World Hepatitis Day: the obstacle course to the cure
A study in 5 middle-income countries

On the eve of World Hepatitis Day (July 28th), Coalition PLUS is launching at AIDS 2018 the summary of a report titled “Mind the Gap: HCV policies versus community experiences” [1]. The product of a study of five middle-income countries (India, Indonesia, Malaysia, Morocco, Thailand), the report highlights that while new medicines effectively cure hepatitis C, direct-acting antiviral treatment remains widely inaccessible. Even in settings that benefit from generic DAAs, it is becoming clear that while low medicine prices are necessary to enable a scale up of treatment, the presence of bottlenecks elsewhere in the hepatitis C response means that price reductions alone will not be sufficient. In many cases, the pathway for diagnosing and treating hepatitis C, a viral infection that attacks the liver and can lead to possible death by cirrhosis or cancer, resembles an obstacle course.

In confronting the hepatitis C (HCV) epidemic, the countries featured in the report—Morocco, India, Indonesia, Malaysia and Thailand—are among the few countries in the Global South to have access to the reduced prices offered by generic medicines and potential to allocate robust public health budgets. Nevertheless, our study shows that the pathway for people living with hepatitis C remains a massive challenge in these 5 middle-income countries.

Based on interviews with 240 at-risk individuals (in this case: people who inject drugs and / or co-infected with HIV and HCV) and 51 HCV health professionals [2], our study reveals and explores many of the key barriers that make access to diagnostics and treatment extremely difficult—and in some cases impossible—for a very large number of those most in need.

The lack of awareness

In interviews, both health professionals and service recipients denounced the lack of awareness about HCV and the lack of easily accessible, high-quality information on HCV and HCV services. Health professionals also pointed out the lack of training on HCV, as well as the insufficient time for exchange with patients on the disease and the process for treating it.

The inefficiency of the delivery of care

The study also shows that the services are often not adapted to the needs, lifestyle or financial capacities of the people who are supposed to benefit from them. First of all, the diagnosis path is described by focus group participants as expensive, long and complex. Access to diagnosis can require numerous expensive trips that can result in, as a consequence of long travel/waiting times, hidden costs such as lost wages. Furthermore, in some cases delays of two to three weeks to receive test results were reported, while the number and complexity of appointments was also cited.

As for treatments, stock-outs were denounced by study participants in Jakarta. In addition, hoping to benefit from free treatment (via government programs) is a real challenge. In Delhi, to obtain a prescription renewal without paying, one must go to the hospital once a month, where queuing takes hours. In Thailand, treatment guidelines impose special conditions on patients, such as abstaining from drugs for at least six months. As a result, the risk of patient loss to follow-up increases. In fact, many patients are stuck in care after the initial stage of screening.
Urgency to reform in depth

To successfully treat 80 per cent of the world’s 71 million infected people by 2030, as Member States pledged to achieve at the 2016 World Health Assembly, it is urgent to launch national awareness campaigns (toward the public and health workforce) and to reform HCV services—through simplification and decentralization—to make them more operational and accessible. Today, WHO’s latest estimates suggests that only 12% of people infected with HCV have been diagnosed and only 4.2% have accessed treatment [2].

We, the community-based anti-HCV associations within Coalition PLUS and partners of the HIV/HCV Drug Affordability Project, are asking governments to:

• Develop national information tools and campaigns
• Strengthen the training of health professionals
• Simplify HCV care protocols
• Decentralize HCV services
• Integrate HCV services into HIV and harm reduction programs

Press conference at AIDS 2018 Amsterdam (in English)

Title: A reality check on progress towards elimination in five middle-income countries
Day / time: Wednesday, July 25, 13:00-13:45
Venue: PCR1, Room G106-107, Level 1 of RAI Amsterdam
Participants: Maria Donatelli, Coalition PLUS (France); Mehdi Karkouri, ALCS (Morocco); Caroline Thomas PKNI (Indonesia)

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sources

HIV/HCV DRUG AFFORDABILITY PROJECT
This study was carried out as part of the Coalition PLUS’s HIV/HCV Drug Affordability project, funded by UNITAID. Since its launch in 2015, the project has established partnerships with 15 local civil society organizations in seven countries: Brazil, Colombia, India, Indonesia, Malaysia, Morocco, and Thailand. Through outreach at the community level and engagement in the domestic policy dialogue, project partners promote increased awareness, access to diagnostics, and access to treatment.

COALITION PLUS
Founded in 2008, Coalition PLUS is an international coalition of community-based organizations against AIDS and viral hepatitis. Coalition PLUS is now present worldwide with 100 partners in 40 countries. Through the 14 member organizations of our Board, the decision-making process involves associations from both the Global North and Global South. With our community-based approach, we advocate for people who live with HIV / viral hepatitis and key populations to be systematically involved in the design, implementation and evaluation of the healthcare programs that directly affect them. Through our action and our 6 regional platforms, we aim to strengthen the capacity of our members and partners, as well as to expand the space for their participation in important dialogues.