

The urgent need for improved hepatitis C prevention, care and treatment for people who inject drugs in Indonesia

Hepatitis C: an urgent public health crisis

Hepatitis C is a major public health, economic and social crisis. Globally, approximately 184 million people are chronically infected with the hepatitis C virus (HCV).¹ More than 25% of liver disease worldwide is attributed to HCV, and can manifest as liver fibrosis, dysfunction, failure, and eventually cirrhosis and cancer of the liver.² Co-infection with HIV, which accelerates HCV progression, is a growing concern. In 2008, an estimated 4-5 million people living with HIV (PLHIV) also had HCV.³

People who inject drugs (PWID) are particularly vulnerable to HCV infection, especially in low- and middle-income countries. HCV is efficiently transmitted through the sharing of needles and syringes, as well as through the sharing of drug preparation equipment such as containers and materials used to mix and filter heroin and other drugs for injection.⁴ The global prevalence of HCV among PWID was estimated at 67% in 2010, with over 10 million PWID living with the virus.⁵

In Asia, rates of HCV are disproportionately high among PWID, reaching 90% in Thailand, 41% in India, and 67% in China, and almost universal among those also infected with HIV.⁶

In Indonesia, HCV prevalence among PWID is as high as 77%,⁷ with co-infection rates with HIV ranging from 60% to 90%.⁸

National profile on viral hepatitis among people who inject drugs

Written national strategy on the prevention and management of viral hepatitis: Yes
Inclusion of viral hepatitis in national policy documents addressing programmes for PWID: Yes
Routine national surveillance for viral hepatitis: No

Number of people who inject drugs: 105,784 (73,663–201,131)⁹
HIV prevalence among people who inject drugs: 36%¹⁰
HCV prevalence among people who inject drugs: 77.3%¹¹
Hepatitis B prevalence* among people who inject drugs: 57.6%¹²

Needle and syringe (NSP) programmes: 194 sites¹³
Opioid substitution therapy (OST): 85 sites (methadone)¹⁴
NSP in prison: No
OST in prison: Yes (9 prisons)¹⁵

* Represents prevalence of hepatitis C core antibodies, indicating previous exposure to the hepatitis C virus.

Indonesia has one of the highest rates of viral hepatitis in the South East Asia region, with an estimated 28 million people living with hepatitis B virus (HBV) and/or HCV, and only 1 in 5 aware of their infection.¹⁶ In 2007, the Ministry of Health's Directorate for Disease Control reported that more than 2% of Indonesia's population, or 6-7 million people across 21 provinces, were infected with HCV, most of them men between 20-40 years of age.^{17 18} Of the 28 million people with viral hepatitis across the country, 50% could potentially progress to chronic liver disease, 30% to liver fibrosis, and 5% to liver failure or cancer.¹⁹ Liver disease, including hepatitis, is now the second leading cause of death among the general population in Indonesia.

While HIV rates among PWID have decreased from 52% in 2007 to 36% in 2011,²⁰ HCV has remained disproportionately high among this group. Among the estimated 105,784 people who inject drugs in the country, over two-thirds have HCV infection.²¹ Although Indonesia does not collect surveillance data on viral hepatitis, anecdotal program data from two community organisations²² from 2007 indicates that HIV/HCV co-infection rates among PWID may range from 60% to 90%.²³ Incarceration has been recognized as an independent factor for HCV transmission.²⁴ In many countries, HCV is more widespread in prisons than in the general population, and significant proportions of the incarcerated populations in many countries inject

drugs.²⁵⁻²⁴ While there are presently no data available on HCV rates among Indonesian prisoners, injecting drug use has been widely documented in Indonesian prisons, as has high HIV prevalence associated with unsafe injecting practices.²⁶

The urgent need for improved hepatitis C prevention, care, and treatment among people who inject drugs: Recommendations

To strengthen the national response to HCV among people who inject drugs in Indonesia, we urge policy-makers and the Ministry of Health to immediately take the following actions:

1. Advocate for the price reduction of antiviral treatment, consisting of pegylated interferon alfa 2a and 2b and ribavirin.
2. Include HCV antibody testing in routine national surveillance, particularly among populations who are disproportionately affected such as people who inject drugs and people living with HIV.
3. Indonesia's Ministry of Health should develop national guidelines for the prevention, care and treatment of HCV, with a special focus on people who inject drugs, based on international guidance by the World Health Organisation, and national treatment consensus for hepatitis C infection developed by the Indonesian Association for Study of the Liver (Ina-ASL).
4. Include pegylated interferon and ribavirin in the national essential medicines list.
5. Include HCV screening and diagnostic tests as part of harm reduction programming in community health centres (*puskesmas*). In particular, HCV-RNA and genotype testing should be made accessible as part of existing HIV testing services.
6. Increase evidence-based harm reduction service coverage, including awareness and monitoring of acceptance and availability of low dead-space syringe among PWID.
7. Implement the existing provision in Narcotic Law no. 35/2009 on diversion of people who use drugs to rehabilitation rather than prison.
8. Inform and encourage hospital management to adhere to the national treatment consensus that recommends pegylated interferon alfa 2a and 2b with ribavirin for the treatment of chronic hepatitis C.
9. Ensure the meaningful involvement of PWID in all stages of program and policy design, implementation, monitoring and evaluation.

Effective strategies for preventing HCV transmission among PWID

Effective strategies for preventing HCV amongst PWID consist of high-coverage harm reduction services such as needle syringe programmes (NSPs) and opioid substitution therapy (OST) in combination with the provision of antiviral treatment for HCV.²⁷⁻²⁸ Recent mathematical modeling projections have suggested that scaling up OST and high-coverage NSP substantially reduces the treatment rate required to have a significant impact on HCV prevalence.¹ Importantly, combining antiviral treatment with OST with high-coverage NSP is critical for achieving substantial reductions of >50% in HCV chronic prevalence over 10 years.³⁰

However, such an impact requires long-term sustained coverage of each intervention. Due to the insufficient scale up of NSPs on a global level, coverage in many countries is too low to have a discernable impact on HIV or HCV infection rates: it is estimated that only 22 syringes are provided per person per year, compared to the >200 that WHO, UNAIDS and UNODC recommend should be distributed.³¹ In addition, affordable antiviral treatment is largely unavailable to PWID in a majority of low- and middle-income countries.³²

Since HCV is effectively transmitted through drug preparation equipment, it is important that in addition to the provision of sterile injecting equipment, NSP services in the community also provide sterile preparation equipment such as containers and materials used to mix and filter drugs for injection. Additional interventions are required to increase awareness of HCV and improve testing and treatment take up, including promoting awareness and increasing acceptability and access to low dead space syringes among communities of PWID, and the promotion of non-injecting modes of drug administration.³³

In prisons, availability and access to prevention and treatment is more limited than in the community. The provision of testing and treatment for hepatitis C to prisoners has been shown to be a cost-effective strategy to limit transmission and manage the disease.³⁴

¹ Projections show that if OST and high-coverage NSP coverage were increased to 40% each (assuming no coverage at baseline), then annually treating 10, 23, or 42 per 1000 PWID over 10 years would halve prevalence for 20%, 40%, or 60% baseline chronic HCV prevalences, respectively.

The World Health Organization (WHO) recommends implementing NSPs and OST interventions in prisons and other closed settings as an effective way to prevent HCV transmission.³⁴ A recent report by the Global Commission on Drug Policy recommends reform of drug policies that criminalize people who use drugs, effectively driving them away from existing harm reduction services in the community and exacerbating mass incarceration and prison overcrowding.³⁵

“Involving people who use drugs in the design, implementation, monitoring and evaluation of programmes is vital to the success of HCV prevention programmes. The success of peer interventions in reducing the transmission of viral hepatitis among PWID is well-documented,³⁶ and is included as a key recommendation in guidance on the prevention of viral hepatitis by WHO (see below).”

International guidance for HCV prevention among people who inject drugs

WHO, UNAIDS and UNODC recommends the implementation and scale up of a comprehensive package of 9 interventions for HIV prevention, treatment and care among people who inject drugs. This comprehensive package is also relevant for addressing viral hepatitis, particularly OST and NSP:

1. needle and syringe programmes
2. opioid substitution therapy and other drug dependence treatment
3. HIV testing and counselling
4. antiretroviral therapy
5. prevention and treatment of sexually transmitted infections
6. condom programmes for people who inject drugs and their sexual partners
7. targeted information, education and communication for people who inject drugs and their sexual partners
8. vaccination, diagnosis and treatment of viral hepatitis
9. prevention, diagnosis and treatment of tuberculosis.

In addition to the comprehensive package, new guidance from WHO in 2012 added specific recommendations for further addressing viral hepatitis among PWID:

1. It is suggested to offer people who inject drugs the rapid hepatitis B vaccination regimen.*
2. It is suggested to offer people who inject drugs incentives to increase uptake and completion of the hepatitis B vaccine schedule.†
3. It is suggested that needle and syringe programs also provide low dead-space syringes for distribution to people who inject drugs.‡
4. Psychosocial interventions are not suggested for people who inject drugs to reduce the incidence of viral hepatitis.
5. It is suggested to offer peer interventions to people who inject drugs to reduce the incidence of viral hepatitis.

* A higher dose HBV vaccine should be used with the rapid regimen; standard and rapid regimens should be offered to PWID, with first priority given to delivery of the first dose and then to completion of three doses.

† This recommendation is conditional on local acceptability and resource availability; vaccinations should be provided at a location and time convenient for PWID.

‡ Syringe programmes should offer all types of syringes appropriate for local needs.

Effective treatments for hepatitis C

There is currently no vaccine for HCV infection, but various treatments can reduce virus replication and help slow or stop disease progression. HCV is now considered curable in up to 70% of those who undergo treatment.¹ Currently the recommended antiviral treatment for HCV consists of pegylated interferon alfa and ribavirin, with a 50-85% cure rate.³⁷ Although HCV can be effectively managed and cost-effective, access to treatment, where it is available, remains very limited amongst people who inject drugs.³⁸⁻⁴⁰ Even where treatment may be accessible, uptake among people who inject drugs can be as low as 3-4% in some settings.⁴¹ This may be partly due to physician reluctance to treat due to concerns around treatment compliance and adherence, especially among people actively using drugs.⁴² However, evidence suggests that rates of compliance and adherence to HCV treatment for current drug users is the same as that of adherence rates for non or ex-drug users.⁴³

A recent systematic review and meta-analysis of treatment among active PWID showed an overall sustained virologic response (SVR)¹ of 56% - similar to non or ex-drug users.⁴⁴ Although data on re-infection rates for PWID after treatment are scarce, available small-scale studies have shown low rates of re-infection at 1%-5% per year.⁴⁵

¹ Sustained virologic response (SVR) is defined as absence of detectable RNA of the hepatitis C virus in the blood serum 24 weeks after completion of antiviral therapy for chronic HCV infection.

The national response to the prevention, treatment and care of HCV among people who inject drugs in Indonesia

The national response to the prevention, care and treatment of HCV among people who inject drugs in Indonesia remains fragmented. Indonesia does not conduct routine national surveillance for viral hepatitis.⁴⁶ Existing data on HCV among people who inject drugs are outdated, unavailable to public and scientific scrutiny, and based largely on laboratory and hospital records rather than representative community samples. Although deaths, including from hepatitis, are reported to a central registry, information on the type of hepatitis is unavailable,⁴⁷ and hepatitis C-attributed morbidity and mortality among people who inject drugs is largely unknown.

Although the Ministry of Health has produced written guidelines for the management of hepatitis C, including among PWID, in 2012, the government has not effectively disseminated or implemented these strategies. The Ministry of Health first established a national program focused on viral hepatitis in 2011, under the Sub-Directorate for Gastrointestinal Infection, Diarrheal Diseases, and Hepatitis. The thirteen full-time staff in the Sub-Directorate presently share responsibilities for hepatitis, gastrointestinal and diarrheal diseases.

Although the provision of harm reduction services has increased in scale in recent years,⁴⁸ the coverage of interventions such as opioid substitution therapy (OST) and needle and syringe programmes (NSPs) in Indonesia remains too limited to have a major impact on the HCV epidemic. The number of NSP sites distributing sterile needles and syringes has increased steadily, yet in 2011 only seven needles and syringes were distributed per person injecting drugs at the national level.⁴⁹ The availability and scope of OST is limited by poor programme quality, including inappropriate dosing levels and lack of follow-up among those who drop out.⁵⁰

The implementation of harm reduction services in Indonesian prisons is far more limited than provision in the community. Out of 429 prisons across the country, including 13 prisons designed specifically for drug offenders, only nine prisons provide some level of OST.⁵¹ There is no provision of sterile injecting equipment within Indonesian prisons or detention centres, despite its recommendation by WHO, UNAIDS and UNODC.⁵²

In 2009, Indonesia launched a new law on narcotic drugs (Narcotics Law no. 35), which introduced mechanisms for diverting people who use drugs away from prison and towards drug rehabilitation.⁵³ However, the new legal provisions on diversion are rarely implemented. The number of prisoners incarcerated for drug-related offences in Indonesia grew significantly from 7,122 (10% of all prisoners) in 2002 to 56,208 (35% of all prisoners) by the end of June 2013.⁵⁴ The ongoing criminalisation of drug use has resulted in high rates of imprisonment of people who use drugs, with existing facilities remaining at least 148% over capacity.⁵⁵

Limited access to HCV treatment in Indonesia

Antiviral treatment for hepatitis C, consisting of pegylated interferon and ribavirin, continues to be out of the reach of the majority of people who inject drugs in need.

Officially, HCV treatment in Indonesia is publicly funded under a number of insurance schemes, including Askes, which covers health costs including treatment for HCV and HBV for government employees, Jamsostek, which acts as social insurance for workplaces that register with the scheme, and Jamkesmas, Indonesia's health waivers for low-income individuals.

However, the reach of existing insurance and support schemes is extremely limited, particularly among people who inject drugs. A majority of people either do not know about these subsidies or do not qualify for them,⁵⁶ and among those who are aware that they exist, access is limited by a number of factors. For instance, many PWID are ineligible for subsidies either because they are unemployed, or because they lack awareness of the availability of HCV testing and treatment. Most PWID cannot personally afford treatment due to the exceedingly high cost of medications.

Even when medication costs are covered, supporting tests required to assess whether and what treatment is feasible for an individual - such as liver function tests, HCV RNA viral load, and genotype testing - remain the responsibility of individuals. These costs can exceed \$650 (IDR 6,500,000) - an exorbitant amount for many PWID [for a breakdown of costs for supporting diagnostic tests and HCV treatment, see text box in next page.]

Hepatitis C (HCV) Diagnostics and Treatment Costs in Indonesia

Supporting diagnostic tests for HCV[§]

- * Hepatitis C antibody test: US\$ 25 – 30 (IDR 250,000–300,000)
- * Hepatitis C RNA test: US\$ 120 (IDR 1,200,000)
- * Hepatitis C genotype test: US\$ 325 (IDR 3,250,000)^P
- * Abdomen ultrasound: US\$ 25 – 30 (IDR 250,000–300,000)
- * Liver function tests: \$7.50 (IDR 75,000)
- * Liver biopsy: \$60 (IDR 600,000)
- * Fibroscan: \$85 (IDR 850,000)

Treatment costs:

- * Dual therapy with Pegasys[®] (180 Mcg) + ribavirin:
Per dose: US\$ 300 (IDR 3,000,000)
24-week course: US\$ 7,200 (IDR 72,000,000)
48-week course: US\$ 14,400 (IDR 144,000,000)
- * Dual therapy with Pegasys[®] (135 Mcg) + ribavirin:
Per dose: US\$ 220 (IDR 2,200,000)
- * Dual therapy with PegIntron[®] + ribavirin (100 Mcg):
Per dose: US\$ 290 (IDR 2,900,000-3,260,000) per dose

§ Costs for supporting diagnostic tests for HCV based on price ranges quoted by one or more government-run hospital(s) in the Greater Jakarta area as of July 2013. In cases where a government-run hospital reported that a particular diagnostic test is not provided or available, private clinics in the Greater Jakarta area were approached for a quotation. Where this is the case, it is indicated through a P symbol.

§§ Costs for hepatitis C treatment based on prices quoted by at least one pharmacy in the Greater Jakarta area as of July 2013.

P Cost quoted by private clinic in Greater Jakarta area.

The government's obligation to provide access to HCV prevention, treatment and care for people who inject drugs

Although Indonesia co-sponsored a viral hepatitis resolution that established “goals and strategies for disease control, increasing education and promoting screening and treatment” of people living with HBV and HCV at the 63rd World Health Assembly,⁵⁷ progress in the country on commitments in the resolution is very limited. While strategies to prevent HCV and increase access to screening and treatment are in development, existing efforts are not reaching the majority of PWID in need.

International guidance and targets support this commitment. As of July 2013, first-line treatment for HCV in the form of pegylated interferon was included for the first time in the complementary list¹ of the WHO's Model Essential Medicines List, an internationally recognizable set of safe, cost-effective medicines to guide countries in treating critical health needs.⁵⁸ WHO has also highlighted people who inject drugs as a key population to be targeted for HCV, recently publishing new guidance for the prevention and treatment of viral hepatitis among this group.⁵⁹

The Indonesian government has an obligation to ensure the highest attainable standard of health as a fundamental right of every citizen.⁶⁰ This includes accessible HCV prevention, care, and treatment, including supporting the costs of diagnostic tests for all those affected, and particularly for key populations at higher risk of HCV infection such as people who inject drugs.

¹ Pegylated interferon was included on the complementary list rather than the essential list because of the potentially prohibitive costs of treatment in most countries. The updated WHO Essential Medicines List 2013 is available at http://www.who.int/medicines/publications/essentialmedicines/18th_EML_Final_web_8Jul13.pdf.

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9. Ensure the meaningful involvement of PWID in all stages of program and policy design, implementation, monitoring and evaluation.

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