BARRIERS TO HEPATITIS C DIAGNOSIS, MANAGEMENT AND TREATMENT AMONG PEOPLE WHO INJECT DRUGS IN 4 ASIAN COUNTRIES

A COMMUNITY LED STUDY IN INDIA, INDONESIA, MALAYSIA, & NEPAL

ANPUD
Asian Network of People who Use Drugs
ABOUT ANPUD

The Asian Network of People who Use Drugs (ANPUD) is the first registered regional network of people who use drugs in Asia. ANPUD is an issues based membership organization driven by the principle of Meaningful Involvement of People Who Use Drugs (MIPUD).

ANPUD was established by people who use drugs to:

- unify and amplify the voices of their communities
- advocate for changes in drug laws and policies that negatively affect their lives, and
- improve access to prevention, treatment and care services for people who use drugs across Asia.

Published in 2011 by:
Asian Network of People who Use Drugs (ANPUD)
51/2 Fl 3, Ruam Rudee Building III
Soi Ruam Rudee; Ploenchit Road,
Lumpini, Phatumwan,
Bangkok 10330, Thailand

© The contents of this document and methodologies, innovations and ideas herein remain the sole property of ANPUD. Readers may copy or translate this document for non-profit use, provided copies or translations are distributed free of cost.

Suggested citation: The Asian Network of People who Use Drugs, 2011. Barriers to hepatitis C diagnosis, management and treatment in four Asian Countries
# CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Abbreviations and acronyms</td>
<td>4</td>
</tr>
<tr>
<td>2. Acknowledgments</td>
<td>5</td>
</tr>
<tr>
<td>3. Executive Summary</td>
<td>6</td>
</tr>
<tr>
<td>• Key recommendations</td>
<td>8</td>
</tr>
<tr>
<td>4. Introduction</td>
<td>9</td>
</tr>
<tr>
<td>5. Overview of Hepatitis C</td>
<td>10</td>
</tr>
<tr>
<td>5.1 Regional overview of hepatitis C</td>
<td>10</td>
</tr>
<tr>
<td>5.2 India</td>
<td>12</td>
</tr>
<tr>
<td>5.3 Indonesia</td>
<td>12</td>
</tr>
<tr>
<td>5.4 Malaysia</td>
<td>12</td>
</tr>
<tr>
<td>5.5 Nepal</td>
<td>13</td>
</tr>
<tr>
<td>5.6 Thailand</td>
<td>13</td>
</tr>
<tr>
<td>6. Methods</td>
<td>13</td>
</tr>
<tr>
<td>7. Results</td>
<td>16</td>
</tr>
<tr>
<td>8. Discussion</td>
<td>22</td>
</tr>
<tr>
<td>9. Recommendations</td>
<td>23</td>
</tr>
<tr>
<td>10. References</td>
<td>24</td>
</tr>
<tr>
<td>11. Appendices</td>
<td>25</td>
</tr>
<tr>
<td>11.1 List of documents reviewed</td>
<td>25</td>
</tr>
<tr>
<td>11.2 Study team members</td>
<td>26</td>
</tr>
<tr>
<td>11.3 Consent form for PWID interviews/FGD</td>
<td>27</td>
</tr>
<tr>
<td>11.4 PWID survey questionnaire</td>
<td>28</td>
</tr>
<tr>
<td>11.5 PWID focus group discussion guide</td>
<td>31</td>
</tr>
<tr>
<td>11.6 Treatment providers survey questionnaire</td>
<td>33</td>
</tr>
<tr>
<td>11.7 Service providers survey questionnaire</td>
<td>37</td>
</tr>
</tbody>
</table>
1. Abbreviations and Acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
<td></td>
</tr>
<tr>
<td>AIVL</td>
<td>Australian Injecting &amp; Illicit Drug Users League</td>
<td></td>
</tr>
<tr>
<td>ANPUD</td>
<td>Asian Network of People who Use Drugs</td>
<td></td>
</tr>
<tr>
<td>ART</td>
<td>Anti-Retroviral Therapy</td>
<td></td>
</tr>
<tr>
<td>ATS</td>
<td>Amphetamine-type Stimulants</td>
<td></td>
</tr>
<tr>
<td>CBO</td>
<td>Community Based Organization</td>
<td></td>
</tr>
<tr>
<td>CCM</td>
<td>Country Coordinating Mechanism</td>
<td></td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
<td></td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
<td></td>
</tr>
<tr>
<td>HBV</td>
<td>Hepatitis B Virus</td>
<td></td>
</tr>
<tr>
<td>HCV</td>
<td>Hepatitis C Virus</td>
<td></td>
</tr>
<tr>
<td>HR</td>
<td>Harm Reduction</td>
<td></td>
</tr>
<tr>
<td>IEC</td>
<td>Information Education Communication</td>
<td></td>
</tr>
<tr>
<td>NGO</td>
<td>Non Government Organization</td>
<td></td>
</tr>
<tr>
<td>NSP</td>
<td>Needle Syringe Program</td>
<td></td>
</tr>
<tr>
<td>NSEP</td>
<td>Needle Syringe Exchange Program</td>
<td></td>
</tr>
<tr>
<td>OW</td>
<td>Outreach Worker</td>
<td></td>
</tr>
<tr>
<td>OST</td>
<td>Opioid Substitution Therapy</td>
<td></td>
</tr>
<tr>
<td>PLHCV</td>
<td>People living with HCV</td>
<td></td>
</tr>
<tr>
<td>PLHIV</td>
<td>People Living With HIV</td>
<td></td>
</tr>
<tr>
<td>PUD</td>
<td>People Who Use Drugs</td>
<td></td>
</tr>
<tr>
<td>PWID</td>
<td>People Who Inject Drugs</td>
<td></td>
</tr>
<tr>
<td>SOP</td>
<td>Standard Operating Procedure</td>
<td></td>
</tr>
<tr>
<td>SP</td>
<td>Service Provider</td>
<td></td>
</tr>
<tr>
<td>SVR</td>
<td>Sustained Virologic Response</td>
<td></td>
</tr>
<tr>
<td>TAG</td>
<td>Technical Advisory Group</td>
<td></td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>TP</td>
<td>Treatment Provider</td>
<td></td>
</tr>
<tr>
<td>TSF</td>
<td>Technical Support Facility</td>
<td></td>
</tr>
<tr>
<td>TTAG</td>
<td>Thai AIDS Treatment Action Group</td>
<td></td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
<td></td>
</tr>
<tr>
<td>UNAIDS-RST</td>
<td>Joint United Nations Programme on HIV/AIDS-Regional Support Team</td>
<td></td>
</tr>
<tr>
<td>UNODC</td>
<td>United Nations Office on Drugs and Crime</td>
<td></td>
</tr>
<tr>
<td>WAC</td>
<td>World AIDS Campaign</td>
<td></td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
<td></td>
</tr>
</tbody>
</table>
2. Acknowledgments

Infection with the hepatitis C virus is a major threat to the health of people who use drugs (PUD) in Asia, and action against it is perceived as a priority, and an urgent need, by this community. The Asian Network of People who Use Drugs (ANPUD) has recognised this need, and has therefore undertaken this study to document barriers to hepatitis C diagnosis, management and treatment among People Who Inject Drugs (PWID) in Asian countries.

This community led study would not have been possible without the strong support and cooperation of the community of PWID and several of the stakeholders involved. ANPUD would like to express our gratitude to the PWID who volunteered to participate in the survey. Without their cooperation, the study would have not been possible.

ANPUD is grateful to our donors and supporters, the Open Society Foundation (OSF), New York; Joint United Nations Programme on HIV/AIDS - Regional Support Team (UNAIDS-RST), Bangkok; Technical Support Facility (TSF) in Malaysia and Nepal; World AIDS Campaign (WAC); and Australian Injecting & Illicit Drug Users League (AIVL) for supporting the process of the study and programs at the country level.

ANPUD thanks the Technical Advisory Group (TAG) for their valuable input and guidance towards making the study a success: Professor Lisa Maher, Dr Nick Walsh, Professor Nick Crofts, Jimmy Dorabjee, and Anand Chabungbam.

ANPUD thanks the consultant Ms Sangeeta Sraan Singh for her involvement and assistance in the study from the planning phase to the final report.

We would also like to convey our sincere thanks to the four country data collection teams, Mr Giten Khwairakpam - Regional Program Coordinator of 7 Sisters and the Secretariat staff of ANPUD for their time and contribution to the study.

Last but by no means least; the study team would like to express our thanks to the Executive Board Members of ANPUD for their continued guidance, support and cooperation in making the study a success.
3. Executive Summary

Exposure to HCV is very common among PWID in Asia, as elsewhere; it is virtually universal among PWID living with HIV. However, the response to the HCV epidemic among PWID in the Asia and Pacific regions is almost non-existent, compared with the scale of the epidemic. While needle and syringe programs (NSP) are being established in many countries, and opiate substitution programs are being introduced and in some cases scaled-up, these programs are being driven by the need to control HIV – and are currently inadequate in scale to achieve this. While access to anti-retroviral therapy (ART) is increasing, the currently coverage and scale is inadequate, and does not take into account of the impact of untreated HCV co-infection.

Emerging challenges, or those previously existing but only now being recognised, are having an impact on efforts to control and respond to HIV, and will continue to do so; these include viral hepatitis co-infections (B and C), and dramatically changing patterns of drug use, especially the massive rise in the use of amphetamine-type stimulants (ATS), which are increasingly being injected in the region.

Given the much higher prevalence of HCV than of HIV among PWID in the region, and its much higher ‘infectiousness’ (i.e. a much smaller amount of blood necessary to carry infection), the coverage of preventive interventions necessary to control HCV transmission will be much greater than that necessary to control HIV transmission in the same communities.\(^\text{10,11}\)

HCV infection can be treated effectively with pegylated interferon and ribavirin combination therapy. However, the current cost of pegylated interferon is so high that the treatment is either not available or affordable for the vast majority of people who need it in low and middle income countries. Pharmaceutical companies hold patents on these drugs, and there are currently no generic versions available; Schering Plough’s patent on pegylated interferon α2b expires in 2015, while Roche’s patent on pegylated interferon α2a expires in 2017.

Co-infection with HCV and HIV increases morbidity and mortality and complicates treatment for both: poorer outcomes on ART, “flares” of HCV-related disease during immune reconstitution, less tolerance of treatment interruptions and a reduced response to HCV treatment.\(^\text{12,13}\) Increased treatment access for HCV is most urgent in those regions where co-infection with HIV is most prevalent, across Asia and in Eastern Europe; it is here that HIV epidemics are driven by largely uncontrolled epidemics among and from PWID – so HIV/HCV co-infection is a major feature of such epidemics.

The primary challenge for clinicians and patients for the treatment of hepatitis infections in low- and middle-income countries is the high cost of medicines.

WHO, UNAIDS and UNODC guidelines setting targets for national governments for universal access to HIV prevention, care and support include treatment for HCV and hepatitis B virus as part of the comprehensive package of services for PWID,\(^\text{14}\) but countries are unable to implement these treatments at scale because of their expense.

It is against this background that ANPUD embarked on this project, to begin to investigate and document the barriers to diagnosis, management and treatment of HCV amongst PWID. Four countries were chosen for the pilot study: India, Indonesia, Nepal and Malaysia, as being representative of these wide and varied regions.

This investigation and documentation provides some of the necessary foundations for the next steps, in which ANPUD will develop a regional hepatitis C advocacy strategy based on the study findings. These findings will help ensure that this strategy addresses the key issues in a prioritised manner, responding to and being driven by the needs of the community.
Findings

- A total of 189 PWID were interviewed, roughly a quarter from each country. Most (90%) were male, most (82%) were in the age range 18-40 years; half were unmarried, and a third married, of whom a quarter had children. Most (87.3%) had some education, and two-thirds had some employment, but a third had a monthly income less than USD100.

- Most (86%) were aware of HCV, their main source of information being their peers; but detailed knowledge was sparse. High proportions (40%+) reported sharing injecting equipment, and only 29% of sexually active respondents reported always using condoms during sex.

Blood borne viruses

- Testing: A majority (56%) had never been tested for HCV, most were unsure if they should be and how and what results would mean to them; but most (85%) wanted to be tested. (Over half were not sure if their government provides HCV testing or not). More than 90% had been tested for HIV. Malaysia was the standout country in terms of provision of free HCV testing at government laboratories; elsewhere, testing was predominantly charged for at private labs. Reported cost of viral testing is very high: USD92-188 for Viral load, USD104-251 for Genotype.

- Prevalence:  
  - India: 82% HCV+ve, 43% HIV+ve (half on ART)  
  - Indonesia: 82% HCV+ve, 58% HIV+ve (59% on ART)  
  - Malaysia: 68% HCV+ve, 12.5% HIV+ve (all on ART)  
  - Nepal (a younger sample): 18% HCV+ve, none HIV+ve

Treatment for HCV

- Only six (11%) HCV-infected PWID were on treatment. Only three had achieved a sustained virologic response (SVR).

- There was enormous variation in provision of treatment services for PLHCV across the two regions: in SE Asia, most accessed government facilities; in South Asia, there was little government service provision, and they accessed private facilities and NGOs. The costs were high, and the majority sold property and went into debt to fund their treatment.

- Most of those HCV-infected desired and planned to seek treatment; the main reasons for not seeking treatment among those who knew were the high cost, side effects and fear of disclosing drug use; but many did not know about treatment of HCV.

HCV Prevention and education

- IEC materials on HCV were very limited, provided by donors or developed by NGOs themselves, and there was no advocacy on HCV due to lack of resource materials. There is some awareness building, some pre- and post-test counselling, but nowhere part of national program for PWID.

Treatment of HCV infection

- Treatment of HCV with Pegylated Interferon+Ribavirin are available in all countries except Nepal, but were extremely expensive, USD11,255-18,202 just for the medications.

- No specific guidelines or Standard Operating Procedures (SOP) for treatment of HCV among PWID exist: in the SE Asia countries there are generic (WHO) guidelines. However, most physicians would not consider treating a current user, even if stabilised on OST.
Key Recommendations

- Rapidly bring evidence-based, comprehensive Harm Reduction programs to scale, with the aim of abolishing transmission of HCV among PWID.
- Increase the awareness of the PWID community by providing comprehensive and accurate information on HCV through an Information Communication Education (IEC) campaigns, treatment literacy programs and targeted media.
- Build capacity of harm reduction programs to develop and support HCV peer educators and their outreach to their communities.
- Provide access to HCV antibody testing and follow-up diagnostic tests (RNA, genotyping) where indicated to the PWID community urgently, with routine pre- and post-test counselling services using a counselling protocol which should also be developed urgently.
- Include HCV screening in country routine infectious diseases surveillance mechanisms, as for HIV.
- Increase capacity of service providers to provide appropriate and high quality diagnosis, care, treatment and support for PLHCV.
- Sensitize stakeholders, especially governments, bureaucracy, donors and multilaterals to issues regarding HCV infection
- Include Pegylated Interferon and Ribavirin in WHO and individual country’s Essential Medicines List.
- Advocate for reduction of the current price of Pegylated Interferon.
- Increase political commitment to exercise legal, TRIPS flexibilities (such as compulsory licences and parallel importation) to gain access to cheaper hepatitis C treatment.
- Ensure Government commitment to treat (and pay for treatment) PLHCV (not excluding PWID) and adopt price reduction strategies including TRIPS flexibilities and negotiation with brand-name producers of HCV medicines.
4. Introduction

More than 20 years after its discovery, it is now well established that the hepatitis C virus (HCV) is a major health issue of global importance, and one which requires concerted, active and comprehensive interventions for its prevention and for diagnosis, treatment, management and care of people living with the virus and its effects on their health and quality of life.

With an estimated 170 million people infected worldwide, HCV has been described by the World Health Organization (WHO) as a ‘viral time bomb’ due to both its prevalence and its potential for causing serious, even life-threatening complications. Although HCV is treatable, HCV treatment remains largely inaccessible for people living with hepatitis C, primarily due the high cost of treatment that limits both governments’ and individual’s ability to pay for treatment.

Historically, the human population reservoir of HCV predated that of HIV. HCV prevalence expanded markedly from the 1960s, associated with a number of factors including the increased use of syringes for both medical and non-medical purposes, the increased injecting of illicit drugs, and increased ease of travel with vastly increased population mixing, allowing and promoting global spread of HCV.1,2

In some places at some times, particular circumstance has led to high rates of HCV infection among whole populations (e.g. Ref 3); but in general, over the last few decades, HCV infection has been highest among those populations at risk of exposure to the blood of HCV-infected people; and in general, this has meant those in receipt of unscreened blood or blood products, and those who inject drugs. With the institution of universal donor screening for HCV, the sole major population now at risk of HCV infection in most countries is that of PWID. In many places, spread of HCV among PWID is extremely rapid – for instance, in Manipur State in India, over 80% of young PWID had been exposed to HCV within twelve months of beginning to inject.4,5,6

In Asia, HCV spread increased through the 1970s and 1980s, especially among PWID, associated with increased availability of heroin, increased injecting, and increased mobility and population mixing, enhanced especially by incarceration in prisons and compulsory detention. Regionally, HCV had spread widely before HIV arrived in the same populations; individually, given its greater prevalence and infectiousness, it is usual for the PWID to have been exposed to HCV before being exposed to HIV. Prevalence of HCV exposure and infection is much higher among PWID in the region than of HIV infection.

Patterns of HCV infection worldwide continue to evolve,7 but generally in the direction of further epidemics among the PWID communities globally: emerging PWID populations are constantly being exposed to HCV, and incidence of HCV infection remains high among PWID except for a few instances where concerted harm reduction efforts, led by and in concert with the affected communities, have seen decreases.8 These latter instances remain rare, but do indicate what might be achieved with political will and adequate resources.

Given the much higher prevalence of HCV than of HIV among PWID in the region, and its much higher ‘infectiousness’ (i.e. a much smaller amount of blood necessary to carry infection), the coverage of preventive interventions necessary to control HCV transmission will be much greater than that necessary to control HIV transmission in the same communities.9,10 However, factors promoting the transmission of HCV among PWID also increase in the region: lack of harm reduction programs and policies, criminalisation and incarceration in prisons and detention centres, marginalisation and lack of access to health services. Relevant data are not collected, or collected inadequately, so that even to advocate for action can be difficult, with a parlous evidence base. But there is enough knowledge about the magnitude, character and impact of this devastating epidemic that inaction is unpardonable.

20 years on from its discovery, the lack of adequate action to date to counter the HCV epidemic among the most marginalised is no excuse for a lack of action now and into the future; this study has been carried out to make the voice of the PWID community heard, to stimulate needed action. And history shows that if this action is to be effective, it must be led by and in partnership with the affected communities, and must address the human rights issues which underlie the current failure to act.

The rationale for the study

1. For reasons of equity, human rights, ethics, effectiveness and efficiency, there is a clear need for community voices and participation at all levels in harm reduction, HIV and HCV prevention, and drug dependency treatment.21 Recent initiatives and progress in decreasing the spread of HIV in Asia among PWID have highlighted the need to address hepatitis C, and all its associated issues. The WHO strategy to halt and reverse the HIV epidemic among people who inject drugs in Asia and the Pacific 2010-2015 clearly articulates the need to begin dealing with HCV-related issues.22 ANPUD played a major role in the development of this strategy, and is engaged in tackling HCV issues among PWID, together with WHO, UNAIDS and UNODC.
At the country level, little has been done either to measure and document the HCV epidemic, especially among PWID, or to gather the qualitative information necessary for understanding its basis and meanings. There is therefore little enough information available for advocacy purposes, and regional, national and community based organizations currently struggle to provide the evidence to advocate for increased access to HCV diagnosis, management and treatment. There is, however, sufficient information about and understanding of the HCV epidemic and its impact in Asia to know that urgent action is necessary to address this epidemic.

The present study has attempted to document gaps in services provided, issues relating to access to services, and gaps in the knowledge (at both the individual and the service provision levels) necessary to guide an effective response to HCV and related issues among PWID in Asia. The findings will inform the development of a regional HCV advocacy strategy for ANPUD, to assist the community of PWID and other stakeholders to persuasively advocate for the introduction and inclusion of HCV diagnosis, management and treatment in policy and practice at country level, inclusive of PLHCV and PWID.

5. Overview of Hepatitis C

Globally, it is estimated that approximately 170 million people are chronically infected with the hepatitis C virus, the vast majority through exposure to infected blood. In developed and many developing country settings, the large majority (60-80%) of these exposures are associated with injecting drug use.13

5.1 Regional overview of hepatitis C

According to UNAIDS, more than 4.5 million people in Asia are estimated to inject drugs, putting them at risk of HIV and HCV infection. Exposure to HCV is very common among PWID in Asia, as elsewhere; it is virtually universal among PWID living with HIV. Little is known about the natural history of HCV infection in PWID in Asia; however, the adverse clinical impact of HCV co-infection with HIV is becoming recognised as ART becomes more widespread.14

Responses to the epidemics of HCV among PWID are virtually non-existent in most low- and middle-income countries. In Asia, countries are just beginning to address HCV. The document “A strategy to halt and reverse the HIV epidemic among people who inject drugs in Asia and the Pacific for the years 2010 - 2015” is a regional strategy to remove the barriers to universal access and harm reduction so as to halt the spread of HIV and HCV among PWID in Asia and the Pacific.12 It was first proposed by WHO and has been developed by the United Nations Regional Task Force on Injecting Drug Use and HIV/AIDS for Asia and the Pacific, in consultation with many other partners. It identifies issues and priorities and provides guidance to countries in the region for developing national strategic responses over the next six years.
In general, there is little information available about HCV in the region, especially when compared with that available about HIV. The data presented here, on both epidemiology and coverage, represent the best estimates currently available; however, lack of uniformity in measures, data collection methodologies and definitions renders cross-national and regional comparisons difficult.

**HCV/HIV Co-infection**

It is estimated that 4-5 million people living with HIV are co-infected with the HCV globally.\(^{15}\) It has further been estimated that there are two to nine million IDU living in the Asia-Pacific Region, of whom an estimated 750,000 PWID are living with HIV.\(^{16}\)

Although data are scarce, many Asian and Eastern European countries have extremely high HCV prevalences among PLHIV. In parts of China, Thailand and Vietnam, for example, where injecting drug use is a key driver of HIV epidemics, the prevalence of HCV co-infection among PLHIV is over 95%.\(^{16}\) Similarly, in Russia and the Ukraine, 70-95% of people living with HIV are co-infected with HCV.\(^{17,18}\) In countries where HIV is predominantly sexually transmitted, HIV/HCV co-infection prevalence may be low among PLHIV in general, but remains much higher among PLHIV who inject drugs (for example, in Manipur, India).\(^{17,18}\)

In fact, the vast majority of people living with HIV/HCV co infection have acquired these viruses through the sharing of equipment when injecting drugs. In many settings, 90% or more of new HCV infections are transmitted through sharing equipment associated with injecting drugs.\(^{17,18}\)

Co-infection with HCV and HIV increases morbidity and mortality and complicates treatment for both: poorer outcomes on ART, “flares” of HCV-related disease during immune reconstitution, less tolerance of treatment interruptions and a reduced response to HCV treatment.\(^{14}\)

<table>
<thead>
<tr>
<th>Countries/territory with reported injecting drug use</th>
<th>PWID</th>
<th>Adult HIV Prevalence amongst PWID</th>
<th>Adult HCV Prevalence amongst PWID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afghanistan</td>
<td>6,900</td>
<td>3.4%</td>
<td>36%</td>
</tr>
<tr>
<td>Bangladesh</td>
<td>30,000</td>
<td>1.35%</td>
<td>48.2%</td>
</tr>
<tr>
<td>Cambodia</td>
<td>1,750</td>
<td>22.8%</td>
<td>74%(^1)</td>
</tr>
<tr>
<td>China</td>
<td>2,350,000</td>
<td>12.3%</td>
<td>62%– 67%</td>
</tr>
<tr>
<td>India</td>
<td>164,820</td>
<td>11.15%</td>
<td>26% - 93%</td>
</tr>
<tr>
<td>Indonesia</td>
<td>219,130</td>
<td>42.5%</td>
<td>60% - 98%</td>
</tr>
<tr>
<td>Malaysia</td>
<td>205,000</td>
<td>10.3%</td>
<td>67.1% - 81%</td>
</tr>
<tr>
<td>Myanmar</td>
<td>75,000</td>
<td>42.6%</td>
<td>79.2%</td>
</tr>
<tr>
<td>Nepal</td>
<td>22,050</td>
<td>41.39%</td>
<td>87.3%- 94%(^3)</td>
</tr>
<tr>
<td>Pakistan</td>
<td>130,460</td>
<td>10.8%</td>
<td>84%</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>not known</td>
<td>not known</td>
<td>not known</td>
</tr>
<tr>
<td>Thailand</td>
<td>160,528</td>
<td>42.5%</td>
<td>69.8%</td>
</tr>
<tr>
<td>Vietnam</td>
<td>135,305</td>
<td>33.85%</td>
<td>74.1%</td>
</tr>
</tbody>
</table>

Table 1. Estimated numbers of PWID, and HIV and HCV prevalences among PWID, for selected Asian countries.


1. G Shaw, pers comm.
5.2 INDIA

<table>
<thead>
<tr>
<th>Estimated number of PWID</th>
<th>Estimated HIV Prevalence amongst PWID</th>
<th>Estimated HCV Prevalence amongst PWID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male: 96,463–189,729</td>
<td>7.2% (2007)</td>
<td>92% (national)</td>
</tr>
<tr>
<td>Female: 10,055–33,392</td>
<td></td>
<td>26–93% (individual Sites)</td>
</tr>
</tbody>
</table>

In India's 2010 UNGASS report, it is stated that there were 7 of a total of 49 districts with PWID sites where HIV prevalence among PWID was over 15%. The highest HIV prevalence amongst this population group was reported in Amritsar at 30.4%, followed by two sites at Churachandpur and Chennai at 28% and 27.2% respectively. In Delhi North and Aizawl the prevalence estimates were 20% and 16.6% respectively. While HIV prevalence among PWID has been reported at up to 30% in some sites, the estimated prevalence of HCV among PWID stands at 92%. Given these figures, it is likely that most PWID who are living with HIV are co-infected with HCV.

At the HIV/HCV Co-infection - "Planning The Way Forward", 1st South and Southeast Asia Regional Community Meeting held in Bangkok in June 2010, participants from India highlighted that there is a lack of information about HCV in the country compared to HIV and that screening for HCV is currently not included in the national surveillance programme. There is a real need for doctors to be equipped with the necessary information and skills to treat people with a HIV/HCV co-infection.

5.3 INDONESIA

<table>
<thead>
<tr>
<th>Estimated number of PWID</th>
<th>Estimated HIV Prevalence amongst PWID</th>
<th>Estimated HCV Prevalence amongst PWID</th>
</tr>
</thead>
<tbody>
<tr>
<td>190,460–247,800 Mean: 219,130</td>
<td>52%</td>
<td>60–98%</td>
</tr>
</tbody>
</table>


The HIV epidemic in Indonesia is among the fastest growing in Asia. At the end of 2009, it was estimated that there were 333,200 people living with HIV in Indonesia. The cumulative number of reported AIDS cases has risen sharply from 2,682 cases in 2004 to 19,973 by December 2009.

At the HIV/HCV Co-infection – “Planning The Way Forward”, 1st South and Southeast Asia Regional Community Meeting held in Bangkok in June 2010, representatives from Indonesian National PLHIV Network informed that:

- an estimated 7 million people are living with HCV in Indonesia (Ministry of Health, 2009)
- there is an estimated 60% to 90% HIV/ HCV co-infection rate among PWID. (Yayasan Pelita Ilmu (YPI), Yayasan Harapan Permata Hati Kita (YAKITA), 2007).

5.4 MALAYSIA

<table>
<thead>
<tr>
<th>Estimated number of PWID</th>
<th>Estimated HIV Prevalence amongst PWID</th>
<th>Estimated HCV Prevalence amongst PWID</th>
</tr>
</thead>
<tbody>
<tr>
<td>170,000</td>
<td>22.1%</td>
<td>67.1%, 85%, 20%</td>
</tr>
</tbody>
</table>


The HIV epidemic in Malaysia is mainly driven by injecting drug use and heterosexual transmission. Amongst men, the main mode of HIV transmission continues to be via injecting drug use where HIV prevalence is estimated to be 22.1%.

5.5 NEPAL

<table>
<thead>
<tr>
<th>Estimated number of PWID</th>
<th>Estimated HIV Prevalence amongst PWID</th>
<th>Estimated HCV Prevalence amongst PWID</th>
</tr>
</thead>
<tbody>
<tr>
<td>38,750 (2006)</td>
<td>35%</td>
<td>85.5% Kathmandu valley</td>
</tr>
</tbody>
</table>


There is not much data or information that has been published on the situational analysis of HIV and hepatitis C in Nepal. At the HIV/HCV Co-infection – “Planning The Way Forward”, 1st South and Southeast Asia Regional Community Meeting held in Bangkok in June 2010, representatives from Nepal informed that treatment for HCV is not available in Nepal, and that most patients are referred to India.

5.6 THAILAND

<table>
<thead>
<tr>
<th>Estimated number of PWID</th>
<th>Estimated HIV Prevalence amongst PWID</th>
<th>Estimated HCV Prevalence amongst PWID</th>
</tr>
</thead>
<tbody>
<tr>
<td>38,380 (2004 data)</td>
<td>48%</td>
<td>90%</td>
</tr>
</tbody>
</table>

The statistics on HIV and HCV among PWID in Thailand are staggering. These numbers most likely underestimate the severity of HIV and HCV among Thai PWID because of the lack of accurate data on PWID in Thailand and even fewer studies assessing the prevalence of HCV co-infection.

In the report “Illuminating a hidden epidemic: the public health crisis of HIV/HCV co-infection among injecting drug users (PWID) in Thailand”, in 2010, the Thai AIDS Treatment Action Group estimates that of 610,000 Thais living with HIV, at least 5-10% contracted HIV from injecting drugs, at least half (50%) of PWID in Thailand are living with HIV/AIDS., and up to 90% of Thai PWID have contracted HCV. They comment that “These numbers most likely underestimate the severity of HIV and HCV among Thai PWID because of the lack of accurate data on PWID in Thailand and even fewer studies assessing the prevalence of HCV co-infection.”

6. Methods

Summary

The study was carried out in four countries in South and SE Asia, chosen for their representativeness of widely varying situations across the regions, in mid-2011.

In each country, the study consisted of three parts: a survey of PWID, group discussions with PWID, and interviews with service providers (NGOs and CBOs) and treatment providers (physicians). A consultant worked with peer interviewers in each country, and consolidated and analysed the results, under the guidance of an international Technical Advisory Group.

Aim

To contribute to the development of a basis for community-led advocacy for effective HCV policy and programming for PWID in Asia

Objectives

- To better understand the needs of the PWID community in Asia in relation to the HCV epidemic and its impact upon them and meaning to them;
- To better understand the nature and scale of the current response to the HCV epidemic and its impacts;
- To identify shortcomings and needs in relation to knowledge of HCV among the affected communities, service and treatment providers and other stakeholders;
- To identify shortcomings and gaps in provision of and access to services for PLHCV and treatment of HCV infection and disease.
Technical Advisory Group

The technical advisory group (TAG) formed for the study provided necessary technical support, reviewed and approved all tools developed for data collection, provided comments on the draft report and approved the final study report. Membership of the TAG:

- **Professor Nick Crofts** - Professorial Fellow in International Health
  Melbourne School of Population Health
  University of Melbourne, Australia.

- **Dr. Nick Walsh** - Public Health Physician,
  Consultant in Substance Use

- **Professor Lisa Maher** - Program Head & NHMRC Senior Research fellow
  Viral Hepatitis Epidemiology & Prevention program
  Kirby Institute, Sydney, Australia

- **Jimmy Dorabjee** - Principal Fellow Harm Reduction,
  Burnet Institute for Medical Research and Public Health, Australia
  Chairperson, Asian Network of People who Use Drugs

- **Anand Chabungbam** - Coordinator, Regional HCV Initiative,
  Asian Network of People who Use Drugs

Study Sites and Partners

The four countries in which the study was carried out were India and Nepal in South Asia, and Indonesia and Malaysia in SE Asia. These countries were chosen because resources were inadequate to conduct the study in all countries in South and SE Asia; because these four are broadly representative of both drug use, with high prevalence of use, and of the issues confronting PWID in Asia in relation to their drug use, HIV and HCV; and because ANPUD has partners in each of these countries capable of assisting in the country study. As well, ANPUD has been successful in either establishing or strengthening the country network of PUD in these countries and already had contacts in these countries.

Study sites: India - Delhi and Manipur; Indonesia - Jakarta and West Java; Malaysia - Penang and Alorstar; Nepal – Kathmandu and Pokhara.

Study Methods

I). Desk review of secondary literature (see Appendix 11.1 for list of references reviewed).

II). Interviews with PWID

Participant criteria: PWID were eligible for the study if they were self-referred or referred by staff of the NGO, had a history of injecting drugs and were over 18 years of age. In each country, 25 PWID respondents chosen randomly by staff of the local partner or self-referred were enrolled at each site, giving a sample of 50 PWID per country and 200 overall. The questionnaire/interview guide had 45 questions covering demographic characteristics, socio-economic profile, knowledge about hepatitis C, behaviour and practices in the context of vulnerability to hepatitis C, and access to treatment and services related to hepatitis C. The questionnaire was administered by the trained peer interviewer.

To understand the type of services available and gaps in addressing HCV among PWID in the four countries, Non-Governmental Organisations (NGO) working with PWID as Service Providers (SP) and/or as Treatment Providers (TP – in general, physicians), familiar with health issues of PWID, were administered a questionnaire. SPs and TPs were chosen by staff of the local partner organisation as having PWID clients and being familiar with the issues. A total of 15 NGOs and 15 physician were administered the questionnaire, two of each from each site except for Malaysia, where one of each was not enrolled (three rather than four per site).

III). Interviews with treatment providers (Physicians)

Physicians were eligible for the study if they were involved in providing treatment for HCV to PWID. From the two sites selected in each country for the PWID surveys, two physicians involved in provision of HCV treatment were chosen, for a sample of four physicians per country. But only 15 TP were interviewed (only 3 physicians were available for interview in Malaysia).
IV). Interviews with service providers (NGOs working with PWID)
NGOs and CBOs were eligible for inclusion in the study if they were delivering harm reduction or support services to a clientele that was predominantly PWID and their community. Similarly, two service provider organisations were chosen from each survey site in each country, for a sample of four organizations per country. But only 15 SPs were interviewed (only 3 service providers were available for interview in Malaysia).

V). Group Discussions
Again, two group discussions with 8-10 PWID in each group were held in each site, four per country and 16 overall. There were two main groups identified for the FGDs: PWID who had been treated for HCV and PWID who had not been treated for HCV. To avoid duplication of responses in the study, participants for the group discussions had not participated in any other component of the study.

Tools developed for the study (attached as Appendices)
- Consent form and Questionnaire for PWID
- Question guide for interviews with treatment providers.
- Question guide for interviews with service providers working with PWID.
- Checklist and prompting guide for group discussions with PWID

Data collection team
Twelve community representatives involved in HIV and PWID programmes in India, Indonesia, Nepal and Malaysia were selected and invited for the training, which was held from the 13th to 15th June 2010 in Bangkok.

The objective of the training was to equip the participants with all the necessary information and skills needed to play their respective roles in the study as data collectors. Primary objectives of the training were to provide the data collecting team with:
- core information about issues relating to HIV and HCV;
- an understanding of how the study is structured, and how the study would be implemented at country level;
- detailed information of the tools designed for the study, encouraging discussion on how the tools could be further adapted at ground level;
- an overview of the mapping assessment mechanisms and the application of selection criteria;
- the knowledge and skills to decide on the target groups to make contact with and areas for the study.

Limitations of the study
The PWID enrolled in the survey and in the discussion groups formed convenience samples from the different sites at which they were selected; responses may therefore not be representative of the experience of the entire community of PWID in any particular country; nor may their responses map the entire territory of the PWID experience. Inter-group comparisons are therefore fraught. This is similarly the case with the physicians, NGOs and CBOs interviewed. However, the study has collected a range of views and experiences which demonstrate a degree of consistency around key themes.
7. Results

7.1 People who inject drugs

Demographics

A total of 200 respondents participated, but only 189 questionnaires were usable with 49 in India, 50 in Indonesia, 40 in Malaysia and 50 in Nepal. While there was no quota sampling, female PWID were difficult to find; 90% (171) of the respondents were male, 9% female (17) and 0.5% (1) transgender.

The youngest PWID surveyed were 18, a criterion of enrolment; most were under 40 (see Figure 2). A large proportion (87.3%) of the overall sample had primary or secondary school education (Table 3). Those without formal education accounted for just 4.2% of the total. The level of education was broadly similar in the case of Indonesia, Malaysia and Nepal. The Indian sample, on the other hand, had a higher concentration of university graduates compared to the rest. The majority of the respondents (52.4%) were unmarried; 33.9% were married, and 13.7% were divorced, widowed or separated. Among those who were married 26% had one or more children.

The majority (64%) of respondents were employed; of 189, 141 had some source of income of their own. However the level of income was generally inadequate for their needs as well as those of their dependents. Almost half (47.5%) of the sample had spouse, children and parents dependent on them. Given the youthful nature of the sample from Nepal it was not surprising to note that only 29.2% reported having dependents. Among respondents, 32.6% had a monthly income of less than 100 USD per month, while 41.8% had a monthly income of less than 300 USD (Figure 3).

Knowledge about HCV

Of 186 usable responses, the majority (86%) had heard of HCV. However, it does not necessarily indicate that they have accurate and comprehensive information about HCV, as was clearly observed during the Group Discussions (GD); as for instance in these examples:

“I am not so aware about hepatitis C and I haven’t found anyone who knows detail of it. However I know that hepatitis C is not a big deal. It is a liver problem like jaundice”.

“I heard that among drug users 99% are hepatitis C positive. I also heard hepatitis C will go eventually when you slowly stop using drugs”.

“When I was diagnosed HCV positive, I started doing physical exercise every day because I heard that HCV can be cured if a person exercise, which means HCV goes out of your system once you sweat out”.

(PWID GD, Pokhara, Nepal, July 2011)

“If you continue to use your own needles for a long time like 6 months or so, even without sharing also you can get HCV”.

(PWID GD, Delhi, India, July 2011)
The most important source of information on HCV for these PWID was their peers (35.2%), followed by doctors (18.2%), counsellors (15.8%) and ORWs (14.5%). Peers were the major important source in India, Malaysia and Nepal, while ORW featured prominently in Indonesia and Nepal. Doctors were an important source in India, Indonesia and Malaysia as well (Figure 4).

While the majority (84%) responded that HCV can be transmitted through the sharing of injecting equipment, 5% of the sample responded “No” and another 11% did not know if sharing of injecting equipment can transmit HCV or not. This suggests that there is a reasonable degree of awareness regarding the risk of HCV transmission associated with sharing of injecting equipment, but some remaining major gaps in awareness. For instance, when the respondents were asked if sharing of drug cooking pot could spread HCV, only 49% responded in the affirmative while 22% were certain that it did not, and 29% responded that they ‘did not know’. This suggests that while awareness on the risk of sharing injecting equipment was relatively high, there is a need for further education on modes of transmission of HCV among PWID. The highest proportion of those who thought that sharing of drug cooking pots could spread HCV was found in the Malaysian sample (66.7%), and the lowest proportion was in the sample from Nepal (22.7%). The highest concentrations of those who were totally ignorant of whether such a practice could or could not spread HCV were found in the Indian (46.2%) and Nepali (43.2%) samples.

Injecting behaviours

Most (70.8%) of the respondents had injected drugs within the previous six months (Figure 5). In the Indian, Indonesian and Nepali samples, more than three quarters of the respondents reported injecting drugs over this period; the Malaysian sample was proportionately lower at 50%.

Most (60.5%) respondents reported that they did not share injecting equipment, but 39.5% reported sharing their injecting equipment over the last 6 months (Figure 6), this proportion being highest in India (over half) and Indonesia (nearly 46%). The Indian sample contained the highest proportion of respondents who thought sharing injecting equipment did not spread HCV.
Sexual behaviour

Two-thirds (65%) of respondents reported being sexually active over the previous six months. Sexual activity was highest among in the Indonesian (73.5%) and Nepali (75.5%) samples and lowest (53.2%) in the Indian sample. However, the Nepali was relatively younger and the Indian sample relatively older.

Only 29% of the respondents reported always using condoms during sex. A greater proportion (31%) never used condoms during sex, while the rest used them irregularly (Figure 7). The largest proportion of respondents who reported regular condom use was from the Indian sample (36.1%) and the lowest from the Malaysian sample (19.2%). In fact, in the Malaysian sample 46.2% never used a condom during sex over the previous six months.

Barriers in accessing HCV diagnosis, treatment and management

The majority (56%) of the respondents had never been tested for HCV. By jurisdiction, 52.2% of respondents from India, 56.3% from Indonesia, 46.2% from Malaysia and 66% from Nepal had not been tested for HCV. It was observed during the group discussions in all the sites in the four countries that the awareness and information related to HCV testing was low; for instance:

“I wanted to check my hepatitis C status but I feared I will not be able to afford the cost of the test. I always wonder why NGO are not providing hepatitis C testing”. (PWID GD, Pokhara, Nepal, July 2011)

“I did not know much about hepatitis C but before starting ART, the doctor advised me to go for hepatitis C testing and I was found to be positive. Now I have to live with two viruses”. (PWID GD, Manipur, India, July 2011)

Among those who were not tested (n=102), 96 PWID responded when asked if they wished to be tested for HCV infection. Most (85%) of the sample expressed the desire to be tested – more than 90% in India and Indonesia, and 78-79% in Nepal and Malaysia.

When asked if their government provides HCV testing, 32% said “Yes” and 16% said “No”, but the majority (52%) response was that they were not sure if their government provides HCV testing or not. The response only captures the knowledge of the respondent regarding the testing services provided by their respective governments; it is not an indication as to whether or not the service is actually being provided.

Overall 81 PWID respondents (44% of usable responses) knew and were willing to disclose their HCV status. Comparing these responses with those who had been tested for HCV (above) provides an estimate of HCV prevalence in the different countries: India - 81.8%, Indonesia - 81.8%, Malaysia - 68.2%, Nepal - 18.2%.

Only in the Malaysian sample was there a high reliance on government laboratories for HCV testing. Most (70%) of those who were tested for HCV in Malaysia were tested at a government laboratory; whereas in India and Nepal less than 15% of those tested did their test at a government laboratory. In Indonesia slightly over one third relied on a government laboratory.

Of those tested at a government laboratory, for nearly all the respondents in Malaysia (94.4%) the HCV test was done free of cost. In contrast, in Nepal only 35.7% tested at a government laboratory had their HCV test free of cost. In India and Indonesia the comparable proportions were 60.9% and 40.9%, respectively.

When asked if HCV testing was provided free of cost by their government, 58% of the sample said “Yes” and 42% said “No”, indicating a lack of clarity among respondents about testing facilities either provided or not by their governments.

HIV infection

More than 90% of the overall sample had tested for HIV. The Indonesian sample had the highest proportion of respondents who reported being HIV positive (58%) while Malaysia had the lowest (12.5%). In India, 42.9% of the total was positive, and in Nepal nobody was reported HIV positive.

Overall 60% of those who reported being HIV positive were on ART; 100% of the Malaysian, 58.6% of the Indonesian, and 52.4% of the Indian samples. In these three jurisdictions, the single most important provider of ART was government ART centres.
Hepatitis C related health services for PWID

There was enormous variation in provision of services for PLHCV across the four countries. In Malaysia, all 18 PWID living with HCV infection obtained health services from government facilities; in Indonesia, 75% obtained services from government facilities, 19% from private services and the rest from NGOs. In Nepal three out of the four HCV positive respondents obtained HCV-related health services from private facilities. In the Indian sample, NGOs provided health services for 87% of the HCV positive cases; government provision was low.

Only six out of the 55 HCV positive cases (10.9%) were on treatment. In Nepal, none of the 4 HCV positive people had received treatment ever; in India only 2 of the 18 people had received treatment (Interferon and Ribavirin); in Indonesia, only 3 out of the 18 people reported receiving some kind of treatment (but not Interferon and Ribavirin); while in Malaysia only 1 of the 15 people was receiving treatment (Interferon and Ribavirin).

Only 2 cases from the Indian sample and 1 case from the Malaysian sample had achieved sustained virologic response. There was no response recorded in the samples from the other two jurisdictions.

To cover the cost of the treatment, one of the two HCV positive respondents who had received Interferon and Ribavirin treatment in India had exchanged property and borrowed money to cover the treatment costs. In Indonesia one of the 3 such people also had to rely on exchanged property and borrowed money to cover the cost of the treatment.

All 16 (out of the total of 18 HCV positive people) in India who were currently not on treatment expressed the desire to seek treatment in future. This was the case too for 6 (out of the 15) people in Indonesia, and 2 (out of the 4) cases in Nepal. All 14 (out of the 15 HCV positive people) who were presently not under treatment in Malaysia planned to seek treatment in future.

When asked for the reasons of not seeking treatment for HCV infection, the primary reasons from among the PWID respondents were ‘the high cost of the treatment’, ‘fear of side effects’, ‘did not know about treatment of hepatitis C’, ‘fear of disclosing drug use’ – all of which remain as major barriers towards their access to getting themselves treated.

“I heard that there is hepatitis C treatment in Kathmandu but too expensive. But where in Kathmandu, I don’t know”
(PWID GD, Pokhara, Nepal, July 2011)

“Once, a government doctor told me - if you have money we can talk about treatment, go … come later when you have money”
(PWID GD, Manipur, India, July 2011)

“Now many people are dying and I got scared and got tested and found to be HIV and HCV reactive. I was depressed because many people are dying in my locality; they are not dying of HIV but due to HCV with their skin getting blackened! Later, I heard that there is medicine to treat HCV and was happy but again became sad as the cost of treatment was very expensive”
(PWID GD, Manipur, India, July 2011)

7.2 Treatment and Service Providers

In general, Treatment (TP) and Service Providers (SP), aside from a few Indian TP, were unable to estimate HCV prevalence among PWID in their community; these few Indian TP provided an estimation of greater than 90% HCV prevalence among PWID in their settings. This is not surprising, as no HCV prevalence among PWID has been published by their governments.

Since all the respondents were working directly with PWID, the level of awareness on the risk of sharing injecting equipment in relation to transmission of HCV was extremely high. These respondents, especially the SPs, were already working with PWID on HIV-related programs with support from their government or donor agencies, but information, education and services related to HCV were not integrated across existing programs; though a few SP reported taking up some awareness initiatives within their own capacity.

Information Education and Communication (IEC) materials on HCV were very limited, with only three SP in Indonesia and one each in India and Nepal reporting disseminating such materials to PWID in the form of leaflets and bulletins. These materials were either provided by their donor or developed by the NGO themselves. No advocacy initiatives on HCV issues were observed among the respondents, due to lack of resource materials and tools.

Services related to hepatitis C available for PWID

The majority of the respondents reported the availability of various Harm Reduction (HR) services for PWID including needle and syringe programs (NSP), outreach services, condom distribution, counselling, and opioid substitution therapy (OST). However, the extent of the services amongst the countries and the respondents differed markedly: for instance, in India 100% of the SP reported providing needles and syringes to PWID, while only a third of the Malaysian SP respondents provide needles and syringe to PWID. In Indonesia and Nepal, 75% and 50% of the SP respondents reported providing needles and syringes to PWID respectively.
To ascertain how easily and supportively PWID were accessing health care services, issues around stigma and discrimination were discussed. The responses varied from country to country. However, despite more than two decades work to sensitize general communities and families, 73% of the SP respondents reported that PWID face stigmatization and discrimination from their family members, and Doctors and Paramedical staff in general health care settings (Figure 8).

Figure 8: Stigma towards PWID as perceived by SPs (n=15)

“When I was working for an NGO, I once took a very sick client to the hospital and the sisters (nurses) were not ready to touch the client”
(PWID GD, Delhi, India, July 2011)

“I found that at the hospital, when I revealed my drug use habit, they behave very differently. It’s easy if you don’t say anything about your drug use. Even if the doctor is not wearing a mask, he will wear it immediately when you say you are a drug user”.
(PWID FGD – Pokhara, Nepal-July 2011)

“Stigma and discrimination is still faced by PUD community. Current users get maximum abuse/discrimination. For e.g., at the ART centre the staff will say look at him, he is high on drugs – mocking”.
(PWID FGD – Manipur, India-July 2011)

“Bed number 4 is a drug addict, he needs dextrose said by one nurse to another in front of all the other general patient inside the ward in the hospital. The nurses will tell all other in the ward what I am suffering from and the risk”.
(PWID FGD – Manipur, India-July 2011)

“Some service providers say – stop your drug use first and come later for service. There is more SD in Government service provider... I was in MRI (NGO) 3 month, medical department I disclosed my status (HIV, HCV) and he told all other team/inmates to take care. Not to share drinking glass, keep distance between beds, warned other that body sweat is danger”
(PWID FGD – Manipur, India-July 2011)

The SPs interviewed reported initiating some activities around HCV across the countries. Awareness building on HCV was reported from all the four countries; while capacity building and pre- and post- HCV test counselling was reported from India and Indonesia only. These activities were observed not to be part of the national program for PWID. None of the SP reported any form of advocacy campaign around HCV issues, nor do they provide treatment services for HCV (Figure 9). However, during the group discussions, the majority of the PWID reported that most of the SP or other NGOs are not providing any information on HCV.

Figure 9: HCV-related activities undertaken by Service Providers (n=15)
“I never heard any NGO in our city talking about Hep C but they used to talk about HIV.”
(PWID FGD – Pokhra, Nepal- July 2011)

While 47% of the SP respondents reported that their government provides testing facilities for HCV, 33% did not know if the testing facility was available or not, and 20% reported the facility was not available (Figure 10).

Only one SP respondent, from Malaysia, reported that HCV testing was available free of cost at the government facility. All the other respondents reported that testing was not available free of charge in their government facilities.

Again, only one respondent, from Indonesia, reported that HCV pre- and post-test counselling was provided, while the rest of the respondents either said it was not or were unsure if it is being provided at government testing facilities.

The average estimated cost of HCV viral load and genotype testing as reported by the respondents are given in the below Table 2. Respondents from Nepal and Malaysia were generally not aware of the costs, with only one response each from these countries. These figures are average estimated costs of these tests as understood by the SP.

<table>
<thead>
<tr>
<th>Type of Test</th>
<th>India (cost in USD)</th>
<th>Indonesia (cost in USD)</th>
<th>Malaysia (cost in USD)</th>
<th>Nepal (cost in USD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCV Viral load test</td>
<td>132</td>
<td>92</td>
<td>188</td>
<td>126</td>
</tr>
<tr>
<td>HCV Genotype test</td>
<td>143</td>
<td>104</td>
<td>251</td>
<td></td>
</tr>
</tbody>
</table>

Table 2: Estimated average cost of HCV Viral load and Genotype test (n= 8 responses)

Majority of the respondents from India reported that the HCV viral load and genotyping test are mostly done in the private laboratory.

Treatment of HCV infection with Standard Interferon+Ribavirin or Pegylated Interferon+Ribavirin was reported to be available in India, Indonesia, Malaysia and Thailand. Both these treatment options were reported to be unavailable in Nepal.

The estimated costs of HCV treatment with Pegylated Interferon+Ribavirin as reported by the respondents are provided below in Table 3. However, these cost estimates do not include administration, monitoring, and side effects management cost.

<table>
<thead>
<tr>
<th>Country</th>
<th>Estimated cost of HCV treatment with Pegylated Interferon + Ribavirin for 48 weeks (cost in USD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>India</td>
<td>15,625</td>
</tr>
<tr>
<td>Indonesia</td>
<td>18,202</td>
</tr>
<tr>
<td>Malaysia</td>
<td>11,255</td>
</tr>
<tr>
<td>Nepal</td>
<td>Not available</td>
</tr>
<tr>
<td>Thailand</td>
<td>17,828</td>
</tr>
</tbody>
</table>

Table 3: Estimated cost of HCV treatment for 48 weeks

“The doctor told me that there is treatment available but it is costly. Since I don’t have money I still haven’t had treatment.”
(PWID GD, Manipur, India, July 2011)

There were no specific guidelines or Standard Operating Procedures (SOP) for treatment of HCV among PWID reported from any of the study countries. It is the individual TP who decides on selection criteria of clients. In most settings it was observed that the TP would not consider treating HCV in a current user, or even in those stabilised on Opioid Substitution Therapy (OST).

The majority of the respondents from India and Nepal reported that there are no guidelines on HCV treatment that have been developed by their governments. While respondents from Malaysia reported having general HCV treatment guidelines, adapted from western countries. Indonesian respondents also reported having their guidelines adapted from WHO guideline.
8. Discussion

HCV infection is endemic among PWID in Asia, as it is globally, at high prevalence. Information on the epidemiology of HCV, including prevalence and incidence among PWID, is poor or non-existent in most Asian countries, including those studied here.

The great majority of PWID interviewed in this survey who had been tested for HCV reported that they had been exposed; the majority of these were likely chronically infected. While very much a convenience sample of PWID in only four countries across Asia, they provide us with a very broad sample of life experiences in different settings – and common elements and experiences show through the more clearly, because of this wide variation.

The PWID interviewed tended to be young, in a sexually active and economically productive period of life. Information on current health status was not specifically sought, so the possible impact of their HCV infection on their lives is not known: but the severity of HCV disease with chronic infection suggests that with time, there will be significant health care and loss of productivity costs in this group. Studies are needed to gauge these costs, so as to estimate cost-effectiveness of different policy settings and responses to HCV.

Among the PWID themselves, most had heard of HCV but had poor understanding of its meanings, not having been educated; there was a dearth of educational material and programs, whether in government or NGO sectors. Among participants, awareness of risks of transmission of blood borne infections, including HCV, through the sharing of injecting equipment was high, but not perhaps detailed: many were not sure whether sharing of drug cooking pots could spread HCV.

As usual, peers are the main source of information on HCV (as on most other issues of importance) for most PWID interviewed. Depending on their availability, Peer counselors and Peer OW are valued as trusted sources of information. Occasionally, and unusually, individual physician also provides HCV related information, but this does not seem to be part of existing service delivery mechanisms in the public health systems in these countries.

A high proportion of the respondents who injected drugs in the last six months reported sharing of injecting equipment. As well, condom use among those who were sexually active in the last six months was inconsistent. Together the high rates of these behaviours give reason for grave concern about continuing HIV and HCV transmission among and from these PWID. The comprehensiveness and coverage of existing harm reduction services urgently need boosting.

Almost all the respondents who had not been tested for HCV expressed their desire to get tested, but in general they were not sure where to get testing done and if government provided testing free of cost. Among those who had been tested for HCV, the vast majority did not receive pre- and post-test counselling.

A very small proportion of the respondents have received HCV treatment. The primary reason for the majority not accessing treatment was the cost of treatment; other reasons included fear of side effects and ignorance regarding the availability of hepatitis C treatment. In India and Nepal, NGOs facilitate treatment for those who can afford it; in Indonesia and Malaysia, government plays a larger role.

Many of the respondents were also HIV positive, the majority of whom were on ART; however, it is rare for HCV status to be assessed or taken into account when initiating ART for HIV infection. There is therefore the possibility that the effectiveness of ART programs may be impaired, even substantially, by the existence of and failure to treat HCV infection.

Stigma and discrimination towards PWID is heavy in all the study countries. Programs for PWID must diligently strengthen activities which address stigma and discrimination from all stakeholders towards PWID. Unless this wider issue around stigma and discrimination is addressed in an inclusive manner targeting all the stakeholders, the impact of these programs is likely to be compromised to a great extent.

This is the case generally; but it is especially the case in relation to HCV issues. A particular challenge with HCV is that because it is generally not sexually transmitted, it is clear that the only major population group at risk are PWIDs; governments therefore have little to fear from inaction on HCV, because there is so little political benefit in it for them to act, and so little negative impact if they do not. In terms of building political will for action by government, therefore, it may be preferable to concentrate on building the core and collaborative constituency among services dealing with PWID issues and with HCV – NGOs and other service providers, physicians and others involved in HCV treatment and so on – to become members of an advocacy team and movement. Integrating HCV into on-going activities for PWID could be a cost-effective way of raising awareness and building capacity of the service providers and other stakeholders on issues around HCV, which is affecting the same population for whom they are working.

While majority of the PWID respondents wished to get tested for HCV, the lack of testing facilities and the cost of the test are major barriers.
The high cost of HCV treatment is the major barrier to access to treatment, even should it be available. None of the respondents mentioned intellectual property issues, or the patents on Pegylated Interferon. Though most of the respondents were keenly aware of the high price of Pegylated Interferon, they seemed to accept this as the natural state of affairs – there was no consideration of how costs might be brought down, and treatment made affordable. Demand for treatment needs to be generated among PWID, through community mobilization efforts that not only focus on educating the community about prevention and transmission of HCV, but also on building treatment literacy (particularly among co-infected people), and also education on why treatment is so expensive and how wrong this is, and what can be done about it.

There is an urgent need for the development of national policy on HCV, and just as urgent a need that this policy be focused around the core group, where the HCV is, where the need is – among the PWID Community.

9. Recommendations:

- Immediately increase access to HCV diagnostics and treatment by increasing services, integrating HCV services into primary health care and other health providers, decreasing costs.
- Increase number, comprehensiveness and coverage of evidence-based Harm Reduction programs to prevent further transmission of HCV among PWID.
- Increase the awareness of the PWID community by providing comprehensive and accurate information on HCV through IEC campaigns, treatment literacy programs and mass media.
- Develop the capacity of PWID peers as counsellors and educators and utilize their services while reaching out to the community.
- Provide access to HCV testing and follow-up diagnostic tests with mandatory pre and post-test counselling services to PWID community urgently. Counselling protocol should be developed on an urgent basis.
- Increase capacity of medical professionals and service providers to provide useful and meaningful HCV services, ensuring that not only are PWID not excluded from treatment because of their drug use, but they are in fact prioritised, as the community who are suffering most and in whom increased treatment will do the most good.
- Increase knowledge and understanding of HCV epidemiology including prevalence at country level; include HCV in the country communicable disease surveillance mechanisms.
- Working with WHO and national governments and other stakeholders, push for and lead development of national policy, guidelines and standard operating procedures based on international best practices for HCV treatment and care.
- Increase the capacity of the service providers and other relevant stakeholder on issues concerning HCV through sensitization and capacity building programs at the country level.
- Include Pegylated Interferon and Ribavirin in WHO and country’s Essential Medicines Lists.
- Advocate for reduction of the current price of Pegylated Interferon.
- Increase political commitment to exercise legal, TRIPS flexibilities (such as compulsory licences and parallel importation) to gain access to cheaper HCV treatment.
10. References


6. Hagan H et al recent meta-analysis


8. Declines in HCV incidence in Sydney and NY (Lisa Maher)

9. Kwon and Palmateer paper in Addiction


13. Ref to impact of HCV/HIV co-infection

14. Ref to impact of HCV/HIV co-infection


11. Appendices:

11.1 List of documents reviewed

5. Evolving epidemiology of HCV, D. Lavanchy, Clinical Microbiology and Infection Journal, February 2011
7. ibid.
8. Schering Plough’s patent on pegylated interferon α2b expires in 2015, while Roche’s patent on pegylated interferon α2a expires in 2017.
### Study Team Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Team position</th>
<th>Location/Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mr. Umesh Hidangmayum</td>
<td>Focal Person</td>
<td>Manipur/India</td>
</tr>
<tr>
<td>Mr. Henminlun Gangte</td>
<td>Peer Researcher</td>
<td>Delhi/India</td>
</tr>
<tr>
<td>Mr. Sunil Aheibam</td>
<td>Peer Researcher</td>
<td>Manipur/India</td>
</tr>
<tr>
<td>Mr. Samuel Nugraha</td>
<td>Focal Person</td>
<td>Jakarta/Indonesia</td>
</tr>
<tr>
<td>Mr. Suhendro Sugiharto</td>
<td>Peer Researcher</td>
<td>Jakarta/Indonesia</td>
</tr>
<tr>
<td>Mr. Edo Agustian</td>
<td>Peer Researcher</td>
<td>West Java/Indonesia</td>
</tr>
<tr>
<td>Mr. Bijay Pandey</td>
<td>Focal Person</td>
<td>Katmandu/Nepal</td>
</tr>
<tr>
<td>Mr. Dipu Joshi</td>
<td>Peer Researcher</td>
<td>Katmandu/Nepal</td>
</tr>
<tr>
<td>Mr. Roshan Sapkota</td>
<td>Peer Researcher</td>
<td>Pokhara/Nepal</td>
</tr>
<tr>
<td>Mr. Mohd Firdaus Zakaria</td>
<td>Focal Person</td>
<td>Penang/Malaysia</td>
</tr>
<tr>
<td>Mr. Mohd Razalee Ayub</td>
<td>Peer Researcher</td>
<td>Penang/Malaysia</td>
</tr>
<tr>
<td>Ms. Noor Siha Binti Abdul Wahab</td>
<td>Peer Researcher</td>
<td>Alorsetar/Malaysia</td>
</tr>
<tr>
<td>Ms. Sangeeta Sraan Singh</td>
<td>Consultant</td>
<td>Malaysia</td>
</tr>
<tr>
<td>Mr. Giten Khwairakpam</td>
<td>Regional Coordinator</td>
<td>7 Sisters/Bangkok</td>
</tr>
<tr>
<td>Mr. Dean Lewis</td>
<td>Regional Coordinator</td>
<td>ANPUD Secretariat/Bangkok</td>
</tr>
<tr>
<td>Mr. Anand Chabungbam</td>
<td>Coordinator-HCV Initiative</td>
<td>ANPUD Secretariat/Bangkok</td>
</tr>
</tbody>
</table>
Introduction
Asian Network of People Who Use Drugs (ANPUD) is the first registered regional network of people who use drugs. ANPUD was established by people who use drugs to:

• unify and amplify the voices of their communities
• advocate for change in drug laws and policies that negatively affect their lives, and
• improve access to prevention, treatment and care services across Asia.

ANPUD aims to focus its advocacy efforts by understanding the current situation related to the barriers to hepatitis C diagnosis, management and treatment among PWID. With this objective, ANPUD and country representatives from India, Indonesia, Malaysia and Nepal are conducting a small study to understand these barriers. The findings of this study will be used to inform and develop hepatitis C advocacy strategy on the urgent need to introduce policies and programs for the diagnosis and treatment of hepatitis C among PWID.

Before you agree to take part in this study, it is important that you understand the study procedures.

Study Procedures
As a participant with history of injecting drug use, you will be asked a series of questions related to your knowledge on hepatitis C, your health status as well as risk associated to injecting drug use behaviors. These responses will be recorded on paper and then keyed into an information system, where it will be further analysed and finally presented as an advocacy report to government, funders and key stakeholders.

If you are a part of the focus group discussion, a facilitator and a note taker will be present at the session where you together with 8-10 of your peers will be asked the similar questions as above. These sessions will be audio taped and transcribed, and the relevant sections will be included in the final report.

Participants’ Rights & Confidentiality
Your decision whether or not to participate in this study will not affect your medical care, or any other support you may currently be receiving. If you have read this form and have decided to participate in this study, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time.

Your identity will not be disclosed in any published and written material resulting from the study. Your responses will be collected anonymously, and the questions contained in this study are not meant to provide any information that can identify you. You are free to decline to answer any particular question you do not wish to answer for any reason or to end your participation at any time.

Time Involvement
Your participation in this study will take approximately 40-45 minutes.

Study Incentive
You will receive an incentive in appreciation of your time and commitment.

Benefits of study
This project will provide no direct benefit to individual participants, but the process will enable ANPUD and its country representatives to understand the issues and challenges PWID face while diagnosis or when accessing treatment for hepatitis C in the 4 mentioned Asian countries. This in turn, will provide ANPUD with a platform to develop a regional hepatitis C advocacy strategy to persuade governments and funding agencies into initiating policies and programs for the diagnosis, treatment and management of hepatitis C among PWID; thus benefitting the community as a whole.

Contact Information
If you have any questions, concerns or complaints about this study and its procedures, you should address them to Mr. Anand Chabungbam <anand.chabungbam@anpud.info>, Hepatitis C, Project Coordinator at ANPUD. You can also contact representatives at country level at any time if you require further information on this study.

Signature
You are not required to provide your name for this study. By writing down your initials on this consent form, you agree to participate in this study and confirm that you have read or had the interviewer explain the overview of this study.
11.4 PWID survey questionnaire

Respondent's Code : __________________________
Country Code : __________________________
Site Code : __________________________
Time started : __________________________

1. **Socio-demographic characteristics**

1.1 Gender
   [ ] Male [ ] Female [ ] Transgender

1.2 Age

1.3 Education level
   [ ] No education [ ] Primary [ ] High School [ ] University

1.4 Marital status
   [ ] Single [ ] Married [ ] Divorced
   [ ] Widow/er [ ] Separated

1.5 Number of Children

2. **Socio-Economic Profile**

2.1 Do you have a job? [ ] Yes [ ] No
   (If answered no, move to question 2.2.1)

2.2 What is your average monthly income? Local currency

2.2.1 What are your sources of income?
   ___________________________________________________
   ___________________________________________________

2.3 Do you have any dependents? [ ] Yes [ ] No
   (Dependents could be spouse, children, parents, relatives)
   If yes, number of dependents

3. **Knowledge**

3.1 Have you ever heard about Hepatitis C? [ ] Yes [ ] No
   If YES proceed to next sentence, if NO proceed to (question no 4)

3.1.1 If yes, from whom/where did you hear about it for the first time?

   Doctors [ ] Nurse [ ] Counselor [ ] Peers [ ]
   Outreach workers [ ] Media [ ] Others (specify):

3.2 Can you get infected with Hepatitis C, through sharing of injecting equipment? [ ] Yes [ ] No
   [ ] Do not know

3.2.1 Can you get infected with Hepatitis C if you share the drug cooking pot? [ ] Yes [ ] No
   [ ] Do not know
4. Behavior and Practices

4.1 Have you injected drugs in the last 6 months? [ ] Yes [ ] No

4.2 In the last 6 months, did you share any of your injecting equipments? [ ] Yes [ ] No

4.3 Have you had sex with anyone in the last 6 months? [ ] Yes [ ] No

4.3.1 Do you use condom while having sex?
   Always [ ] Sometime [ ] Once in a while [ ] Never [ ]

5. Health Status

5.1 Have you ever been tested for Hepatitis C? If YES proceed to next question (5.1.1), If NO, Would you prefer to be tested? [ ] Yes [ ] No
   If no ask the following sentence and proceed to 5.2

5.1.1 Does your Government provide Hepatitis C testing? [ ] Yes [ ] No [ ] Do not know

5.1.2 Would you feel comfortable to reveal your Hepatitis C test results to me? [ ] Yes [ ] No
   If no, proceed to 5.1.4

5.1.3 What is your Hepatitis C status? [ ] +ve [ ] -ve

5.1.4 When was the test done? Year

5.1.5 Where was the test done?
   [ ] Govt. Lab [ ] Private Lab [ ] Others

5.1.6 Was the test done free of cost? [ ] Yes [ ] No
   If No, What was the cost? Local currency

5.1.7 Did you receive pre Hepatitis C Test Counseling? [ ] Yes [ ] No

5.1.8 Did you receive post Hepatitis C Test Counseling? [ ] Yes [ ] No

5.2. Have you been tested for HIV? [ ] Yes [ ] No

5.2.1 Would you feel comfortable revealing your HIV test results to me? [ ] Yes [ ] No
   if no, proceed to Question 7

5.2.2 What is your HIV status? [ ] +ve [ ] -ve

5.2.3 If HIV positive, are you on Anti Retroviral Therapy (ART)? [ ] Yes [ ] No
   if no, proceed to 5.3

5.2.4 If yes, from where do you get your ART?
   [ ] Govt. [ ] NGOs [ ] Self purchase [ ] Others

5.3. Have you been tested for Tb? [ ] Yes [ ] No
   if no, proceed to 6
5.3.1 Would you feel comfortable revealing your Tb test results to me?  [ ] Yes  [ ] No

5.3.2 What is your Tb status?  [ ] +ve  [ ] -ve

5.3.3 If, TB+ve, are you on TB treatment, now?  [ ] Yes  [ ] No

6. Hepatitis C Treatment and service provision

6.1 If you are Hepatitis C positive, where do you go for Hepatitis C related health services?
[ ] Govt.  [ ] NGOs  [ ] Private facility  [ ] Others (Please specify ____________________________)

6.2 If you are Hepatitis C positive, have you ever received treatment for Hepatitis C?  [ ] No treatment, proceed to 6.3

[ ] Interferon + ribavirin
[ ] Pegylated interferon + ribavirin
[ ] Other, specify ____________________________

6.2.1 If yes, where did you get treatment from? (multiple responses expected)
[ ] Govt.  [ ] NGOs  [ ] Pharma company
[ ] Self  [ ] Others (Please specify ____________________________)

6.2.2 How much did the treatment cost you? Local currency ____________________________

6.2.3 What has been the outcome of your treatment?  [ ] Achieved SVR  [ ] Relapsed
[ ] Non responder

6.2.4 Has any of your family property been exchanged with money/borrowed to cover your treatment cost?
[ ] Yes  [ ] No

6.3 If you are Hepatitis C positive and not treated yet, do you plan to undergo Hepatitis C treatment in the near future?  [ ] Yes  [ ] No

6.3.1 If no, what are the reasons?
[ ] Cost  [ ] Fear of side effects  [ ] Fear of disclosing drug use and Hepatitis C status
[ ] Did not know about treatment  [ ] Others (specify) ____________________________

7. Would you like to share any other information, that would help the objective of this study?
________________________________________________________________________________

________________________________________________________________________________

Signature of interviewer ____________________________

Date ____________________________

Time End: ____________________________

30
11.5 PWID focus group discussion guide

Introduction
Asian Network of People Who Use Drugs (ANPUD) is the first registered regional network of people who use drugs. ANPUD was established by people who use drugs to:

• unify and amplify the voices of their communities
• advocate for change in drug laws and policies that negatively affect their lives, and
• improve access to prevention, treatment and care services across Asia.

ANPUD aims to focus its advocacy efforts by understanding the current situation related to the barriers to hepatitis C diagnosis, management and treatment among People Who Inject Drugs (PWID). With this objective, ANPUD and country representatives from India, Indonesia, Malaysia and Nepal are conducting a small study to understand these barriers. The findings of this study will be used to inform and develop hepatitis C advocacy strategy on the urgent need to introduce policies and programs for the diagnosis and treatment of hepatitis C among PWID.

Before you agree to take part in this study, it is important that you understand the study guideline.

Participants’ Rights & Confidentiality
Please understand your participation is voluntary and you have the right to discontinue participation at any time.

Your identity will not be disclosed in any published and written material resulting from the study. Your responses will be collected anonymously, and the questions contained in this study are not meant to provide any information that can identify you. You are free to decline to answer any particular question you do not wish to answer for any reason or to end your participation at any time.

Time Involvement
Your participation in this study will take approximately 1.30-2 hours.

Benefits of study
This project will provide no direct benefit to individual participants, but the process will enable ANPUD and its country representatives to understand the issues and challenges PWID face while diagnosing or when accessing treatment for hepatitis C in the 4 mentioned Asian countries. This in turn, will provide ANPUD with a platform to develop a regional hepatitis C advocacy strategy to persuade governments and funding agencies into initiating policies and programs for the diagnosis, treatment and management of hepatitis C among PWID; thus benefitting the community as a whole.

Contact Information
If you have any questions, concerns or complaints about this study and its procedures, you should address them to Mr. Anand Chabungbam <anand.chabungbam@anpud.info>, Hepatitis C, Project Coordinator at ANPUD. You can also contact representatives at country level at any time if you require further information on this study.

My name is ______________________

Mechanism and Questions on FG

STUDY OBJECTIVE : to understand barriers to hepatitis C diagnosis, treatment and management

PARTICIPANTS : 8-10 PWID

METHOD : Dual moderator

Welcome the participants, explain the objective of the discussion as stated above and start with an introductory discussion about PWID and hepatitis C in general, in your setting.

I would like to start by asking you to tell me a little bit about what PWID in your community know about hepatitis C

1. Level of basic knowledge on Hepatitis C among the PWID community.

PROBES
Have you ever heard of Hepatitis C?
What do you know about Hepatitis C?
Do you know anyone who has Hepatitis C?
2. **Hepatitis C diagnosis and treatment among the PWID community.**

**PROBES**

How aware do you think the community is about Hepatitis C treatment information including side effects and its management?

- is testing and treatment of Hepatitis C available for the general community
- is testing and treatment of Hepatitis C available for PWID
- if yes, who provides the treatment?
- cost of the Hepatitis C, qualitative and quantitate and genotyping testing
- cost of treatment
- cost of other test like LFT, liver biopsy, ultrasound, etc.
- if no, does your government has a plan to test and treat Hepatitis C
- does your government have some policy and guideline on Hepatitis C prevention and treatment
- what suggestion do you have for your government on Hepatitis C issues

3. **Access to regular medical and healthcare from Government or General Medical Practitioner.**

**PROBES**

- Where do you go for your general health care services? Govt. hospital? Private clinic?
- are you comfortable telling the health care providers that you are/were using drugs?
- what sort of services are available in these facilities?
- how much would you pay to access such services; meaning is there a fee for such services?
- how much would it cost for you to get there and back from such service centers?
- is there any other expenses in accessing such services? what about time? how long does this take?
- would you consider treatment if the service providers were easily accessible? in terms of time and cost

4. **Access to services from NGO/CBOs working with PWID.**

**PROBES**

- do service providers request information on your drug use?
- do you pay money to access such services now? meaning cost on getting to the NGO/CBOs or a fee?
- what services are available from these NGO/CBOs?
- are these services available when you need them?

5. **Stigma and Discrimination.**

**PROBES**

- Do you feel that there is stigma and discrimination against people who use drugs especially when accessing services and treatment?
- Please give me an example of an occasion when you felt you were discriminated against?
- where does this mostly happen? At the Govt. settings or NGOs/CBOs who provides services for PWID or any other settings?
- what would make you feel comfortable in a treatment facility?

6. **Ask for any suggestion or feedback towards this study**

*Summarize the discussion for the participants*
11.6 Treatment providers survey questionnaire

Introduction
Asian Network of People Who Use Drugs (ANPUD) is the first registered regional network of people who use drugs. ANPUD was established by people who use drugs to:

• unify and amplify the voices of their communities
• advocate for change in drug laws and policies that negatively affect their lives, and
• improve access to prevention, treatment and care services across Asia.

ANPUD aims to focus its advocacy efforts by understanding the current situation related to the barriers to hepatitis C diagnosis, management and treatment among People Who Inject Drugs (PWID). With this objective, ANPUD and country representatives from India, Indonesia, Malaysia and Nepal are conducting a small study to understand these barriers. The findings of this study will be used to inform and develop hepatitis C advocacy strategy on the urgent need to introduce policies and programs for the diagnosis and treatment of hepatitis C among PWID.

Before you agree to take part in this study, it is important that you understand the study guideline.

Participants’ Rights & Confidentiality
Please understand your participation is voluntary and you have the right to discontinue participation at any time.

Your identity will not be disclosed in any published and written material resulting from the study. Your responses will be collected anonymously, and the questions contained in this study are not meant to provide any information that can identify you. You are free to decline to answer any particular question you do not wish to answer for any reason or to end your participation at any time.

Time Involvement
Your participation in this study will take approximately 40-45 minutes.

Benefits of study
This project will provide no direct benefit to individual participants, but the process will enable ANPUD and its country representatives, to understand the issues and challenges PWID face while diagnosis or when accessing treatment for Hepatitis C in the 4 mentioned Asian countries. This in turn, will provide ANPUD with a platform to develop a regional hepatitis C advocacy strategy to persuade governments and funding agencies into initiating policies and programs for the diagnosis, treatment and management of hepatitis C among PWID; thus benefitting the community as a whole.

Contact Information
If you have any questions, concerns or complaints about this study and its procedures, you should address them to Mr Anand Chabungbam <anand.chabungbam@anpud.info>, Hepatitis C, Project Coordinator at ANPUD. You can also contact representatives at country level at any time if you require further information on this study.

Respondent’s Code :______________________
Country Code :______________________
Site Code :______________________
Time started :______________________
Private or Government :______________________

1. What is the prevalence of Hepatitis C at state/province level, among general population and PWID?
   General Population _____________________ PWID _____________________ Don’t know [ ]

2. Who provides information on Hepatitis C to PWID?
   Doctors [ ] Nurse [ ] Counselor [ ] Peer Educators [ ]
   Outreach workers [ ] None [ ] Others: ________________________________
3. Is Hepatitis C testing available at your facility?  
   [ ] Yes  [ ] No  
   If No, why not and proceed to question 4

3.1 If yes, what type of testing is available?  
   Hep. C rapid test [ ]  
   Hep. C qualitative & quantitate test [ ]  
   Hep. C genotyping test [ ]

3.2 If yes, is the testing free of cost?  
   [ ] Yes  [ ] No-if no what is the cost  
   Hep. C rapid test [ ] Cost in Local Currency___________________  
   Hep. C qualitative & quantitate test [ ] Cost in Local Currency___________________  
   Hep. C genotyping test [ ] Cost in Local Currency___________________

4. Which Hepatitis C genotype is most commonly found in your state/province?  
   (multiple responses expected)  
   Genotype 1 [ ]  Genotype 2 [ ]  Genotype 3 [ ]  Genotype 4 [ ]  
   Others _________________________

5. How many patients have received Hepatitis C treatment under your care? ________

6. What is the selection criterion for Hepatitis C treatment?  
   HIV-Hepatitis C co-infection [ ] Yes [ ] No  
   Current PWID [ ] Yes [ ] No  
   Former PWID [ ] Yes [ ] No  
   PWID on OST/MMT [ ] Yes [ ] No  
   None of the above [ ]  
   Others pls specify__________________________

7. How many have achieved Sustain Viral Response (SVR)? ________  
   how many relapsed?__________  
   how many are non-responders?______________________

7.1 Specific reason for relapse (in reference to question 7)?

8. Who pays for Hepatitis C genotyping testing?  
   [ ] Govt.  [ ] NGOs  [ ] Pharma company  
   [ ] Self  [ ] Others (Please specify______________________________)

8.1 Who pays for Hepatitis C qualitative and quantitative testing?  
   [ ] Govt.  [ ] NGOs  [ ] Pharma company  
   [ ] Self  [ ] Others (Please specify______________________________)

9. Who pays for liver function test?  
   [ ] Govt.  [ ] NGOs  [ ] Pharma company  
   [ ] Self  [ ] Others (Please specify______________________________)

   How often are they done, during treatment?______________________________

9.1 Who pays for liver biopsy test?  
   [ ] Govt.  [ ] NGOs  [ ] Pharma company  
   [ ] Self  [ ] Others (Please specify______________________________)

   How often are they done, during treatment?______________________________
9.2. Who pays for Hepatitis C treatment? ______________________
   [ ] Govt.  [ ] NGOs  [ ] Pharma company
   [ ] Self  [ ] Others (Please specify ________________________)

10. What type of treatment is available?
   [ ] No treatment, proceed to question 12
   [ ] Interferon + ribavirin
   [ ] Pegylated interferon + ribavirin
   [ ] Other, specify ________________

11. What is the total cost required for a full course treatment?
   [ ] Interferon+ ribavirin Cost in local currency ________________
   [ ] Pegylated interferon + ribavirin Cost in local currency ________________
   [ ] Other, specify ________________ Cost in local currency ________________

12. What are the cost factors, a patient has to consider?
   for example diagnostics, monitoring or follow-up cost!
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

13. What are some of the challenges on treating people living with Hepatitis C, especially for PWID, in your state/province? multiple answers, may apply
   High cost of Hepatitis C treatment                   ( )
   Availability of Hepatitis C treatment                  ( )
   Complicated treatment regime/side effects                   ( )
   Lack of government response    ( )
   Lack of demand from community   ( )
   Lack of skills and infrastructure   ( )
   Any other remarks:
   __________________________________________________________

14. Do you have your own country specific treatment guidelines or Standard Operating Procedures (SOP) for treating Hepatitis C?
   [ ] Yes      [ ] No
   If no, which guideline or SOP you refer to while treating your patients?
   __________________________________________________________

15. Does your facility/state/province have adequate capacity and infrastructure to provide Hepatitis C treatment to those who need it?
   [ ] Yes                                         [ ] No
   15.1 If no, what are the gaps and challenges? __________________________________________
       __________________________________________
       __________________________________________

16. Do you think the policy and program on Hepatitis C need to be developed/strengthened in your state/province?
   [ ] Yes                                         [ ] No
   16.1 If yes, what are some of your suggestions and recommendations?
   __________________________________________________________
   __________________________________________________________
16.2 If no, why do you think so?

_____________________________________________________________

_____________________________________________________________

17. Do you have any suggestion for ANPUD, who is doing this regional study to identify barriers to diagnosis and treatment of hepatitis C among PWID?

_____________________________________________________________

_____________________________________________________________

_____________________________________________________________

________________________       _____________________
Signature of interviewer                         Date

Time End : __________
11.7 Service providers survey questionnaire

Introduction
Asian Network of People Who Use Drugs (ANPUD) is the first registered regional network of people who use drugs. ANPUD was established by people who use drugs to:

• unify and amplify the voices of their communities
• advocate for change in drug laws and policies that negatively affect their lives, and
• improve access to prevention, treatment and care services across Asia.

ANPUD aims to focus its advocacy efforts by understanding the current situation related to the barriers to hepatitis C diagnosis, management and treatment among People Who Inject Drugs (PWID). With this objective, ANPUD and country representatives from India, Indonesia, Malaysia and Nepal are conducting a small study to understand these barriers. The findings of this study will be used to inform and develop hepatitis C advocacy strategy on the urgent need to introduce policies and programs for the diagnosis and treatment of hepatitis C among PWID.

Before you agree to take part in this study, it is important that you understand the study guidelines.

Participants’ Rights & Confidentiality
Please understand your participation is voluntary and you have the right to discontinue participation at any time.

Your identity will not be disclosed in any published and written material resulting from the study. Your responses will be collected anonymously, and the questions contained in this study are not meant to provide any information that can identify you. You are free to decline to answer any particular question you do not wish to answer for any reason or to end your participation at any time.

Time Involvement
Your participation in this study will take approximately 40-45 minutes.

Benefits of study
This project will provide no direct benefit to individual participants, but the process will enable ANPUD and its country representatives, to understand the issues and challenges PWID face while diagnosis or when accessing treatment for hepatitis C in the 4 mentioned Asian countries. This in turn, will provide ANPUD with a platform to develop a regional hepatitis C advocacy strategy to persuade governments and funding agencies into initiating policies and programs for the diagnosis, treatment and management of hepatitis C among PWID; thus benefitting the community as a whole.

Contact Information
If you have any questions, concerns or complaints about this study and its procedures, you should address them to Mr Anand Chabungbam <anand.chabungbam@anpud.info>, Hepatitis C, Project Coordinator at ANPUD. You can also contact representatives at country level at any time if you require further information on this study.

Respondent’s Code :______________________
Country Code :______________________
Site Code :______________________
Time started :______________________
1. What kind of service do you offer? (multiple responses expected)

   Please tick which services are available

   [ ] NSEP  [ ] Outreach Services  [ ] Drug treatment  [ ] Basic health care
   [ ] HIV Rapid testing  [ ] Hepatitis C Rapid testing  [ ] Counselling
   [ ] OST  [ ] Condom distribution  Others ________________________

2. How many PWID access services from your organisation? _____________________________________

3. Do you know the prevalence rate of Hepatitis C infection among PWID in your state/province?

   [ ] Yes  [ ] No  [ ] Don't know

   If yes what is the percentage ______________

   How many, among the enrolled PWID, in your organisation are Hepatitis C+ve ______________

   If NO or Don't know, what is the reason__________________________________________________

4. What do you know about Hepatitis C?

   ___________________________________________________________________________________

   ___________________________________________________________________________________

4.1 Do you know the risk of hepatitis C transmission, if people share their injecting equipment?

   [ ] Yes  [ ] No  [ ] Don't know

   Any other comments______________________________________________________________________

5. Is there stigma and discrimination against PWID?  [ ] Yes  [ ] No

   If yes, what type of stigma discrimination issues ______________________________________________

   and by whom? (multiple responses expected)

   [ ] Other PWID  [ ] Service Providers (NGO/CBO)  [ ] Treatment providers  [ ] Community  [ ] Family
   [ ] Relatives  [ ] Friends  [ ] Others ________________________

6. Does your organisation provide any of the following services on hepatitis C to PWID: (multiple responses expected)

   [ ] Pre and Post-test counselling  [ ] Awareness building
   [ ] Capacity building and training  [ ] Advocacy
   [ ] Testing services  [ ] Treatment services
6.1 Does your organisation provide treatment services on hepatitis C to PWID:
[ ] No treatment
[ ] Yes, interferon + ribavirin
[ ] Yes, pegylated interferon + ribavirin
[ ] Other, specify ____________________

7. Do you have any tools and materials to disseminate information on hepatitis C to the PWID community?
[ ] Yes [ ] No [ ] Don't Know (if don't know proceed to Question 8)
If yes, what are those tools & materials?
________________________________________________________________________________________
Who developed those tools & materials?
________________________________________________________________________________________
Are these tools and materials available to PWID community?
________________________________________________________________________________________
If no, what would you need to further strengthen your effort?
________________________________________________________________________________________

8. Does your government provide hepatitis C testing services? [ ] Yes [ ] No
[ ] Don't Know (if don't know proceed to 9)

8.1 If yes, do they provide pre and post test counselling services on Hepatitis C? [ ] Yes [ ] No

8.2 If yes, is the Hepatitis C testing free of cost? [ ] Yes [ ] No
If no, what is the cost for each test? Local currency __________________

8.3 Where do PWID, living with Hepatitis C, go for their viral load and genotype testing?
[ ] Govt. lab [ ] Private lab [ ] BOTH [ ] Don't Know
Others ____________________

8.3.1 Is the Hepatitis C viral load and genotyping test free of cost? [ ] Yes [ ] No
If no, what is the cost of the test?
hepatitis C Viral Load test: Local currency____________________
hepatitis C genotyping test: Local currency____________________

8.3.2 Where do PWID living with hepatitis C, go for their Liver Function Test (LFT), Ultrasound and other necessary tests?
[ ] Govt. lab [ ] Private lab [ ] BOTH [ ] Don't Know
Others ____________________

8.3.3 Is the above mentioned (8.3.2) test free of cost? [ ] Yes [ ] No
If no, what is the cost of the test in local currency?
LFT: ____________________ Ultra Sound: ____________________
Other test (please specify________________________)
9. What type of Hepatitis C treatment is available?
[ ] No treatment, proceed to question 9.3
[ ] Yes, interferon + ribavirin
[ ] Yes, pegylated interferon + ribavirin
[ ] Other, specify __________________________

9.1 Who provides hepatitis C treatment to PWID? (multiple responses expected)
[ ] Govt.     [ ] NGOs       [ ] Pharma company
[ ] Private   [ ] Self
[ ] Others (Please specify________________________

9.2 What is the cost of a full course (48 weeks) Hepatitis C treatment?
Local currency________________________________________

9.3 Do you have medical practitioner treating hepatitis C in your state/province? [ ] Yes   [ ] No
if yes, proceed to question 9.3.1  
[ ] Don't Know  
if no or don't know, proceed to question 10

9.3.1 If they are treating PWID, does the following apply? (multiple responses expected)
Treat current PWID [ ] Treat former PWID [ ]
Treat PWID on OST/MMT [ ] Treat PWID co-infected with Hepatitis C & HIV [ ]
others (please specify)________________________

10. In your opinion, what are the main challenges for PWID to access treatment for Hepatitis C?
__________________________________________________
__________________________________________________
__________________________________________________

11. Does your Govt. have a treatment guideline on Hepatitis C? [ ] Yes [ ] No
[ ] Don't know

If yes, is the treatment guideline specifically for your country or is it an international guideline________________________________________

If no, what should your Govt. do on hepatitis C diagnosis, treatment and management, issues?
__________________________________________________
__________________________________________________

12. Do you have any suggestion for ANPUD, who is doing this regional study to identify barriers to diagnosis and treatment of hepatitis C among PWID?
__________________________________________________
__________________________________________________
__________________________________________________

__________________________________________________

Signature of interviewer ___________________ Date ___________________

Time End: __________