

ACCESS TO HEPATITIS C TREATMENT AND CARE AMONG PEOPLE WHO INJECT DRUGS: FAILING PEOPLE MOST DISPROPORTIONATELY AFFECTED

INTRODUCTION

Accurate, high-quality data on hepatitis C continues to be a struggle for countries that are scaling up treatment access, expanding testing services, and developing national hepatitis plans. There is scarce information about how people who inject drugs (PWID) are factored into national hepatitis plans and to what extent they are being tested, treated, and linked to harm reduction and other healthcare services. Crowd-sourced data from the free, public database, [mapCrowd](#), has been collected between 9 April and 30 October, 2019 from over 44 countries, provided by 60 mapCrowd contributors.

To supplement their contributions, we conducted a review of the literature and exchanged data with the World Health Organization and Harm Reduction International. We managed to gather updated data related to the following points:

- Estimated number of people who inject drugs
- Estimated national HCV antibody and viremic prevalence among people who inject drugs
- Existence of number of treatment restrictions, including abstinence from substances
- Estimated treatment uptake in the general population and among people who inject drugs
- Whether harm reduction services are included in national policies

Based on this data, we summarize key findings, noting that in-country contributors provide project-specific data and may not provide a comprehensive view of all the realities facing people who inject drugs and their health needs, including HCV.¹

The issue brief aims to provide supplemental evidence for advocates on treatment uptake and care among people who inject drugs, which could help inform national and regional campaigns.

2. PEOPLE WHO INJECT DRUGS ARE DISPROPORTIONALLY AFFECTED BY HEPATITIS C

Worldwide there are an estimated 71 million people living with chronic HCV. Injection drug use contributes to global hepatitis C epidemic², and people who inject drugs are disproportionately affected by the blood-borne disease (see Map 1).

- Globally, the HCV antibody prevalence among people who inject drugs is estimated to be 52.3%^{3 4}
- Out of the estimated 15.6 million people (3.2 million are women⁵) who inject drugs globally, 6.1 million of them are chronically infected with HCV⁶ (or have a 39.2% viremic prevalence)⁷
- One in three HCV deaths are attributable to injecting drug use⁸
- Nearly a quarter of the world's new HCV infections occur among people who inject drugs⁹
- Four countries (Brazil, China, Russia, and the United States) have the most people with recent injecting drug use who are living with HCV. Together these countries make over half (51%) of all people with recent injecting drug use living with HCV worldwide.¹⁰

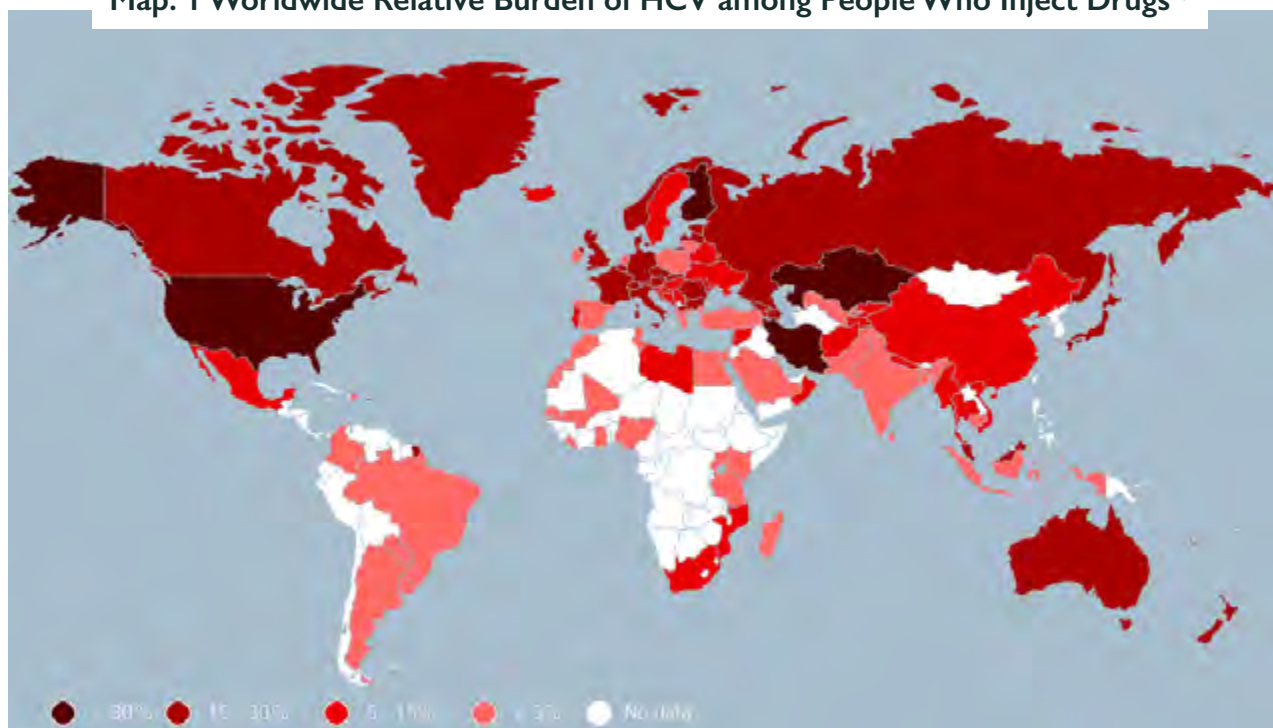
Global targets to have been set to eliminate HCV by 2030:

- 90% reduction in incidence;
- 65% reduction in mortality;
- 90% of people infected with hepatitis C to be diagnosed; and
- 80% of people diagnosed to be treated.

The World Health Organization (WHO)'s global strategy acknowledges the absolute need to include people who use and inject drugs in national viral hepatitis strategies and to promote the following actions for countries:

- Implement a comprehensive package of harm reduction services^{11 12}
- Address legal and institutional barriers to the provision of harm reduction services
- Link hepatitis and harm reduction services to facilitate integrated prevention, treatment, and care for people who use drugs.

Map. 1 Worldwide Relative Burden of HCV among People Who Inject Drugs¹³

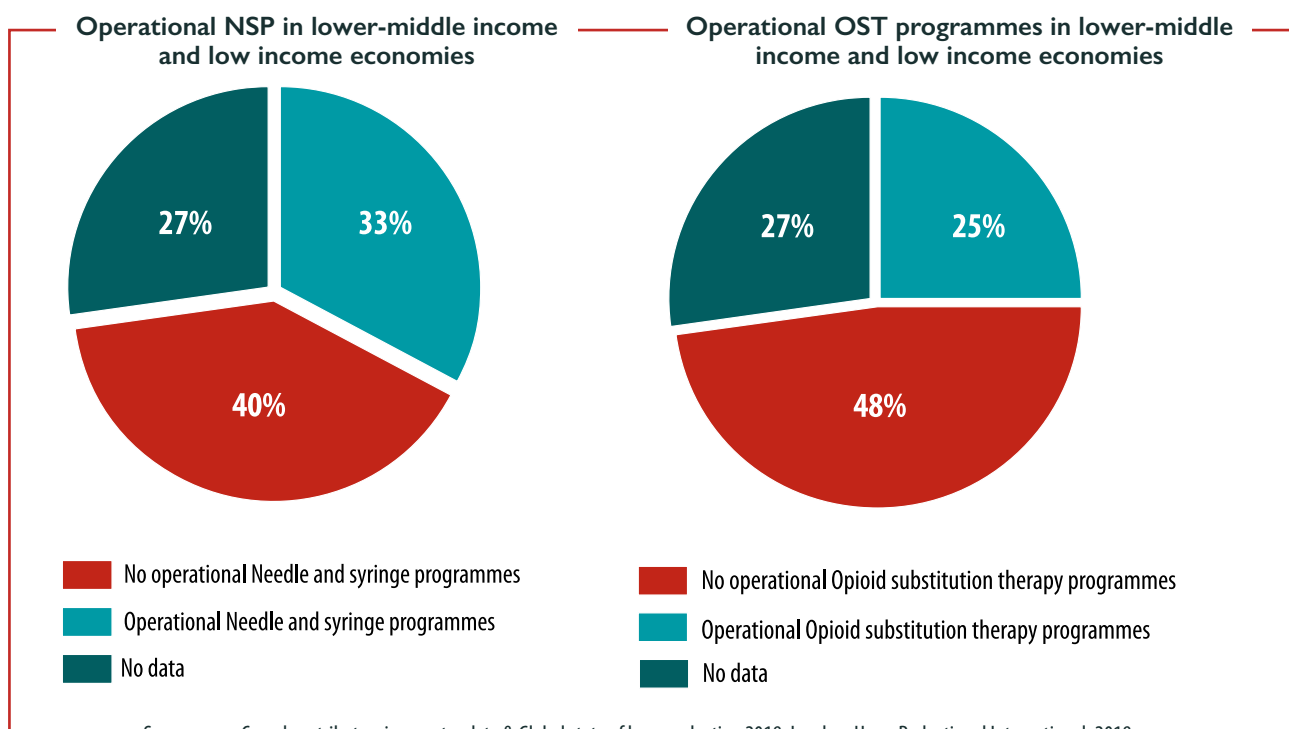


3. LACK OF SUFFICIENT HARM REDUCTION SERVICES

The WHO and many other UN bodies recommend that a combination of high levels of coverage for needle and syringe programs (NSP) and opioid substitution therapy (OST) is a cost-effective intervention that might lead to reducing the risk of HCV infection among people who inject drugs. A systematic review of scientific studies¹⁴ suggests that the risk of hepatitis C infection can be reduced by 74% when both these programs are in place. Just over a quarter of reporting lower-middle and low-income countries refer to harm reduction in their national policies (see Figure 1).¹⁵ There are operational NSP and OST programs available in 86 countries (only 40% of the world's 216 countries).¹⁶

Other countries, such as the Russian Federation, which has one of the highest HCV disease burdens, implement punitive policies towards drug use and counter harm reduction initiatives. The Russian Federation has a national ban on OST and near absence of NSPs, even though its HIV and HCV rates are increasing among people who inject drugs.¹⁷

Figure 1. NSP and OST programmes in lower-middle income and low income economies



The number of countries hides **the high disparity among the different harm reduction services delivered from one country to another**. For instance, in two of the world's most populous countries, the number of syringes distributed per person and per year in India (250) is almost 10 times the number of syringes distributed in Indonesia (26).¹⁸ Overall, in 2015 the global average of 20 syringes distributed per person who injects drugs per year was far from the 2030 WHO HCV target of global average of 300 syringes per year.

Similarly, the **quality and sufficiency of harm reduction services** vary greatly from one country to another one, as well as within a country. In most cases, NSP sites are concentrated in urban centers compared to rural areas. Another issue is the availability within harm reduction sites to HCV care. **Not all sites offered an HCV test and/or made information about hepatitis C available**. Out of the 30 European countries, HCV tests are not offered by harm reduction services in 6 countries: Croatia, Cyprus, Estonia, Lithuania, Poland and Slovakia, where the relative burden of disease among people who inject drugs ranges from 3.78% in Lithuania up to 21.2% in Slovakia.^{19 20}

4. FEW NATIONAL PLANS ON VIRAL HEPATITIS FOCUS ON PEOPLE WHO INJECT DRUGS

More work is needed to increase the number of national plans that specifically focus on people who inject drugs. In September 2016 the first report based on mapCrowd data found that “of the 119 countries where information exists, only 44 (or 37%) have national HCV plans. Where these policies do exist, most fail to include strategies that create or increase access to HCV prevention, diagnostics, and treatment for people who inject drugs, despite their high burden of HCV.”

By comparison, as of September 2019, of the 189 countries where information exists, 111 (or 58%) have national HCV plans. Out of these 111 countries, 32 (or 29%) mention key populations and target them with specific treatment inclusion strategies.

There are some positive trends: more and more countries have adopted or are about to adopt national plan on viral hepatitis.

Reference to the specific needs of people who inject drugs, in particular, the needs of women who are too often overlooked in harm reduction programs, is a positive step, but additional tailored strategies, detailed targets indicators, and budget allocations are needed to ensure they meaningfully participate and help determine the HCV services that work best for them.

mapCrowd questions: Is there a national plan for viral hepatitis? If so, are people who inject drugs mentioned as key population and targeted with specific treatment inclusion strategies?

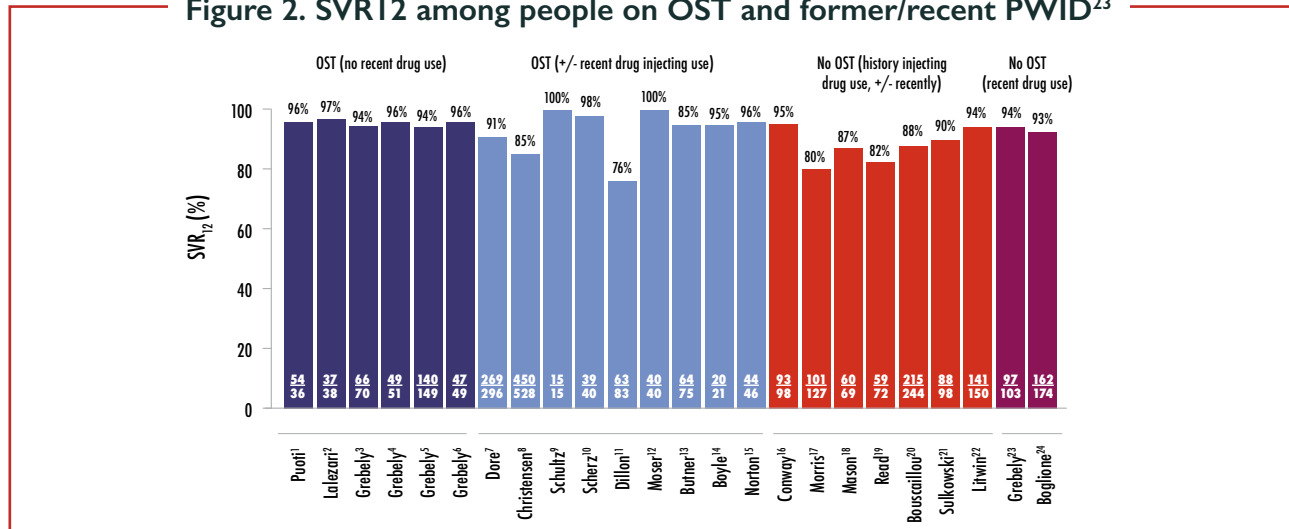
Map 2. Inclusion of people who inject drugs in national hepatitis plans^{21 22}



5. ABSTINENCE-BASED TREATMENT RESTRICTIONS

There is no scientific basis to deny direct-acting antiviral (DAA) treatment to people who inject drugs. **People who inject drugs achieve similar sustained virological responses (SVR) with different DAAs in 12 weeks as people who do not inject drugs.** This is true for people who are actively or formerly injecting drugs, as well as for people regardless whether they are taking OST.

Figure 2. SVR12 among people on OST and former/recent PWID²³



Further, **DAAs are highly effective even without perfect adherence.** Yet medical providers' stigma and bias assumes that people who inject drugs will not complete the DAA treatment course. People who use drugs have significant expertise and lived experience in managing their drug use; this can be highly beneficial to managing and completing a full treatment course! The SIMPLIFY study demonstrated that self-reporting active people who inject drugs could achieve good adherence and SVR when taking sofosbuvir/velpatasvir; 97% of participants achieved SVR at week 12.²⁴

Harm reduction is prevention. Reinfections do occur and national HCV responses must plan for them and test-and-treat people regardless if they have been reinfected with HCV. When drug use is criminalized and people do not have access to correct information, sterile injecting equipment, and are not linked to OST and other prevention and harm reduction services, people who inject drugs are put at more risk to be exposed to HCV and other health conditions. **There are no medical reasons not to treat people who have been reinfected.** Understanding the precautions to take, expanding access to comprehensive, preventative harm reduction and sexual health services, and starting DAAs as early as possible can help reduce the rate of reinfections and prevent onward HCV transmission—acts as treatment as prevention (TasP).²⁵ Offering early treatment across diverse clinical settings, including people who are currently injecting drugs and accessing NSPs, can reduce HCV RNA (viremic) prevalence and increase DAA uptake among this population.²⁶

mapCrowd question: Are people who are currently using or injecting drugs eligible?

Hepatitis clinical guidelines are shown to be available in 44 countries, but they do not all emphasize treatment coverage for key populations. Even worse, from a human rights perspective, in 9 countries where data are available, they exclude people who actively use drugs and require abstinence from substances before initiating any hepatitis C treatment.

Yet overall, **there has been a positive trend in recent years more and more countries are abandoning abstinence-based treatment restrictions.** By comparison, before 2018, out of the 77 countries where data were available, 16 countries had implemented restrictions; today, almost half have changed their policies.

People who are currently using or injecting drugs are not eligible to HCV treatment

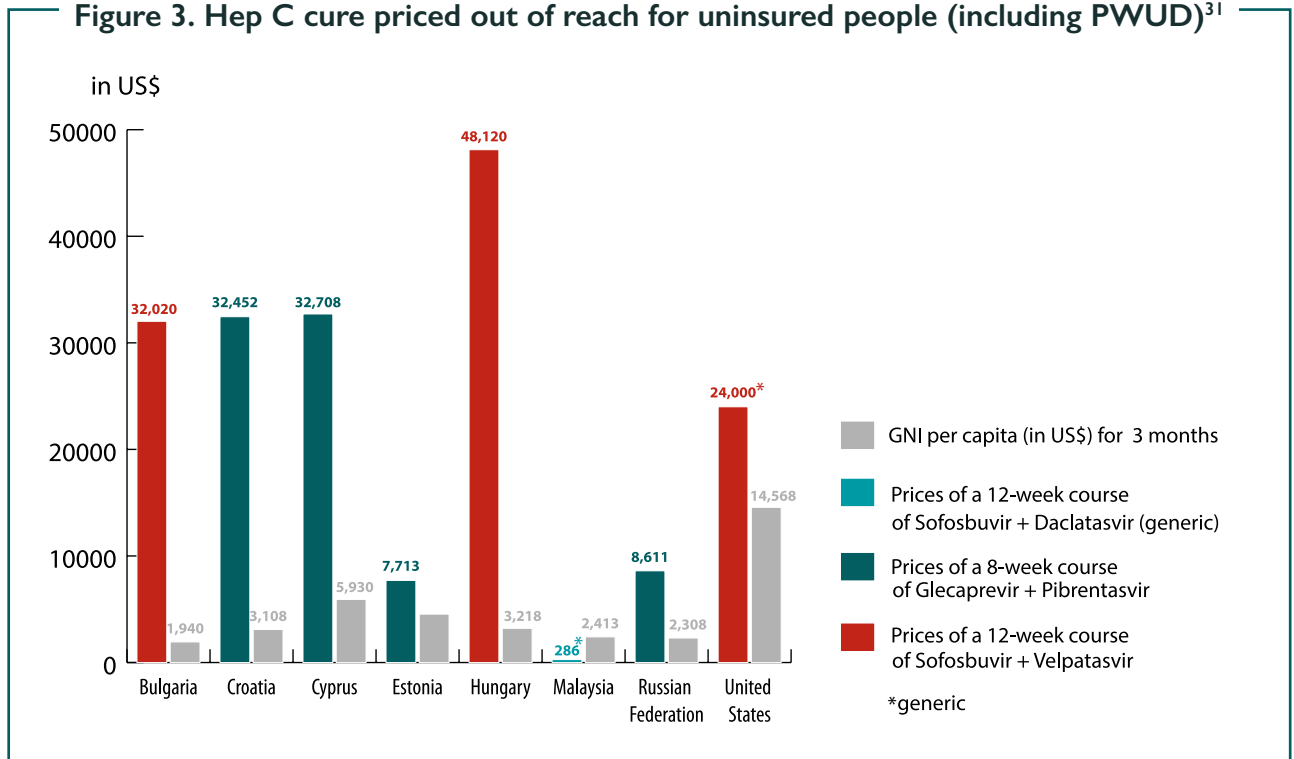
Countries where people who actively use drugs are not eligible for HCV treatment before 2018	Countries where people who actively use drugs are not eligible for HCV treatment in 2019	Countries which are currently rewriting their national hepatitis C clinical guideline to modify or remove abstinence-based restrictions
Bulgaria Burundi China Croatia Cyprus Estonia Hungary Malaysia Malta Myanmar	Poland Romania The Russian Federation The Slovak Republic Ukraine The United States	Estonia Hungary Poland Romania

In the United States, there is some form of abstinence requirements in 18 states (about 35%, including DC and Puerto Rico),^{27 28} particularly for types of insurance that cover low-income people, of which 12%²⁹ are people who use drugs (PWUD).

6. HCV TREATMENT REMAINS OUT OF REACH FOR PEOPLE MOST AT RISK

The majority of people who use drugs are not covered by health insurance³⁰. Where treatment is restricted to abstinent individuals, it means people who use drugs have to pay out-of-pocket to get treatment or must receive a waiver from the payor or insurance company because DAAs are still priced out of reach relative to Gross National Income per capita (calculated at three months, the most common duration of DAA treatment). Other treatment restrictions and lack of insurance coverage for people who use drugs impact treatment initiation among the people most disproportionately affected by HCV.

Figure 3. Hep C cure priced out of reach for uninsured people (including PWUD)³¹



7. TREATMENT RESTRICTIONS BASED ON LIVER DISEASE STAGE

Early treatment for a person with chronic HCV saves lives as well as healthcare costs in the long term. Initiating DAAs as early as possible:

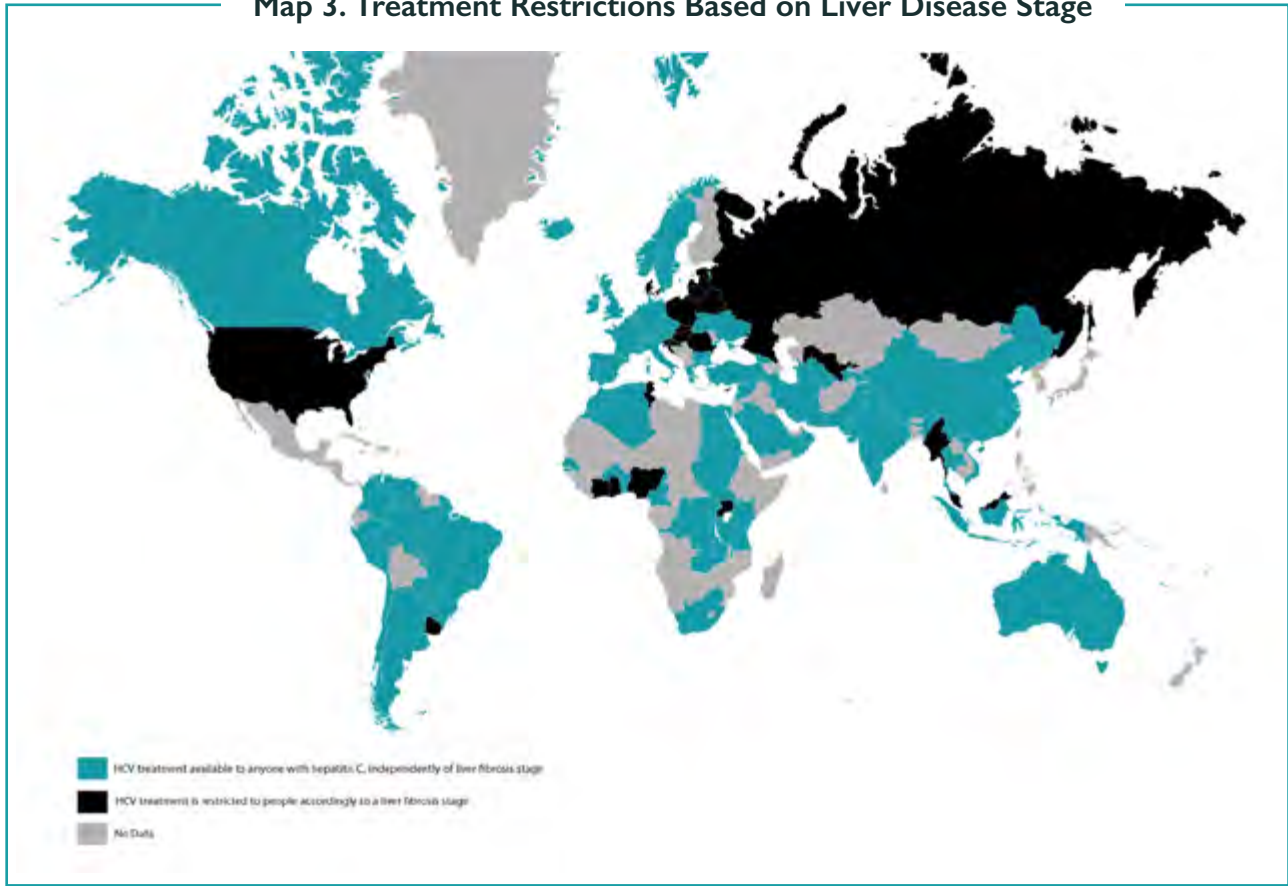
- Stops and even reverses some liver damage (fibrosis).
- Reduces, even avoids, additional costly tests to assess level of fibrosis. Patients often need to pay for liver staging tests out-of-pocket in most low- and middle-income countries.
- Prevents the rapid development of fibrosis and more advanced stages of fibrosis, which are predictive signs of cirrhosis, and therefore other liver-related illnesses like liver cancer, which can lead to death.
- Achieving SVR significantly reduces the risk of HCV transmission.

The public health benefits are enormous, yet high manufacturer prices of DAAs and limited number of prescribers in countries have resulted treatment rationing and prioritizing people with the most advanced stages of liver disease.

mapCrowd question: Is HCV treatment available to anyone with hepatitis C, independently of liver fibrosis stage?

Among the 70 countries where data are available, 23 (33%) restrict HCV treatment to at least people with a score of F2—the level of fibrosis (see Map 3).^{32 33}

Map 3. Treatment Restrictions Based on Liver Disease Stage



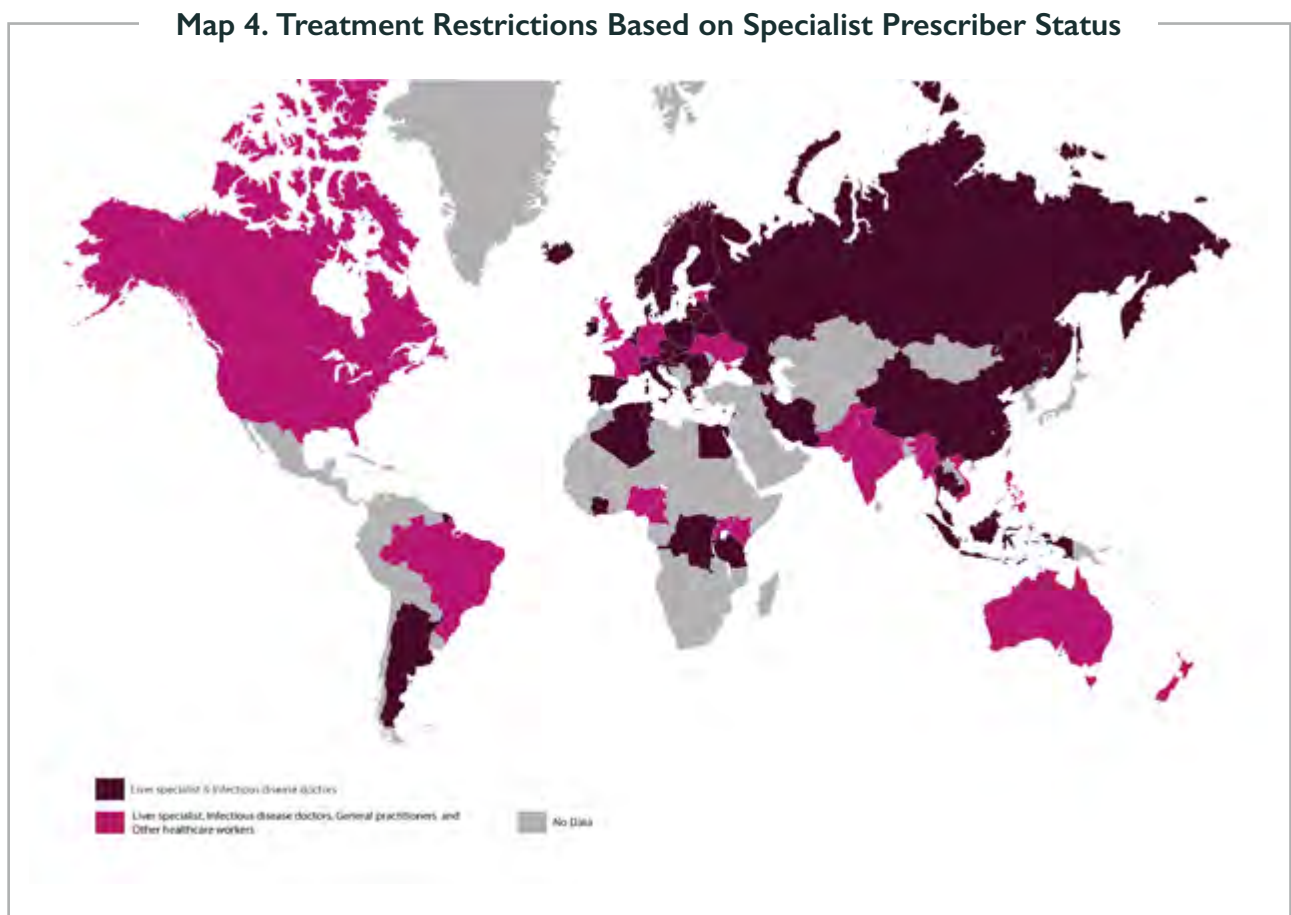
8. TREATMENT RESTRICTIONS LINKED TO SPECIALIST PRESCRIBERS

Permitting and increasing the number of non-specialists to prescribe DAAs can increase treatment uptake.³⁴ However, in the majority of countries where data are available, 42 out of 62 countries (almost 68%), restrict DAA prescribers to specialists only (usually hepatologists and infectious disease doctors), creating an additional barrier for people with chronic HCV and, in particular, people who use drugs. The implications of relying on specialists to scale up treatment are clear:

- Specialists are scarce in countries, thereby de facto restricting treatment uptake.
- They can charge additional fees and consultations become more expensive.
- They might be inexperienced working with people who use drugs and require cultural competency training to reduce stigmatizing and prejudiced attitudes and behaviors.

HCV treatment outcomes are similar between primary care providers and specialists³⁵, however, only 20 countries (or 32%) also allow general practitioners to prescribe DAAs.³⁶

mapCrowd question: Who can prescribe HCV treatment?



Even when national guidelines permit people who use drugs to start DAA treatment, they still face stigma and discrimination from health professionals, usually based on prejudices.

9. CRIMINALIZING PEOPLE WHO USE DRUGS CONTRIBUTES TO POOR TREATMENT UPTAKE

Criminalization of people who use drugs has severe consequences and endangers their lives, with disproportionate impacts on women who inject drugs. Women who inject drugs are more at risk to gender-based violence, rape, trauma, and losing child custody³⁷; harm reduction and healthcare services must address the specific needs of women who inject drugs and who are formerly incarcerated.

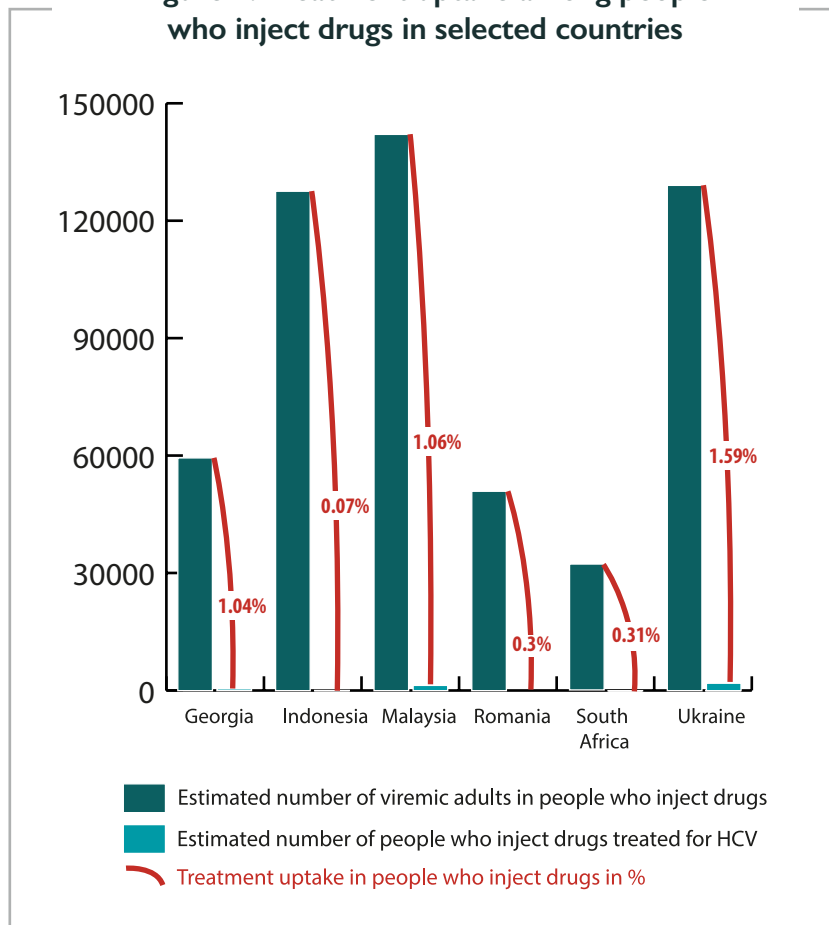
Punitive drug policies lock people into a system of incarceration, perpetuating settings that breed blood-borne diseases like HCV. Access to preventative services is well below the efforts needed to prevent HCV. In 2018, only 10 countries provided NSPs in at least one prison,³⁸ and 54 countries have some form of OST is provided in prisons.³⁹

However, LMICs have scarce data about hepatitis C and PWID. In six selected countries, HCV antibody prevalence among PWID are 12 to 50 times higher than overall population.⁴⁰

According to the estimated number of PWID who have been treated for HCV since the mapCrowd data that were first collected in 2016, there is a huge gap between the need versus actual access to DAAs for people who inject drugs. The rate of treatment uptake for PWID in any given country is less than 2%, even in countries where elimination plans have been launched.⁴¹



Figure 4. Treatment uptake among people who inject drugs in selected countries



Despite having a cure, we are failing people who are most in need and disproportionately affected by HCV.

10. ADVOCACY POINTS

Despite increasing access to DAAs, we won't be able to treat our way out of the global epidemic without scaling up NSPs and access to OST. A comprehensive package of harm reduction services has been adapted for HCV by activists.⁴² To advocate to policy makers Improvement in treatment uptake for people who inject drugs can be achieved with:

- Reliable access to DAAs that treat all-genotypes of the virus; generics have the same active ingredients as branded versions yet cost significantly less at <US\$100 per 12-week treatment course by Indian suppliers;
- Expansion of DAA prescriber status to non-specialists, such as general practitioners, and outside hospital settings⁴³
- Health professionals who are trained in harm reduction and community-friendly health-care approaches that destigmatize substance use, sex work, and the unique experiences of communities disproportionately affected by HCV
- Integrated, gender-responsive harm reduction services designed by and for people who use drugs, and which women address the specific needs of women
- Expansion and high coverage of NSPs and access to OST including in prisons
- Decentralized and simplified diagnostics in settings used by people who inject drugs
- Trained and fairly remunerated peer workers to support people through the HCV care cascade and to navigate the health system
- Possibly cash-based incentives to assist patients with transportation and adhering to clinic visits
- Services that could be offered on-site or referred to other community-friendly sites that include transportation assistance, psychosocial/counseling, non-abstinence-based housing, employment, financial, legal, and other social services
- Programs that provide meeting space, housing, nutrition possibly cash-based incentives to assist patients with transportation and adhering to clinic visits
- Inclusion of people disproportionately affected by HCV, i.e., people who inject drugs, in national elimination processes
- Political and funding commitments by governments (e.g., Ministries of Health, Justice, and Corrections)
- Alignment of national hepatitis plans between Ministries of Health and Justice, which would include opt-out test-and-treat programs in prisons
- Drug policy reforms that decriminalize drug use.

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Treatment Action Group (TAG)

TAG is an independent, activist and community-based research and policy think tank fighting for better treatment, prevention, a vaccine, and a cure for HIV, tuberculosis, and hepatitis C virus (HCV). TAG works to ensure that all people with HIV, TB, or HCV receive lifesaving treatment, care, and information. TAG is comprised of science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions. TAG catalyzes open collective action by all affected communities, scientists, and policy makers to end HIV, TB, and HCV.

For more information, please visit: www.treatmentactiongroup.org

Médecins du Monde

Present in France and in 80 countries, Médecins du Monde (Mdm) is an independent international movement of activists who provide care, testify, and accompany social change. From its 388 innovative medical programs and advocacy based on facts, Mdm places people who are excluded and their communities in the capacity to access health while fighting for universal access to care.

For more information, please visit: www.medecinsdumonde.org

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