of 20 experts on three of the principal access barriers to IDU harm reduction programmes in 11 eastern European countries: age restrictions, user fees and lack of confidentiality, in terms of informing parents when young IDUs participate, in NEPs, OST, HIV testing and HCV testing.

At least one of the barriers we investigated was present in each responding country. However, the few experts that responded to our survey had little knowledge of confidentiality rules and practices. Barriers for IDU access to HIV and HCV prevention efforts can have serious public health implications because they are likely to reduce the utilization of these services by the region's largest risk group for both viruses – as well as reducing contact between this group and health care systems in general.

While this study provides a worrying, albeit limited, portrait of the prevalence of key obstacles to harm reduction efforts in eastern Europe, additional research is needed on the particular conditions in each country. The reasons for resistance, be they political or by health care providers, clients or others, to these programmes also need to be investigated, as do the best ways to encourage access to and utilization of them.

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