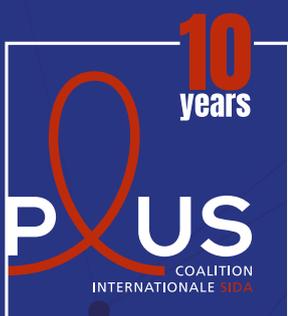


MIND THE GAP

HCV POLICIES
VERSUS
COMMUNITY
EXPERIENCES

AUGUST 2018



HIV/HCV DRUG AFFORDABILITY PROJECT

This study was carried out as part of the Coalition PLUS 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.

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FOREWORD

Across all income settings, hepatitis C continues to impose a significant burden on persons living with HIV. The WHO estimated in 2016 that 2.3 million people living with HIV (PLHIV) are co-infected with hepatitis C virus (HCV), of whom 1.3 million are persons who inject drugs (PWID). Despite the emergence of a revolutionary treatment nearly four years ago, it remains unclear to what extent—or even which direction—burdens of co-infection have since changed. Some countries seem to have made substantial initial progress against the epidemic, others remain near an equilibrium of new infections and successfully treated cases, and several appear to face a rising population of co-infected individuals. However, in far too many settings, baseline epidemiological information is too limited to accurately measure the burden, while monitoring of the cascade is also insufficient or altogether absent.

In spite of weak systems of surveillance, qualitative trends in the HCV response can be clearly identified. In fact, we see that many of the most important barriers to elimination efforts are not unique to hepatitis C, but rather reflect broader challenges the health system encounters in addressing a wide range of diseases. These obstacles include, but are not limited to: insufficient awareness, limited access to diagnostics, overly-centralized service delivery, inefficient referral systems along the continuum of care, exorbitant medicine prices, inadequate financing, stigma towards most-at-risk populations, and policies that criminalize behaviors of certain most-at-risk populations.

For those engaged in the fight against HIV, many of these issues sound familiar. Prior to the influx of generic ARVs and massive international funding, the HIV response faced similar bottlenecks at similar stages along the continuum. And while many of these bottlenecks have since been reduced and HIV cascades have improved, global progress on HIV diagnosis has remained particularly stubborn. Yet of the many lessons that the HCV response can draw from the HIV response, perhaps the most important is the essential role of community engagement. After all, the success of the HCV policy response is not only a function of available resources, but also the extent that most-at-risk populations are able to access health services and empowered to participate in both the design and implementation of the response. Unfortunately, such groups are often marginalized, rather than empowered. In the case of PWID and MSM, their very behaviors are not only stigmatized but frequently criminalized.

While there may be several paths to elimination, it must be emphasized that any successful path must target elimination in most-at-risk communities, particularly co-infected populations. After all, the prioritization of most-at-risk communities is not only a public health

imperative, it is also the shortest road to elimination in nearly all settings. Those governments with policies that discriminate against or criminalize most-at-risk populations are lengthening the journey. In doing so, they are putting at risk both the achievement of elimination and the lives of countless citizens.

The observations above should remind us that elimination of HCV epidemics are not a *fait accompli*. In fact, among HCV intervenors it is expected that Member States' progress updates toward the 2020 targets (to be presented by the 2021 World Health Assembly) will provide a sober illustration of this point. At present, the WHO is engaging Member States in preparation of the reporting process on 2020 targets. These quantitative measurements will provide important evaluations of responses at country level. However, it is crucial to complement this strategic information with structured qualitative information, which is instrumental to both explaining progress and identifying opportunities to improve further.

A core element of a qualitative analysis of a given disease response is the voice of affected communities. For health services and health policy to be people-centered, it must be informed by patient perspectives. Through structured focus group discussions with 238 community members and interviews with 51 healthcare workers, the study detailed by this report explored a wide range of experiences. Across sites in five countries, several messages emerged: gaps in awareness, gaps in affordability, gaps in healthcare workforces, gaps in funding, and gaps in political will. Collectively, these gaps explain the divergence of policies on paper and their realization in practice; in turn, such divergence helps explain the gap between the progress made by countries toward elimination, and the progress they need to have made by now to be on track to 2020 and 2030 targets.

With the arrival of DAAs, one of the most important gaps has been closed; we now have the technology to eliminate hepatitis C. If the global community were to do so, it would mark the first time that a major infectious disease has ever been eliminated through the use of a medicine. Whether we succeed or not will ultimately be, at the end of the day, a question of political will.

To paraphrase a famous quote about a former global challenge, we can say that in the HCV response, we are no longer at the beginning, nor are we near the end. Rather, we are at the end of the beginning. There is much work left to do to reach elimination, and it will only be achieved if the community is an essential participant in the process.

Hakima Himmich
President of Coalition PLUS
July 2018

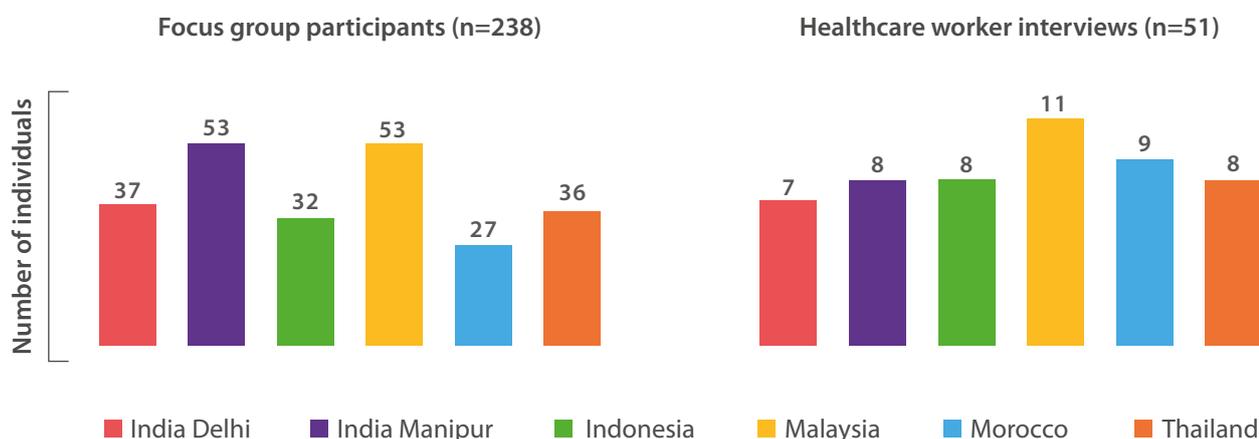
ABBREVIATIONS & ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ALCS	Association de Lutte contre le SIDA
CoNE	Community Network for Empowerment
CBO	Community-based organization
CSO	Civil society organization
DAA	Direct-Acting Antivirals
DNP+	Delhi Network of Positive People
EMRO	WHO Eastern Mediterranean Region
FGD	Focus group discussion
HCV	Hepatitis C Virus
HCW	Healthcare workers
HIV	Human Immunodeficiency Virus
LMICs	Lower- and middle-income countries
MAC	Malaysian AIDS Council
MoH	Ministry of Health
MSM	Men who have sex with men
MTAAG+	Positive Malaysian Treatment Access and Advocacy Group
NGO	Non-Governmental Organization
PKNI	Persaudaraan Korban Napza Indonesia (Indonesian Drug Users Network)
PLHA	People living with HIV/AIDS
PLHCV	People living with hepatitis C
PWID	People who inject drugs
SEARO	WHO South-East Asia Region
TTAG	Thai AIDS Treatment Action Group
TWN	Third World Network
WHO	World Health Organization
WPRO	WHO Western Pacific Region

EXECUTIVE SUMMARY

In 2016, WHO Member States adopted a global strategy to eliminate hepatitis C by 2030. This resolution followed shortly after the arrival of medicines that have revolutionized hepatitis C (HCV) treatment. Known as direct-acting antivirals (DAAs), these medicines offered people living with hepatitis C (PLHCV) a safe, highly-effective cure. To the public health community, DAAs presented an unprecedented opportunity: a means to eliminate an infectious disease through a medicine. Yet while the goal of elimination can appear simple enough on paper, the design and implementation of programs to achieve it require further elaboration of country-level strategies and corresponding budgets. In turn, the translation of strong policies to successful practice at ground-level will prove the key catalyst to elimination. The exploration of such a gap—between policy commitments on paper and the reality of their implementation in practice—represented the focus of a study conducted by Coalition PLUS and its partners. Through over 40 hours of structured focus group discussions with 238 at-risk individuals [primarily people who inject drugs (PWID) and people living with HIV/AIDS (PLHIV)] and PLHCV, the survey provided communities an opportunity to voice their perspectives and experiences. To further strengthen ground-level insights into the HCV response, 51 healthcare workers providing HCV services were also interviewed.

FIGURE 1 - STUDY PROFILE

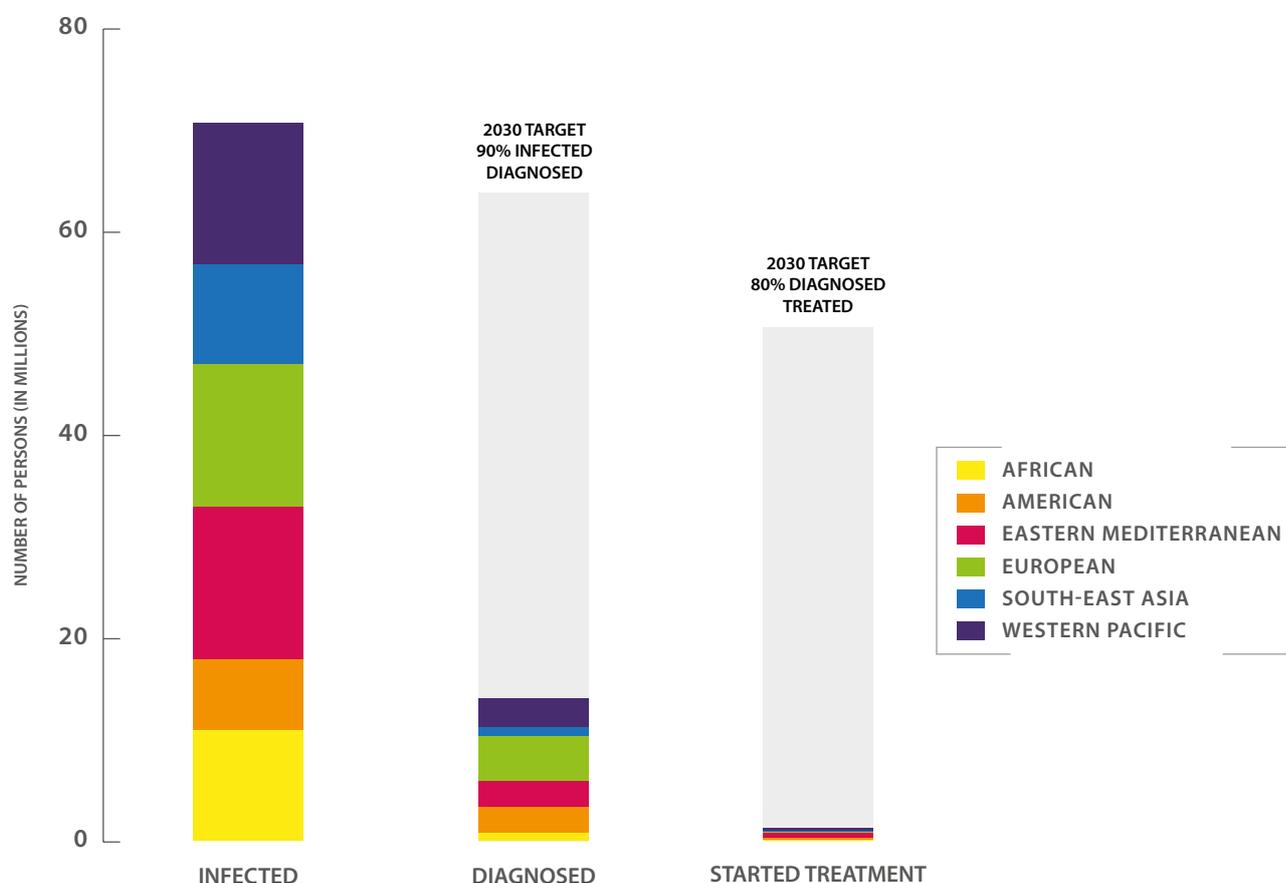


Note: A previous version of the executive summary accidentally misstated the number of participants as 240.

This report complements the evaluations of hepatitis responses conducted by fellow stakeholders. One particular inspiration was the WHO's recent development of country response profiles through a survey on a checklist of indicators of structure (e.g., policy decisions), input (e.g., budget allocation) and process (e.g., implementation of WHO guidelines). To complement the WHO's top-down macro-level overview of HCV responses, the Coalition PLUS survey provides a bottom-up micro-level evaluation of the HCV response at selected sites in five middle-income countries: India, Indonesia, Malaysia, Morocco, and Thailand.

As an explanatory and qualitative survey, the findings and recommendations serve to inform the response in the countries involved in the study. In addition to highlighting potential gaps between policy adoption and policy implementation/coverage, this evaluation exposed a variety of thematic gaps in awareness, health workforce capacity, service affordability, funding, and political will. Analysis of these gaps contributes qualitative context to complement the strategic information that governments have accumulated. In particular, it aims to nourish the dialogue that country updates on the 2020 targets—to be presented at the World Health Assembly in 2021—will surely provoke. Four years away from 2020, the latest global estimations of progress toward those goals (Figure 2 below) show that most regions face a massive gap between present cascades and regional/global targets.

FIGURE 2 - CASCADE OF CARE FOR PEOPLE LIVING WITH HCV INFECTION BY WHO REGION, 2015 BASELINE



*WHO estimates that 1.5 million people started DAA treatment in 2016, compared to around 1 million in 2015; with regards to incidence, WHO estimated 1.75 million new HCV infections in 2015.

Source: Global Hepatitis Report 2017. Geneva: World Health Organization; 2017.

If the raw data of the cascade serves to describe the response, this survey contributes to the process of explaining it by providing a robust sample of individual stories behind the numbers.

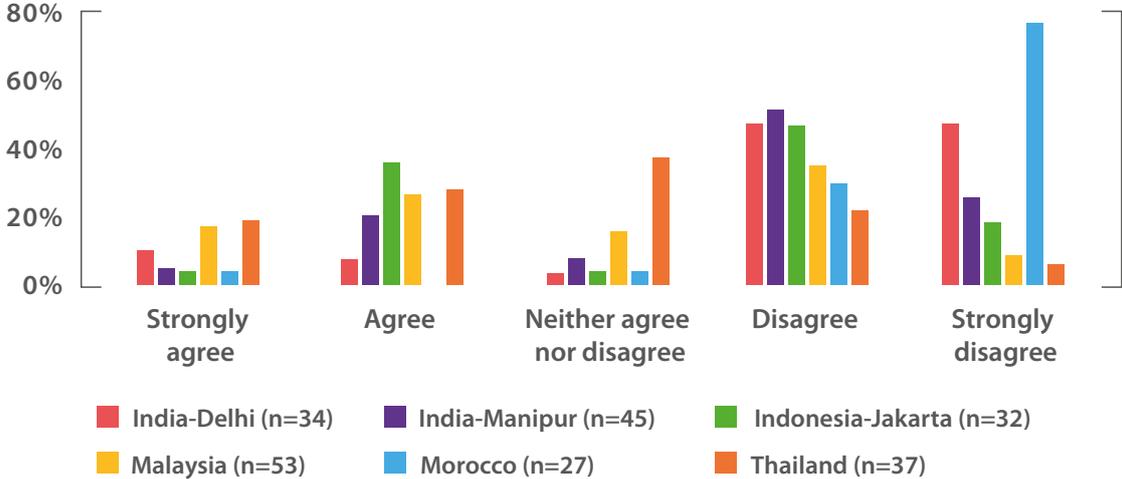
In synthesizing these accounts, two overarching themes emerged from the study, both of which are tied to the **lengthy timeline and logistical complexity of completing diagnosis and treatment**. Those themes are insufficient HCV awareness and insufficient HCV capacity.

INSUFFICIENT AWARENESS

Awareness campaigns are needed to increase understanding of HCV prevention, diagnosis, and treatment. This call was echoed by both the focus group participants (see Figure 3) and healthcare workers. As discussions of *awareness* often employ the word in an overly vague manner, it is important to clarify exactly what sort of information is required. Survey participants emphasized that awareness-raising must deliver knowledge that is **accessible, accurate, and actionable**. While the scope of information needed will vary according to key stakeholders—i.e. patients, healthcare workers, and policy-makers—the report demonstrates that all these groups currently operate under a **significant deficit of information**. To address this gap, comprehensive awareness-raising will require investments. **Resources must be allocated to trainings, education materials, public campaigns, and counseling**. Furthermore, it is important to note that the knowledge deficits of stakeholder groups are often linked. Improved healthcare

worker awareness on HCV—as well as improved understanding of how to effectively communicate such knowledge—would significantly increase patient awareness. On this point, many focus group participants and healthcare workers highlighted the importance of the quality of patient-healthcare worker interaction. Where present, it is a crucial catalyst on the pathway. Yet many participants indicated that both the limited HCV training and limited counseling time afforded to healthcare workers presented obstacles to maximizing this interaction. In particular, the need for more extensive training was expressed by many of the healthcare workers interviewed during the study. In fact, several healthcare workers interviewed for this study demonstrated a lack of knowledge of the full diagnosis protocol, and many (notably in India) indicated the absence of a policy at their facilities for implementing HCV screening tests.

FIGURE 3 - THE PUBLIC IS GENERALLY AWARE OF HEPATITIS C



INSUFFICIENT CAPACITY

The survey demonstrated that the continuum of care—the pathway of services a patient must follow—presents a myriad of complex barriers for patients. **In turn, the length, cost, and complexity of current pathways have a major impact on not just individuals, but on the efficiency and scalability of HCV responses. The process must be simplified.** In some cases, such simplification should apply to the protocol guidelines (i.e. the prescribed pathway of screening, viral load confirmation, liver staging, treatment, etc). But

more broadly, the simplification needs to consider the actual logistical pathway that patients must navigate (i.e. how/where/when one can link to services). **To achieve such simplification, HCV service capacity must be expanded.** Existing limitations in capacity (due to lack of training or due to protocol restrictions) often lead to excessive centralization at tertiary facilities; in turn, such centralization not only saturates capacity, but—as figures 4 and 5 show—imposes significant indirect costs on the patient.

FIGURE 4 - TIME OF TRAVEL TO HEALTH FACILITY FROM MY RESIDENCE OR PLACE OF WORK WAS A BARRIER TO GOING FOR TREATMENT

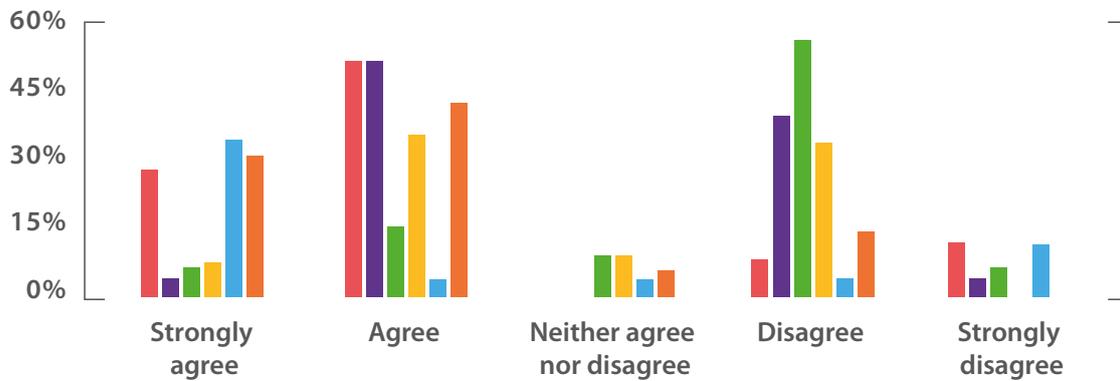
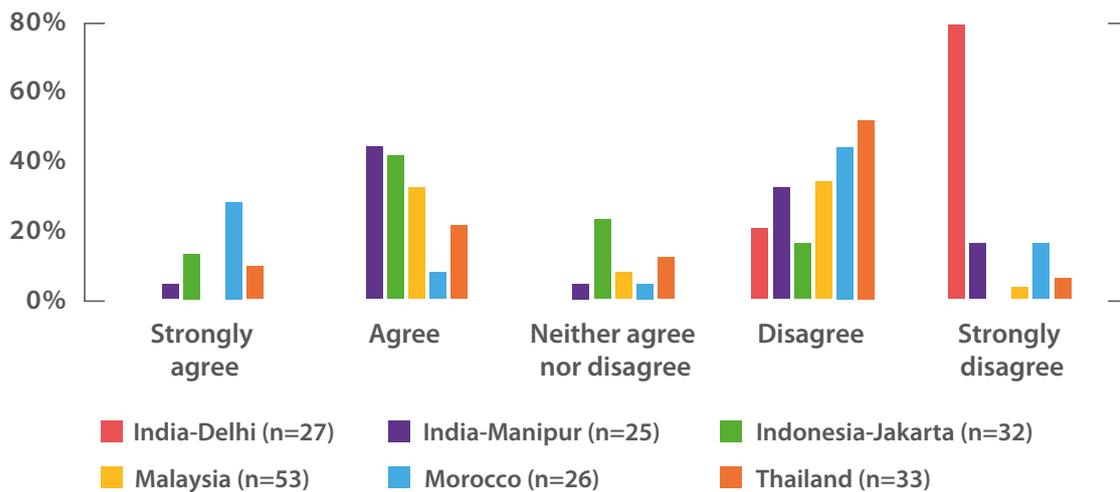


FIGURE 5 - THE WAITING TIME AT HEALTH FACILITIES IS NOT VERY LONG



Through decentralization/integration of services and normalization of quality counseling, the direct and indirect costs of the pathway could be drastically reduced. To accomplish this, **there is a clear need for a wider cadre of healthcare workers to be eligible and trained for delivery of HCV services.** In fact, the strain generated by restrictions on the scope of healthcare workers eligible to deliver HCV services will become even greater bottlenecks for countries that are in the process of expanding HCV programs. **It is therefore imperative that protocols are simplified, service delivery becomes more streamlined, and task-shifting is adopted.**

While the barrier presented by the pathway’s logistical complexity may be exacerbated by the limited awareness of relevant information, even those fully knowledgeable of the process may face significant barriers of time and expense. Far too many individuals confront both obstacles, and far too many countries face the vicious cycle of insufficient awareness and insufficient capacity. Given this interaction, both points should be addressed simultaneously.

While these dynamics are illustrated by responses to the questionnaire that was completed by focus group participants, these issues were explored in far greater detail during the focus group discussions and through interviews with healthcare workers. This more elaborate feedback is captured in the report chapters for each country.

SIMPLIFICATION OF CARE: THE NEED FOR A SHORTER AND STRAIGHTER PATHWAY

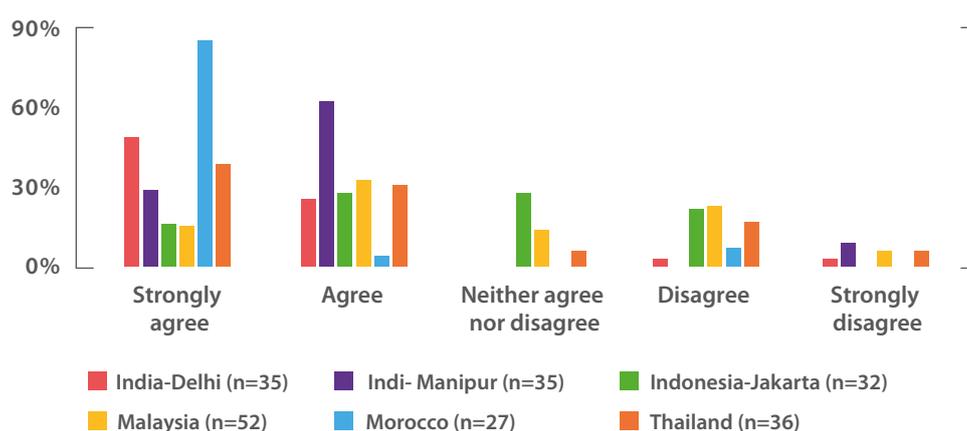
DIAGNOSIS

At present, the stages to complete diagnosis are frequently costly, long, and complex. Each factor alone could lead to voluntary patient drop out or involuntary delays in the pathway. Often, patients must confront all three barriers.

The cost of diagnosis includes both indirect and direct costs. Indirect costs (such as travel expenses, foregone wages, childcare, etc) can represent a significant barrier, particularly where travel or waiting times are substantial. While these indirect costs were

broadly acknowledged by focus group participants as important obstacles, the healthcare workers interviewed did not identify this barrier. In addition to these “hidden” expenses, direct testing costs (i.e. fees charged by the facility for testing services) must be financed out-of-pocket in several of the countries examined in this survey; the impact of such barriers is highlighted in Figure 6. Taken together, these costs can introduce important disincentives or obstacles to completing the diagnosis pathway.

FIGURE 6 - THE COST OF DIAGNOSTIC STEPS WAS A BARRIER TO GETTING DIAGNOSED



The excessive length of the process is often the product of delays due to a limited number of appointment spaces and/or delays in returning test results. For example, participants in several groups cited delays of 2-4 weeks to receive appointments, and another 2-4 weeks to receive test results. If test results are delivered in person, the individual may then need to schedule an appointment (another possible delay) for another trip to the clinic. These delays could also be due to limited capacity of diagnostic infrastructure. In Manipur, for example, blood samples were sent several hours by plane to Delhi for confirmation testing. In the absence of such sample transport networks, the individuals themselves must travel long distances to facilities.

The fragmentation of testing services was also highlighted by focus group participants. Many of the healthcare workers interviewed confirmed this point, as many of their facilities only offered one stage of the diagnosis pathway (i.e. most often it was the screening test). The need to visit multiple facilities not only complicates the pathway, it increases costs (due to greater number of visits) and the risk of referral problems.

TREATMENT

While the focus group discussions and healthcare worker interviews focused heavily on earlier parts of the pathway (i.e. awareness and diagnosis), several points on treatment emerged.

As programs scale up treatment and services reach more rural areas, the logistical complexity of DAA supply will increase and, in turn, stock-outs could become more important. And in fact, the study found cities where supply of DAAs is already an issue. For example, Indonesian participants expressed concern over stock-outs. Moreover, recent communication with Indian colleagues has revealed that stock-outs are also a present concern in Delhi. It should be noted that both—Jakarta and Delhi—are capital cities. One may expect that supply chain management could become even more troublesome in less populated settings.

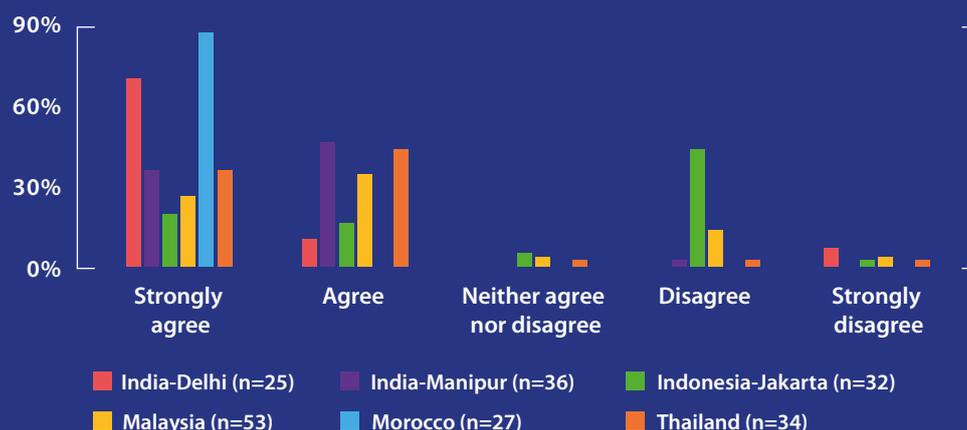
Focus groups also highlighted the potentially burdensome procedure to access free treatment offered by government programs. In Delhi, for example, free treatment currently requires monthly visits to a specific hospital for prescription re-fills, where queues for a re-fill can take hours. In Indonesia, monthly re-fills required the presentation of accompanying blood test results. In fact, it emerged from multiple discussion groups that, in practice, access to “free” services was often limited by the capacity at those public facilities providing them. Many participants explained that they were even advised by healthcare workers at such facilities to pursue services in the private sector in order to expedite diagnosis or treatment.

Thai participants also highlighted concerns over highly restrictive treatment criteria, as Thai doctors and health professionals have often imposed a requirement that patients should be “clean” (not consuming recreational drugs) for 6 months before they could start treatment. This requirement sometimes went beyond the use of banned drugs and included the use of alcohol, tobacco and similar substances.

Moreover, as figure 7 highlights, the survey provided confirmation of the extent that the cost of treatment represents a major factor for treatment access.

Fortunately, many countries included in the survey are in the process of expanding treatment programs. In turn, **the improved affordability and tolerability of DAAs will be crucial to communicate**; after all, the pre-DAA treatment for hepatitis C was notoriously expensive and came with intense side effects, a point acknowledged by several participants during the survey. Awareness campaigns should address this legacy to avoid misconceptions about new treatment.

FIGURE 7 - THE COST OF THE MEDICINES WAS A BARRIER TO GETTING TREATED



ADDRESSING LOSS-TO-FOLLOW-UP

As a result of the myriad barriers highlighted above, many patients will drop out or become stuck in the continuum-of-care pathway. In such cases, there did not appear to be a strong retention system in several sites. In Manipur, for example, only one of the eight healthcare workers interviewed indicated

that they follow up with NGOs or through other relevant channels if a patient drops out of the system during diagnosis or treatment.

Not only must the follow-up be more consistent, but there must also be opportunities to re-link to the pathway. Such channels would likely require funding for additional human resources. **Loss-to-follow-up and re-linkage to care are two crucial issues that policy-makers must highlight as priorities to address.**

DECENTRALIZATION OF SERVICES, “ONE-STOP SHOPS”, AND SERVICE INTEGRATION

The centralization of HCV services may stem from several factors: lack of healthcare worker capacity (due to limited training or protocol restrictions on eligibility), limited diagnosis infrastructure (e.g. access to viral load machines and/or sample transport networks), or absence of strong supply chain management. Whatever the reason, the resulting fragmentation introduces significant barriers. The report elaborates on these obstacles further; the issues highlighted above—as well as those illustrated by Figures 8 and 9—provide a glimpse of the impact of fragmentation and capacity saturation. Taken collectively, **the study highlights that services must be brought closer to the patients and the complexity of the pathway must be reduced.** Simplification and decentralization are thus necessary to both expand capacity and to expand access. In particular, the problems are further exacerbated for individuals living in rural settings, who often face systematically higher indirect costs due to limited HCV services outside major cities. In fact, the distance of rural patients from key services in the pathway raises significant questions about the equity of access to HCV services in many countries.

In urban centers where one-stop clinics (providing all services of the pathway) are feasible, such

models should be explored. In more rural areas, one-stop clinics should also be evaluated, but where not feasible, a streamlined path of decentralized services should be evaluated. For example, the Punjab (India) government—working in collaboration with Project ECHO and leading Indian hepatologists—has implemented one such model; through a recently launched collaboration with FIND, they are exploring models of further decentralization. Such demonstration projects are important catalysts to improved models of service delivery.

Integration of HCV services with other programs should also be improved. For at-risk populations that regularly link with HIV-related or harm reduction services, such specialist facilities should—where feasible—offer HCV services. At the very least, education about HCV—the disease, protocol, and services—should be available. If possible, HCV testing should be provided and should be accompanied by counseling. For these approaches to be successful, a wider cadre of healthcare workers (notably generalists) must be permitted to prescribe and/or administer testing and treatment.

FIGURE 8 - THE COSTS OF TIME OFF WORK HAD AN IMPACT ON MY ABILITY TO COMPLETE DIAGNOSIS OR TREATMENT

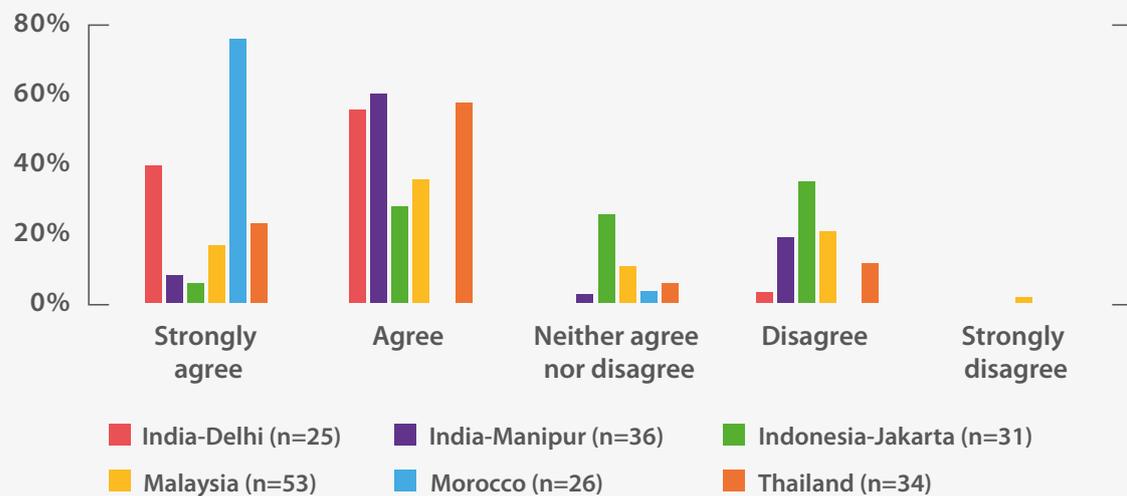
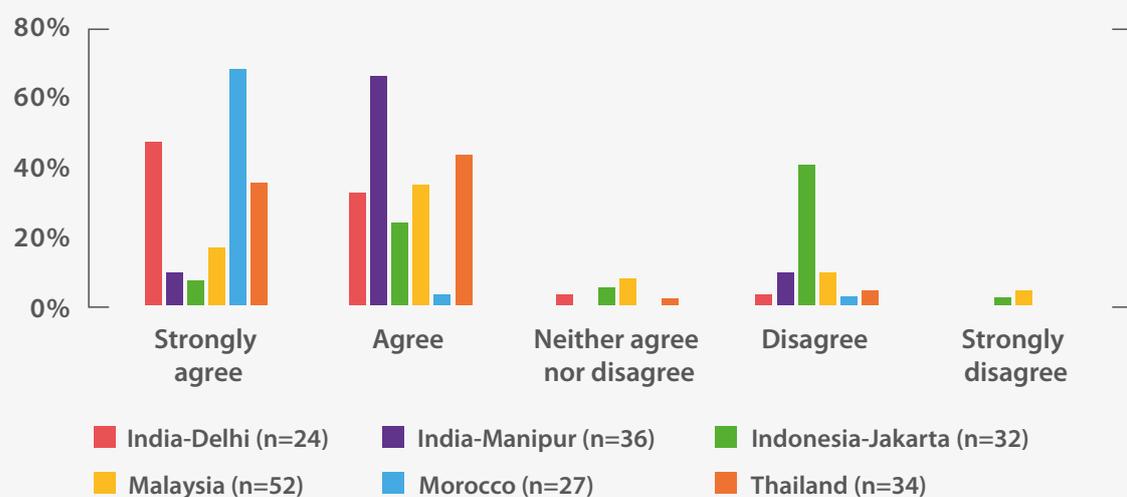


FIGURE 9 - OTHER OUT-OF-POCKET COSTS (E.G. FOR TRAVEL, OR CARE FOR FAMILY) HAD AN IMPACT ON MY ABILITY TO COMPLETE TREATMENT



THE NEED FOR RESEARCH ON AWARENESS-RAISING AND SERVICE DELIVERY MODELS

This report identifies several areas for further research to explore. Research questions stemming from this study could focus on: How to best educate stakeholders? How to improve patient-healthcare worker interaction? How to re-integrate those lost to follow-up? How to address structural barriers to access (notably those stemming from indirect costs and out-of-pocket expenses)?

Many of these questions could be further monitored in future iterations of this survey; future iterations could also explore a broader geographic range of sites. Moreover, the fact that several of the countries involved in this survey have recently launched significant expansions of their HCV response (notably India, Thailand, and Malaysia) means that survey responses related to treatment may—in those cases—be soon outdated. However, access to treatment will need to be monitored. In fact, reduced barriers to DAA access only reinforce the importance of the messages on awareness and diagnosis.

It should be noted that limitations of sample size and geographic reach must inform excessive extrapolation of the survey's results. In this context, it should also be added that as most survey participants were drawn from urban areas, the study may very well underestimate gaps in awareness and service capacity. For example, the Indonesian focus groups took place in Jakarta, a capital city that benefits from a greater concentration of the country's HCV-related services than other cities, let alone more rural areas or peripheral islands. As important disparities in healthcare workforce (especially of specialists) and laboratory infrastructure often exist between major cities and rural areas, a potential implication would be the following: while this survey revealed important gaps in HCV services at study sites, those gaps could be even larger in many settings in the five countries included in this report.

CONCLUSION



An increasing number of countries have adopted encouraging HCV policies (guidelines, strategies, action plans). However, in transforming those policies from paper to practice, **this report highlights the fact that many hepatitis programs face key gaps in the implementation and scale-up of their HCV response.** In synthesizing the experiences and perspectives captured by the survey, two themes emerged: **insufficient awareness** and **insufficient HCV service capacity.** At present, the dynamic between the two creates a vicious cycle. Fragmentation in the continuum of care contributes to the lengthy timeline and logistical complexity of the patient pathway; in turn, limited capacity of healthcare workers means that many PLHCV are not engaged in counseling/testing by healthcare workers, while those who have tested positive often find the rest of the pathway difficult to navigate.

For policy implementation to be successful, the HCV response needs to be adequately prioritized and funded by governments. Appropriate resources will be necessary to launch successful awareness campaigns, to train a wider cadre of existing healthcare workers on HCV, to support HCV counseling, to implement testing strategies, and to procure the required medicines.

Much of the recent attention on hepatitis C has focused—justifiably so—on this last point: namely, the exorbitant price tags that originator companies have placed on DAAs. Indeed, the past two years have reinforced that access to medicines is an absolutely necessary component of a robust HCV response. In many countries facing high prices (most notably in middle-income countries of Latin America and Eastern Europe/Central Asia), the lack of access seems to have stalled the launch of ambitious programs. Yet in those countries where generic medicines are affordable, this survey has demonstrated that accessibility of treatment is not sufficient in itself. It must be complimented by the adoption of policies targeting awareness, prevention, and diagnosis. In particular, the study highlighted that efforts to increase access to treatment must go beyond medicine prices to take into account the entire range of costs: the direct costs of out-of-pocket expenses, as well as the indirect costs of travel and lost wages.

Some of these barriers may be addressed by hepatitis programs; however, many of the obstacles will require the engagement of other government stakeholders. In fact, one may argue that the effort to eliminate hepatitis C provides a litmus test of the key pillars of any health system. After all, the success of the HCV response will depend on the integration of people-centered services, the capacity of the diagnostic infrastructure, access to medicines, the strength of the health workforce, the quality of strategic information systems, and universal health coverage. This study touches on all of these points and, in the process of highlighting existing gaps, makes recommendations for improvements.

The technical and technological means to achieve elimination are available now, the challenge is to more effectively mobilize them. To be successful, that process will require the engagement of communities in both the identification of bottlenecks and the identification of solutions. In documenting community perspectives on key obstacles and key recommendations, this study recognizes and demonstrates the importance of community input on policy responses. They are the individuals most affected and—along with HCV service providers—the individuals who possess the most direct first-hand experience of policy implementation in practice. Communities are therefore best-placed to issue the call heard so often in this report: we must not wait until the 2020 targets are reported to react to existing gaps. We must take action now!

GLOBAL CONTEXT FOR HEPATITIS C

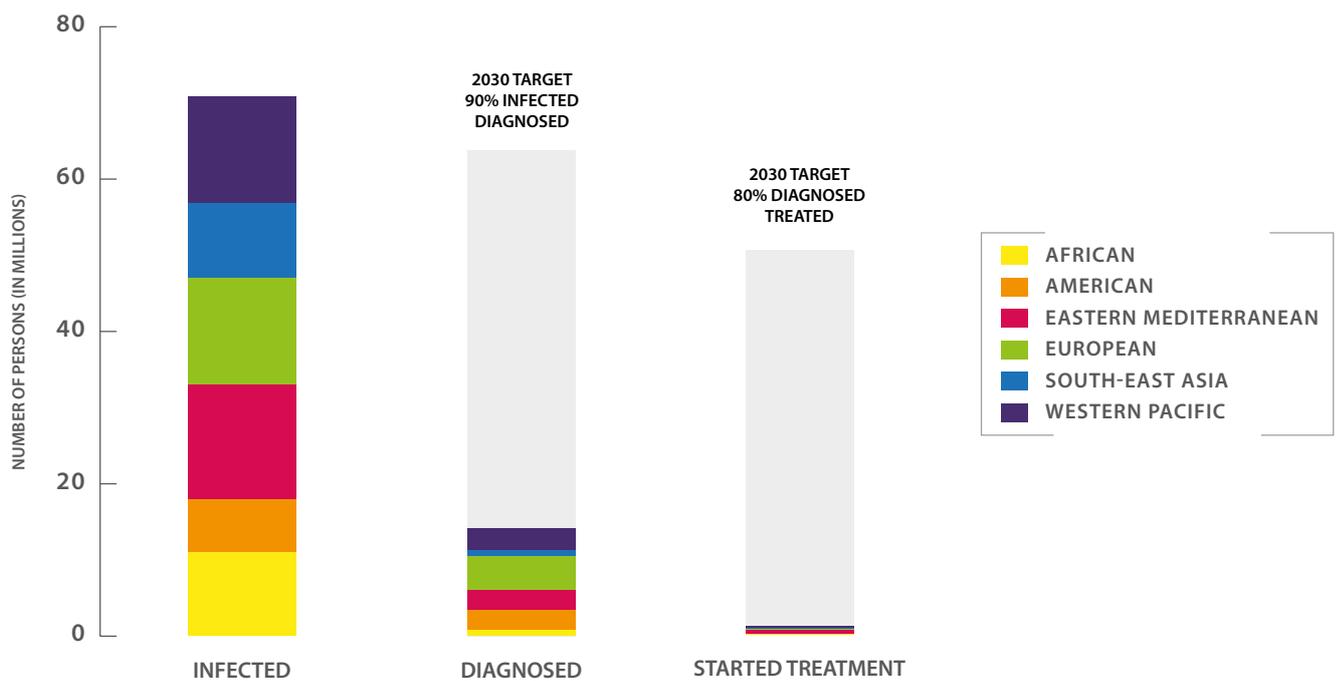
Hepatitis C is a liver disease caused by the hepatitis C virus (HCV). It ranges in severity and includes both acute and chronic forms. Though 15–45% of those who are infected by the virus manage to spontaneously clear the infection, those with chronic infection are at risk of potentially fatal sequelae stemming from liver fibrosis, most notably decompensated liver cirrhosis and hepatocellular carcinoma (liver cancer). HCV is a blood-borne virus whose transmission is most frequently associated with sharing of needles (such as injection drug use or unsafe medical injection).¹

The arrival of new medicines in the mid-2010's, known as direct-acting antivirals (DAAs), have revolutionized treatment options by offering a safe, highly-efficacious regimen that can eliminate the virus. The excitement over a cure, and the outrage over exorbitant prices, have helped propel HCV higher up the public health agenda in recent years. Such attention has been long overdue. While mortality due to high-profile public health diseases such as HIV, TB and malaria have been declining, the global mortality burden of viral hepatitis (i.e. primarily hepatitis B and C) is increasing.²

WHO estimates that there were 71 million people living with chronic HCV infection in 2015. The epidemic is of global scale and affects countries of all incomes. It is estimated that approximately 15% of HCV infections are in high income countries, 73% of persons living with HCV (PLHCV) live in middle-income countries, and PLHCV in low-income countries account for the remaining 12%.³ Country-by-country prevalence estimates vary widely. Ranking among the highest prevalence countries are Egypt, Pakistan, Mongolia, and Georgia. In terms of sheer burden, China is believed to have the highest number of people living with hepatitis C (nearly 10 million).⁴

The WHO's most recent global epidemiological updates have reported PLHCV populations by region. This grouping of estimates reflects the fact that, whether for baseline or monitoring and evaluation, there is not robust epidemiological information for many countries.

FIGURE 10 - CASCADE OF CARE FOR PEOPLE LIVING WITH HCV INFECTION BY WHO REGION, 2015 BASELINE



*WHO estimates that 1.5 million people started DAA treatment in 2016, compared to around 1 million in 2015; with regards to incidence, WHO estimated 1.75 million new HCV infections in 2015.

Source: Global Hepatitis Report 2017. Geneva: World Health Organization; 2017.

Although the WHO's estimates may not provide granularity, the gaps in the global HCV cascade are clear. While the low number of individuals treated to date is notable, perhaps the most important takeaway from figure 10 is the low number of people aware of their status.

The lack of robust epidemiological data extends to sub-populations. For example, the WHO's 2016 report acknowledged that estimates for HIV/HCV co-infection were only available in 45% of countries, and that the quality of country-level estimates of the size of co-infected population were variable.⁵ Such limited data quality is a major challenge to the design and evaluation of effective programs; in turn, the strengthening of strategic information remains a key area for improvement of in-country HCV responses.

Recognizing the global burden and health impact of hepatitis, the global health community has mobilized behind a global strategy to combat viral hepatitis. Following World Health Assembly (WHA) Resolutions in 2010 and 2014, the Global Health Sector Strategy on Viral Hepatitis 2016 – 2021 was approved by Member States of the WHO in May 2016.⁶ This strategy provides guidelines and targets for stepping up interventions to fight all five forms of hepatitis. For hepatitis C, the following targets were set:

TABLE 1: GLOBAL HEPATITIS TARGETS APPROVED BY WHO MEMBER STATES (FROM 2015 BASELINE)

	2020 TARGETS	2030 TARGETS
INCIDENCE OF CHRONIC HBV AND HCV INFECTIONS	30% reduction	90% reduction
MORTALITY FROM CHRONIC HBV AND HCV INFECTIONS	10% reduction	65% reduction
DIAGNOSIS OF HBV AND HCV (aware of status)	30%	90%
TREATMENT OF HBV AND HCV (coverage %)	3 million (HCV)	80% eligible for treatment are treated

Source: WHO Global Health Sector Strategy on viral hepatitis, 2016–2021.

At the global level, the most recent WHO report estimates that nearly 3 million individuals were treated over the course of 2015 (1.1 million) and 2016 (1.8 million) combined.⁷ Yet to average the WHO targets for 2030, global treatment rates would need to reach between 4-5 million per year going forward. Exacerbating the challenge is the matter of ongoing HCV incidence, which a recent WHO report estimated at nearly 1.75 million new infections in 2015 alone.⁸

At the country level, some programs have made exceptional progress. Mongolia and Georgia, for example, have launched very ambitious elimination campaigns. Egypt and Pakistan have treated millions, though incidence in these countries remains a major concern.⁹

Yet aside from the example set by a handful of middle-income countries, most of the progress toward elimination has taken place in wealthy countries. At the World Hepatitis Summit in 2017, nine governments announced that they were on track; the majority of them qualify as high-income countries.¹⁰

In most lower- and middle-income countries (LMICs), progress has been limited. In other words, a gap is emerging between the progress made by countries, even within regions. In many cases, the challenge is not primarily technical or infrastructural, but rather political: a robust test-and-treat approach requires financial support and prevention policies require adoption of policies promoting stronger harm reduction. Where resources are present, it is increasingly clear that aggressive national plans must be accompanied by sufficient political support and financial commitments.

To support domestic efforts, the WHO has led the way in developing tools for policy makers to design their response. By providing a robust conceptual framework and technical assistance on the building blocks of that framework, WHO continues to play a key leadership role. Unfortunately, many countries have not yet fully adopted this framework, nor allocated the resources to implement it. On this latter point, WHO has also provided technical support for HCV investment cases and for HCV cost-effective analyses (available at <https://www.hepccalculator.org/>).

To end the HCV epidemic, investments must be comprehensive and balanced. Reducing the health burden of any disease is based on three main principles: preventing transmission, correct diagnosis, and effective treatment. At present, there are major gaps on all fronts.

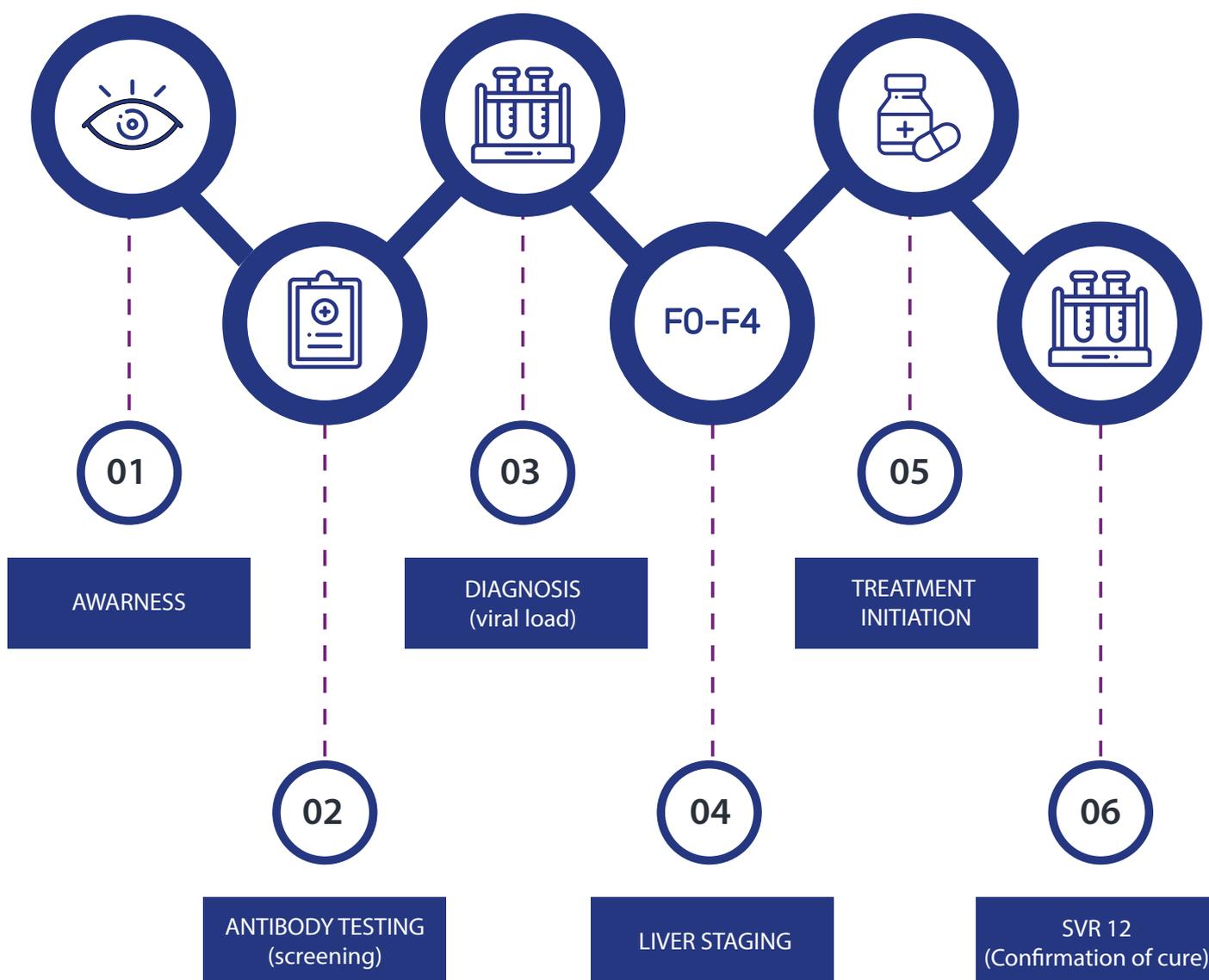
BACKGROUND TO THE STUDY

Since member states approved global elimination targets on viral hepatitis at the World Health Assembly in 2016, an increasing number of countries have adopted strong policies (guidelines, strategies, action plans). However, in transforming those policies from paper to practice, hepatitis programs have faced various obstacles in the implementation and scale-up of their HCV response. While challenges are common in the roll-out of public health programs, it is crucial that such bottlenecks to progress are identified and evaluated. In that vein, this study aims to explore the experiences of patients and healthcare workers at the forefront of HCV service delivery. In doing so, the survey seeks to document ground-level perspectives in order to inform the stakeholders responsible for strengthening the impact of the HCV response. Furthermore, such a survey-based initiative recognizes that people-centered health approaches must take into account the real-life perspectives and experiences of patients.

WHO has recently undertaken a survey of policy makers, to establish a baseline of progress on a checklist of existing national policies, interventions, and treatment options for HCV. Furthermore, in anticipation of country-level updates on progress toward the 2020 targets, the WHO has developed guidance on a reporting system for Member States. The Mind the Gap report contributes qualitative feedback to complement the quantitative aspects of the strategic information systems countries have in place, as well as the progress reports on the targets set for 2020.

The ultimate success of policy implementation will be reflected by patients' experiences of the HCV service pathway. The most basic stages of this pathway—which involves the steps and permutations a patient may face on the road from awareness to treatment—are described by figure 11.

FIGURE 11: KEY STEPS ON THE HCV PATIENT PATHWAY



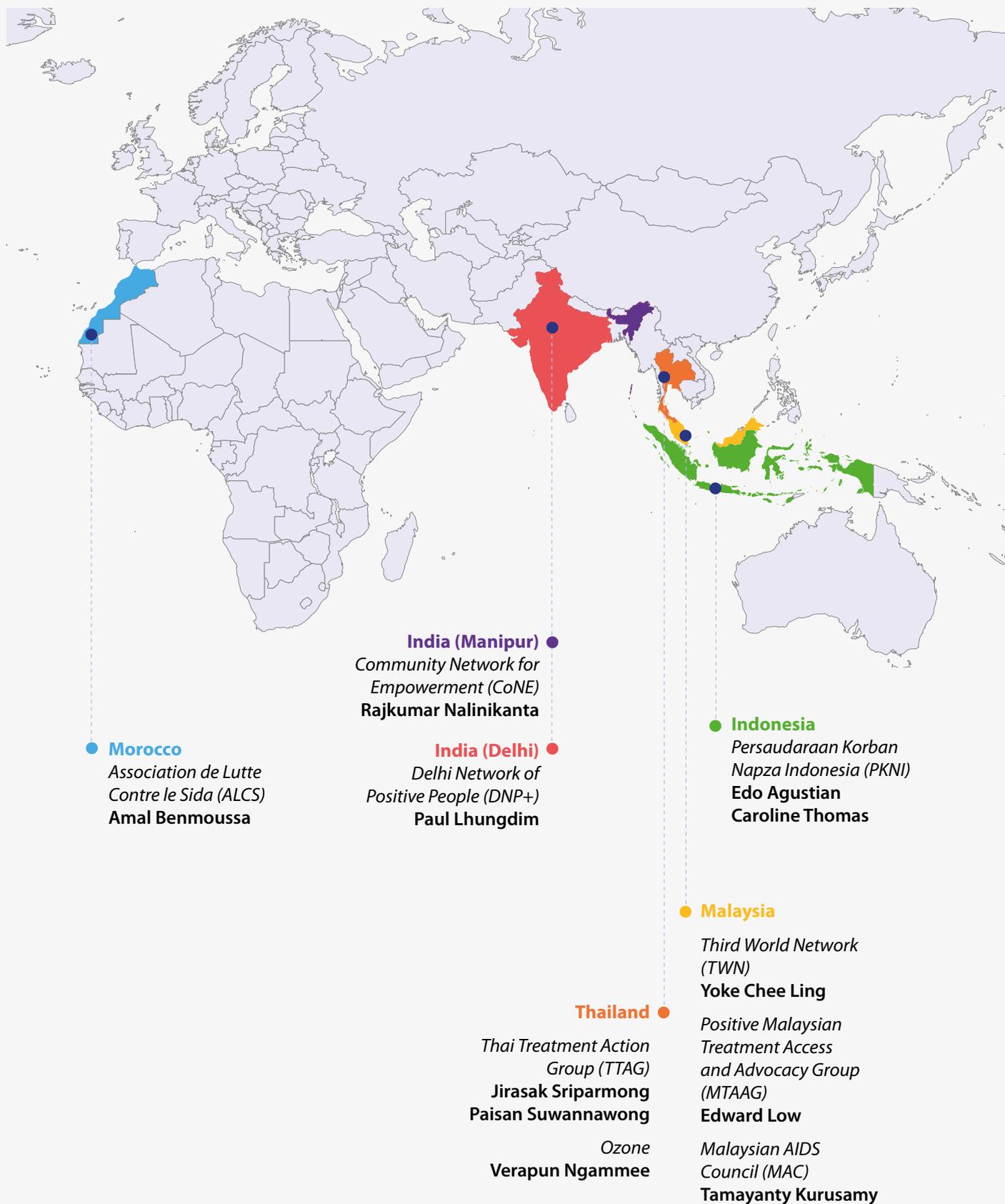
Understanding where, when and how patients experience bottlenecks in the system, and thus what causes patients to drop out, is important to ensure that policy makers and service providers can set up the most efficient and effective interventions. As the report will highlight, the above schema (figure 11) dramatically simplifies the actual pathway that patients must navigate to access the full scope of testing and treatment services.

In the context of this pathway, this report provides insights into the HCV-related experiences encountered by individuals from most-at-risk populations at sites across five countries: India, Indonesia, Malaysia, Morocco, and Thailand. While the qualitative information collected from this survey is limited to specific geographical settings, it does provide a mosaic of the range of barriers that are widely present elsewhere.

The goal of this study was to explore and document the current bottlenecks in access to awareness, prevention, diagnosis and treatment for hepatitis C from the perspective of patients, at-risk populations and healthcare providers, in order to support countries and the global health community in their efforts to achieve commitments of reducing the HCV burden and eventually reach elimination of HCV. Results are analyzed by country to highlight the key bottlenecks identified by patients and healthcare workers at local level.

Local partners led the implementation of the protocol at their sites. The partners and co-investigators who led the national data collection include:

TABLE 2: STUDY SITES, PARTICIPATING ORGANIZATIONS, AND LEAD INVESTIGATORS



METHODOLOGY

This study was a qualitative, exploratory cross-sectional survey to document the perspectives of patients from at-risk populations and healthcare workers on existing services for hepatitis C, in support of progress on the WHO Global Health Sector Strategy on Viral Hepatitis 2016 – 2021, and the elimination of hepatitis C (HCV).

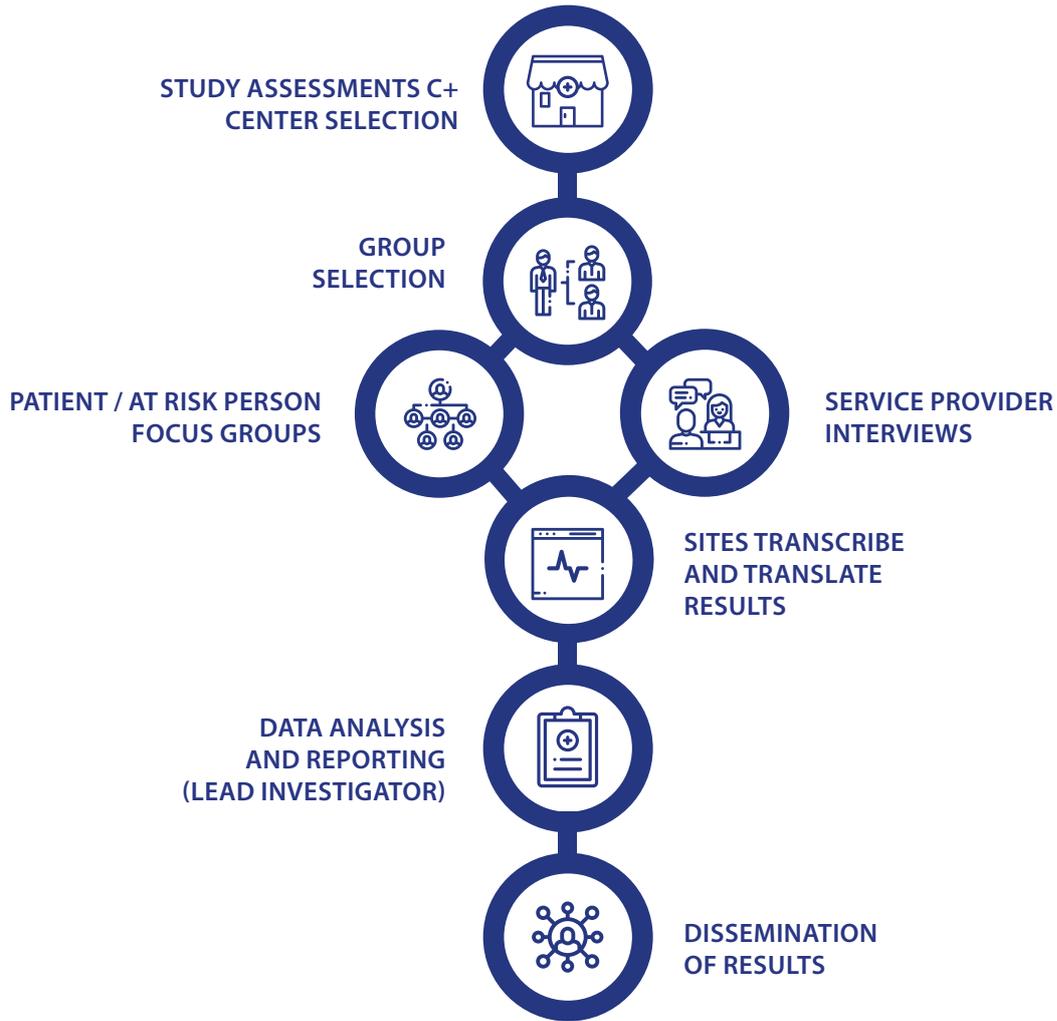
The research question was: *“what are the key bottlenecks experienced by patients and healthcare workers in the pathway from awareness to treatment for hepatitis C?”*. The study sought to identify and articulate user-led recommendations that could be implemented at service or policy level to speed up progress of countries toward achieving global commitments to combat hepatitis C.

While categories of individuals at high-risk of HCV remain broader than only PWID and PLHA, this study focused on PWID and/or PLHA. Therefore, for the purposes of this report, one may assume that at-risk individuals imply PWID and/or PLHA.

Purposive selection was carried out to identify the study centers and a combination of random and purposive sampling of participants. The study consisted of two components (see figure 12):

- focus group discussions (FGD) with patients and at-risk populations exposed to HCV (approximately 90 minutes per discussion group)
- interviews with healthcare workers providing HCV-related services

FIGURE 12: FLOW CHART OF STUDY PROTOCOL



The following inclusion criteria were provided to lead investigators:

Inclusion criteria for the FDGs shall include persons with the following characteristics:

- over the age of 18;
- PLHA, PWID, or former PWID;
- who have had contact with, or are currently involved with services for HCV awareness, prevention, diagnosis or treatment;
- whose contact with services for HCV must have been within last 12 months
- whose contact with services may be successful or unsuccessful but contact must have been initiated (i.e. persons who have not tried to identify status / get diagnosis or treatment will be excluded from the study);
- health on the day of the FGD should allow for active participation in a one hour discussion;
- should be willing and able to give informed consent for participation in the study

Inclusion criteria for the healthcare interviews shall include persons with the following characteristics:

- over the age of 18;
- healthcare workers currently actively engaged in the provision of services for HCV;
- should be willing and able to give informed consent for participation in the study

Where local dynamics did not allow for random sampling, the local investigator was instructed to use purposive sampling and explain their reasons (i.e. they may reach out to specific individuals to participate and explain why these persons are considered representative). Purposive sampling was used where specific populations were insufficiently represented or where the organization is unable to identify a sufficiently large pool of participants of the target population for sampling.

The focus group discussions were recorded by the local investigator and the audio files were translated/transcribed into English by a professional translation service (Global Lingo). Data was anonymised, to ensure no individual patient references could be made. Data were grouped by question and coded. Content analysis was then carried out by the principal investigator to identify commonly emerging themes. The principal investigator analyzed data across all sites and reported on common or critical findings and submitted these to Coalition PLUS.

The research design for this study implied minimal safety risks to participants. In order to further minimize risks, the following steps were undertaken:

- organization of focus groups through existing networks and structures
- meetings held in recognized facilities where HCV patients already gather, such as clinics or support network sites in order to minimize potential stigma
- informed consent was requested from all participants prior to participation
- data management and reporting was organized to ensure anonymity

The study was carried out between January – June 2018, with data collection occurring between March-May. The survey was initially expected to cover 10 sites in 7 countries. However, due to timeline constraints, only 6 sites in 5 countries were able to participate. Each site initially aimed to carry out four focus groups and 8 healthcare worker interviews. A full list of the investigators is provided in table 2 above.

As a research study with operational implications for the implementation of new national hepatitis C policies, the principle investigator and site lead investigators were charged with identifying and complying with ethics approval requirements based on feedback from each site.

In line with the study design (see figure 12 above), the following focus groups and interviews were held between March and May 2018.

TABLE 3: STUDY PROFILE BY SITE

	FOCUS GROUPS	HEALTHCARE WORKER INTERVIEWS
INDIA - DELHI	 4 focus groups  37 people in total	 7 interviews
INDIA - MANIPUR	 5 focus groups  53 people in total	 8 interviews
INDONESIA	 4 focus groups  32 people in total	 8 interviews
MALAYSIA	 4 focus groups  53 people in total	 11 interviews
MOROCCO	 2 focus groups  27 people in total	 9 interviews
THAILAND	 4 focus groups  36 people in total	 8 interviews
TOTAL	 238 participants	 51 interviews

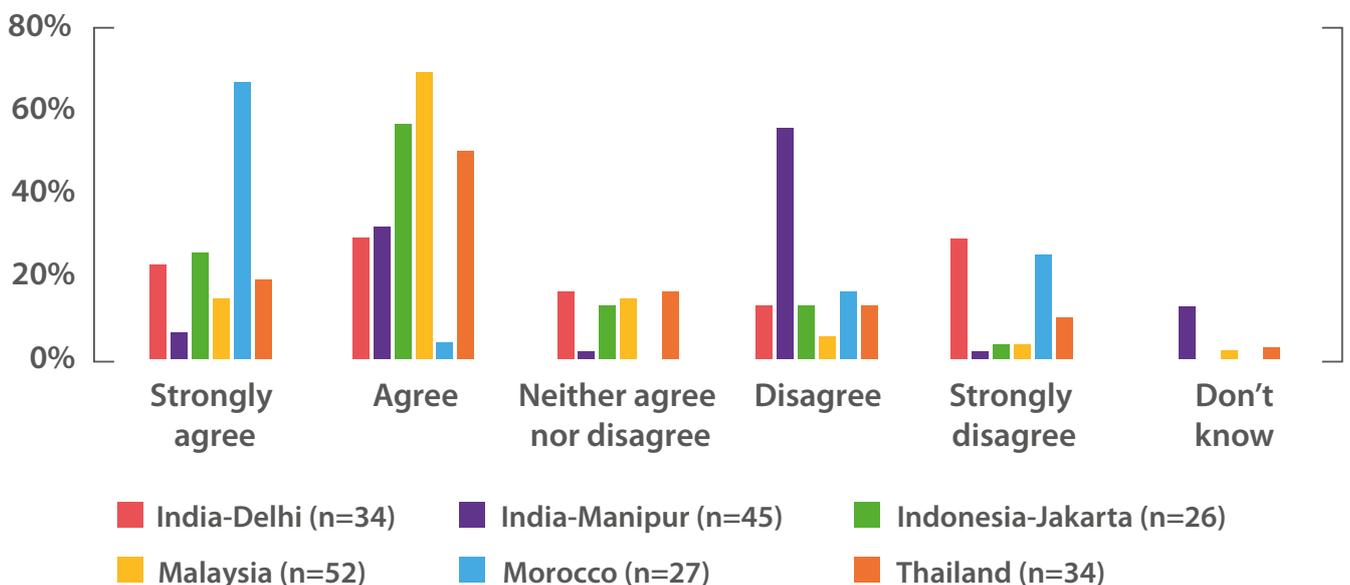
An annex of protocol documents will be made available online on the Coalition PLUS webpage (www.coalitionplus.org). A copy of this report will also be available at the same address.

THEMATIC ANALYSIS

AWARENESS

In nearly all focus groups, participants stressed a very low general knowledge of both the disease and service pathway, as well as a keen desire to learn more. Exacerbating this information deficit, at-risk populations often did not know where to turn to for services, what questions they should be asking, and how to interpret the information they were given.

FIGURE 13: THE INFORMATION I RECEIVED WAS EASY TO UNDERSTAND



At certain sites, at-risk populations felt that they suffered from an 'all-or-nothing' approach. That is to say that they found it difficult to initially access any information, but that once they had found the right entry point, many of them found the information easy to understand and they became extremely conversant with the details of the disease and treatment options.

Focus group participants at several sites reported that they primarily acquired information through specialized NGOs. This source was generally considered to be trustworthy and helpful. Many focus group participants had also obtained information from friends and family or social media. However, those individuals acknowledged that these sources introduce a risk of incorrect or incomplete information being disseminated.

Many at-risk participants indicated that they found it hard to get information through the health system. This was either because healthcare workers did not have the information, they were not sufficiently informed themselves, or the specialists were too busy and conditions did not allow for a dialogue (e.g long waiting lists or patients were seen in crowded spaces which did not allow for confidentiality).

At-risk populations placed a particular emphasis on the importance of quality information on HCV services. Barriers to accessing or validating information was clearly a source of anxiety. Many participants highlighted the challenge of evaluating information in the absence of access to strong support networks. Across sites, there was a strong call for clear, correct information.

In several cases, healthcare workers indicated that they were working hard to reach out to at-risk populations to provide information. However, the

formal approaches and media used by healthcare workers - including journals and conferences - did not correspond with the sources which focus group participants turn to, or the kind of information which they sought. Better alignment between what healthcare workers communicate and what at-risk populations absorb is required. It is important that healthcare workers have access to communication materials and skills which allow them to transmit messages in a manner accessible to patients and the general public.

All participating groups called for a significant increase in awareness-raising. At-risk populations proposed some very specific approaches to increasing awareness, which varied slightly by country. Suggestions included street theatre and posting information around shopping malls, a recommendation that echoed participants' calls for ensuring information is provided at very local levels.

The recommended targets of awareness activities included spouses of HCV-infected persons, at-risk groups and the general population.

There was a divergence of views as to who are the most effective ambassadors for awareness-raising about hepatitis C: peers, HCV-infected persons, or experts such as medical doctors. In some cases, at-risk persons felt that doctors had more authority and stature, while others felt that this stature could be intimidating and therefore counterproductive if it prevented patients from requesting information.

INCREASING AWARENESS: WHAT DOES IT MEAN?

Long known as the “silent disease”, hepatitis C can progress asymptotically for decades, with many patients only learning their status when presenting with advanced liver fibrosis. While hepatitis C has made noise in public health communities, the right messages have not fully reached the public itself, nor in many cases, the cadre of health workforce who will implement the testing and treatment. Instead, far too many at the frontline have heard nothing, while others have incomplete or distorted information.

Stakeholders engaged in the hepatitis C response are increasingly cognizant of the need for greater awareness. While the term “awareness” is consistently invoked in dialogues at meetings and conferences, it is all too often defined or discussed in an overly vague manner. If the importance of awareness is evident, we are less clear about the kind of awareness needed and how to achieve it. For the purposes of this report, we would like to pair our calls for awareness with a concrete definition of awareness as the comprehension of information that is accessible, accurate and actionable.

To further clarify the targets of awareness-raising, it seems useful to divide stakeholders into three groups: general population and at-risk individuals, healthcare workers, and policy-makers. While there may be overlap in the scope of awareness needs of each group; there are also important distinctions to make between them. Patients, for example, do not need a macro-view of the cascade or mapping of service capacity; patients would, however, need an understanding of the pathway of HCV services.

Awareness information could further be categorized into **three themes: preventing transmission, correct diagnosis, and effective treatment.**

THE SCOPE OF INFORMATION: WHAT DO VARIOUS STAKEHOLDER GROUPS NEED TO KNOW?

The scope of information needed depends on the stakeholder concerned.

Patients—whether general public or at-risk populations—need to understand: What is hepatitis C? Why is it a health concern? What are modes of transmission and methods of prevention? What is the protocol for hepatitis C diagnosis? Where/when/how can services along the pathway be obtained? Every focus group site in our study made clear calls to address the deficit of current information on these points.

Healthcare workers need to understand the questions above, but also: How to communicate information to patients in ways that emphasize clearly: Why services are prescribed (e.g. the point of a screening test, viral load, liver staging, etc)? How to minimize stigmatization? How to implement the algorithm for HCV screening? How to counsel patients on next steps? How to refer to the next stage?

Policy-makers need to understand the widest scope of information. In addition to the knowledge needed by patients and healthcare workers, they must also understand: what is the profile of the epidemic? What does the cascade look like? How are services being delivered and where are bottleneck points or excess capacity (in diagnosis, health workforce resources, supply chain management)? How can services be better decentralized and how can services be better integrated with other programs?

HARM REDUCTION

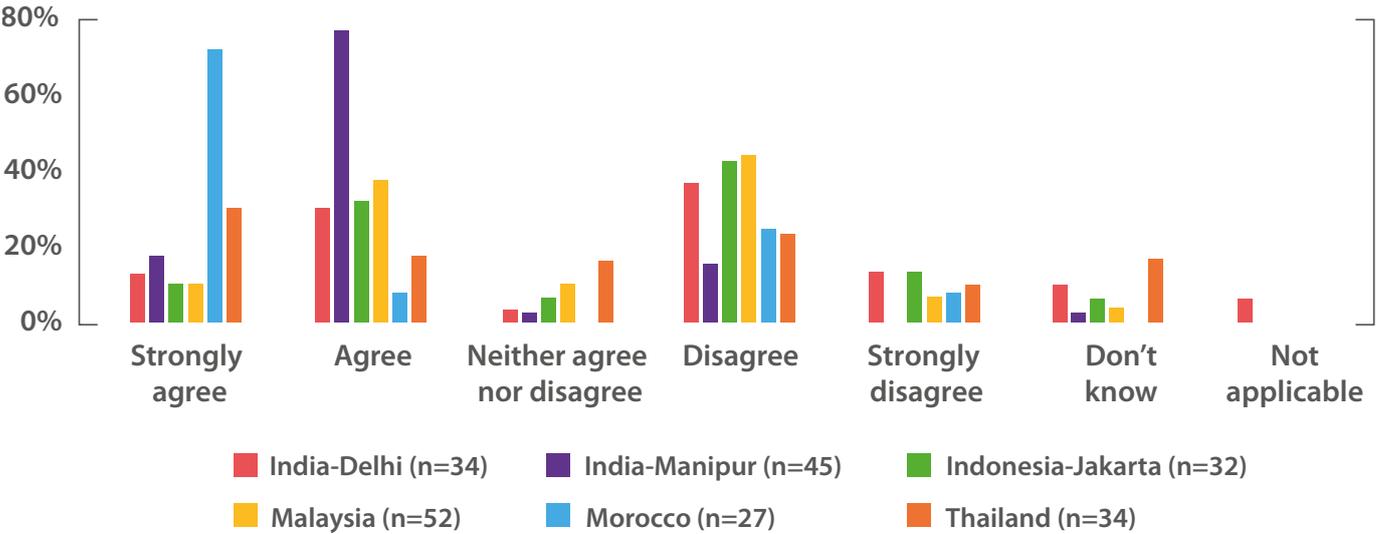


A very high proportion of the at-risk groups had engaged with harm reduction programs at some point. Those who had engaged with harm reduction programs were able to identify some key risk factors and transmission mechanisms of the disease, citing the importance of not sharing needles and other equipment.

Healthcare workers also called for more accessible needle exchange programs, indicating that there

was a strong appreciation of the need for good harm reduction services. However, many of those same healthcare workers indicated that they had no or few points of contact with PWID, raising the question and importance of how outreach services should be improved. Both healthcare workers and at-risk populations welcomed the role of NGOs, but noted that reliance only on NGOs for information creates a risk of leaving these groups over-stretched.

FIGURE 14: PEOPLE WITH HEPATITIS C FACE STIGMATIZATION BECAUSE OF THE DISEASE



Discussion on the issue of stigmatization presented a broad spectrum of response (see figure 14). It was often those patients who were earlier in the process (e.g. screened but not confirmed) who expressed more concern about the possibility of stigma than those who were in or had completed treatment, indicating that the fear of stigma might be an under-articulated barrier to diagnosis. In general, both focus group participants and healthcare workers noted the importance of good communication and the need to avoid stigmatization of at-risk populations. Further training for healthcare workers on these points would therefore be beneficial.

DIAGNOSIS



Navigating the diagnostic pathway and the cost of paying for numerous diagnostic tests were raised as main barrier for patients. This problem starts with lack of knowledge or confusion about the diagnostic process. Those who had the best understanding of all the stages of diagnosis had been guided through the process by an NGO. Patients called for more guidance on diagnosis from health professionals familiar with the systems.

At-risk individuals found it difficult to get referred between services. Patients had to visit numerous clinics and get referrals from one service to another. A large proportion of the difficulties and delays were caused by inefficiencies in health system structures, such as long waiting times for appointments.

Ideally, patients would like to see individual facilities provide a wider range of services. This was one way in which patients felt that the challenges of referrals could be addressed. This would also make appointment systems easier as the facility could manage one integrated appointment system. Both healthcare workers and patients identified the complexity and delays in diagnosis as a serious bottleneck and barrier to improving the situation: new solutions for organizing services are required.

It would appear that the limited number of trained healthcare workers was also a significant bottleneck in many countries. Only certain cadres of healthcare worker (highly trained specialists in most countries) were authorized to order and/or interpret tests and to prescribe treatment. Professionals serving as gatekeepers to the healthcare system (general practitioner doctors / family physicians, nurses, health-focused social workers) saw very few HCV patients. The impact of the centralization of tasks to specialists was also demonstrated in healthcare workers knowledge: in some cases, only half of those interviewed could fully describe all stages of diagnosis. More training for healthcare workers on diagnosis and treatment of hepatitis C is required.

Some countries, but not all, also faced supply chain challenges such as stock-out of reagents or test kits, leading to additional delays.

The driver for diagnosis was often a recommendation by a doctor or an NGO; several people mentioned that they did not seek diagnosis even after becoming aware of the disease out of fear of a complicated pathway, the cost of diagnosis, or not being able to access treatment should they be confirmed with HCV. The greatest dropout rates were reported between screening and viral load confirmation; exploring this in greater detail indicated that cost was a big factor, but so were restrictions on who could carry out certain tests (often limited to specialists) and delays due to the subsequent shortage of specialists allowed to order or conduct tests.

The importance of simplifying the diagnostic pathway cannot be over-emphasized. The inability to follow through with completion of diagnosis and treatment was identified as a major source of stress for many in the focus groups.

In some cases, healthcare workers did not appear to be aware of delays faced by patients, while patients did not feel they were empowered to express their difficulties and concerns.

Patients and healthcare workers identified solutions which they felt could help address the challenges of the diagnostic pathway as well as suggesting new ones based on their own experience. Such solutions included:

- increasing the number of healthcare providers who can offer diagnosis
- explore the feasibility of mobile testing services
- increase coordination across services to simplify appointment systems etc.
- offer discount schemes to encourage patients to complete diagnosis
- increase advocacy based on patients' experiences and case studies

TREATMENT

Concern over the number of healthcare workers permitted to provide services also extended to treatment: participants reported that not enough healthcare workers available—in either the public or private sectors—to deal with demand. This included medical, support and pharmacy staff. Health professionals called for certain components of HCV awareness, diagnosis and treatment to be brought down to primary healthcare level facilities.

If patients did drop out, this was normally after diagnosis and before starting treatment. Reasons for drop-out were generally due to cost due to inconvenience of getting to healthcare services (time and cost), or due to side-effects of the treatment (i.e. of interferon regimens). Healthcare workers assumed that people drop out for many reasons and at all points along the patient pathway: a more elaborate understanding of drop-outs or loss-to-follow-up would be an area to explore further in order to target retention interventions

Focus group participants who had started on treatment did express concerns about a number of practical issues in relation to treatment. Examples included having to sleep outside the treatment center overnight to be among the limited numbers seen each day; how to access food during a hospital stay; and the possibility of stock-out of medicines.

Distance from the hospital was a very significant barrier articulated by participants in focus groups held in areas further from the capital and large health facilities; this was an important dissuasive factor in seeking diagnosis and treatment when patients took into account travel time, likelihood of accessing treatment, and the fact that the 'silent' nature of the disease made it easier to ignore.

COST

The cost of diagnosis or treatment in the private sector was prohibitive for most (figure 15) and was recognized as a major barrier in almost all surveys. Furthermore, it should be noted that while certain programs may claim to provide free services, a lack of capacity in public facilities may mean that patients face long delays that push them toward services in the private sector, where services are more expensive.

FIGURE 15: THE COST OF THE MEDICINES WAS A BARRIER TO GETTING TREATED

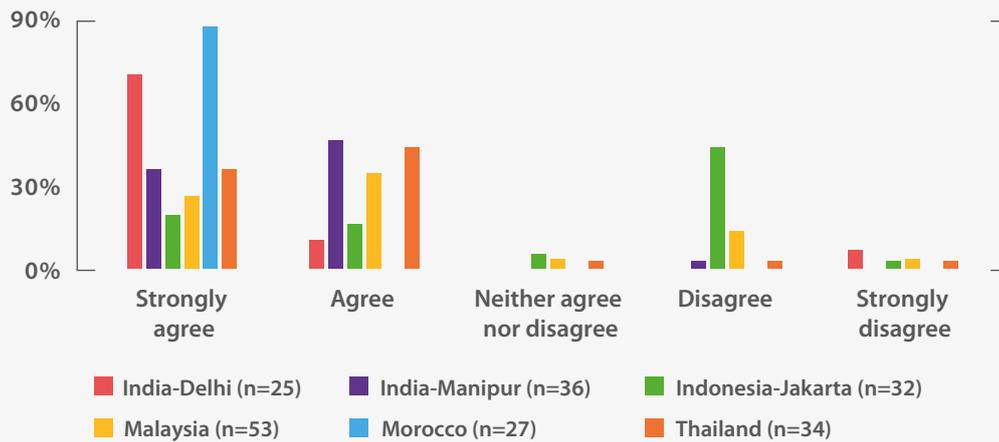
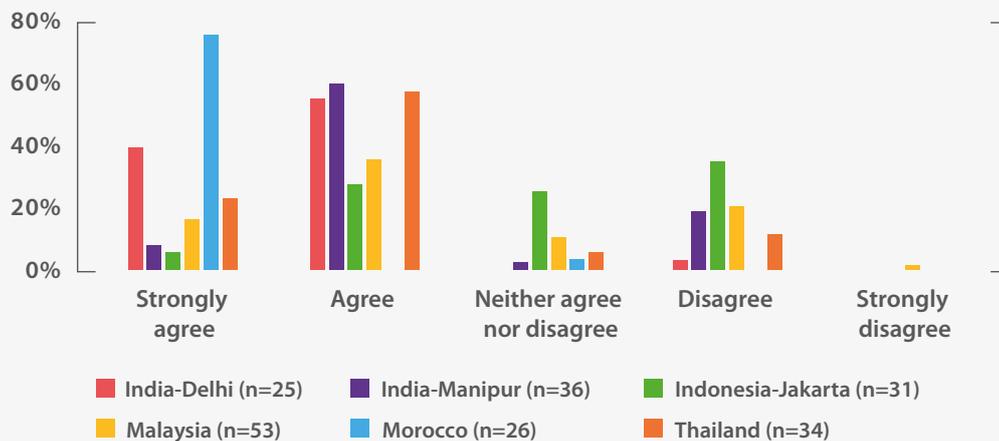


FIGURE 16: THE COSTS OF TIME OFF WORK HAS HAD AN IMPACT ON MY ABILITY TO COMPLETE DIAGNOSIS OR TREATMENT



Many of the participants in the focus groups are daily workers. Taking a day off for a hospital appointment therefore had potentially long-term consequences for their work if they were regularly absent. While healthcare workers may perceive diagnosis and treatment as being free at some sites, they may have been under-estimating these hidden costs borne by patients, and thus not fully appreciating the impact on patients. In some cases, patients mentioned that the worry and stress about the prohibitive cost influenced behaviour significantly, leading those who tested positive but knew they could not afford diagnosis and treatment to turn increasingly to drugs or other substances as a coping mechanism.

INDIA: ONE COUNTRY TWO CONTEXTS



Given the size and diversity of India, Coalition PLUS and its partners decided it was important to explore regional differences. The survey was therefore carried out in two different sites: one in Delhi (the national capital city) and one in Manipur in the far east of the country. These two surveys will be reported on separately in order to highlight differences in findings.

The surveys in India were led by two different Coalition PLUS partners. The Delhi survey was led by the Delhi Network of Positive People (DNP+), a community-based HIV/AIDS organization. The survey in Manipur was led by CoNE (the Community Network for Empowerment), a Manipur-based NGO working to promote the health and human rights of people who use drugs. Both organizations work directly with people at risk of HCV, patients, and healthcare workers.

India has a population of 1,3 billion inhabitants with a per capita Gross National Income (GNI) of USD 1,939; it is classed as a lower middle-income country by the World Bank.¹¹

India is part of WHO's South-East Asia region (SEARO). Estimates of PLHCV in India vary between 6,000,000 and 12,000,000 and 198,756 incident (new) cases per year are reported.¹² Thus, India accounts for a significant share of global HCV infections in the world.

TABLE 4: HCV EPIDEMIOLOGY IN INDIA

2015 ESTIMATES	INCIDENCE	ESTIMATED NUMBER OF PLHCV
INDIA	198 756	8,000,000

There are an estimated 96,463 to 189,729 males who inject drugs and between 10,055 to 33,392 females who inject drugs in India.¹³ This amounts to a cumulative estimate of between 106,518 and 223,121 PWID.

Epidemiological studies of the HCV epidemic in the overall population have yielded varying results. More robust results may soon be available, as the WHO-funded study evaluating HIV in the general population also used study samples to evaluate HCV. The study was conducted in collaboration with the National Aids Control Organization (NACO). As of publication, neither Ministry of Health nor NACO (which sits under the Ministry of Health) had released the data.

As shown by table 4 above, HCV is one of the major uncontrolled diseases in India. Some states (notably Punjab and Haryana) decided to tackle the disease and set up treatment programs independently from the central government. Influenced by the success of the programs in Haryana and Punjab and the mobilization of key community-based organizations (CBO) elsewhere in the country, the federal government recently decided (April 2018) to launch a national program that will be operationalized at the state level. Guidelines are being drafted and an action plan for 2018-2021 will soon be endorsed. Shortly before this report went to printing, the Indian government announced—on July 28th, 2018—the launch of the National Viral Hepatitis Control Program.

India’s robust access to generics will be fundamental to the impact of this budget. India was not only included in the voluntary licenses of Gilead and Bristol-Myers Squibb (BMS), Indian generics also represent the main licensees. Local production has meant that India was among the first countries to market generics; it also means that India has—due to competition and low logistical expenses—some of the lowest prices in the world (e.g. well below USD 100 for 12 weeks of sofosbuvir-daclatasvir in Punjab).

As the chapters on Delhi and Manipur will illustrate, a major issue in India is a lack of awareness concerning hepatitis C. This limited awareness negatively impacts every stage of the cascade and applies to every level of the response: from the public to the health workforce to the policymakers.

INDIA: DELHI

CONTEXT

Until the end of 2017, no guidelines were adopted at the state level nor at the national one, and given that every hospital has its own procedures, patients were entirely depending on their doctor's will and practices. To advance the HCV response, several civil society organizations (CSO) filed a Public Interest Litigation against the Delhi Government in order to obtain free diagnostics and treatment for HCV. In December 2017, the Chief Minister of Delhi state committed to cover the costs of the main pan-genotypic DAAs for people diagnosed positive with HCV. Thus, some people already identified as chronic HCV patients were able to access treatment. However, the State of Delhi did not adopt a treatment program or elaborate clinical guidelines; instead, the state decided to treat people on a case-by-case basis. Furthermore, diagnostics are difficult to access and stock-outs are frequent in Delhi, making the pathway to access to DAAs very difficult. As a result, recent free treatment has been administered on a relatively ad-hoc basis. As the launch of a national HCV response in July 2018 includes state-level budget allocations, there is hope that a more rationale and comprehensive program of public HCV services will be implemented soon. Yet as this broader report shows, gaps between policies and practice can persist, so the success in implementation of a Delhi-level response will need to be monitored.

KEY FINDINGS

AWARENESS

- Participants communicated that their information was mainly obtained from two sources: outreach efforts by community-based organizations such as DNP+; and the more informal channel of friends, family, or social media.
- Participants called for more guidance from health professionals who are familiar with the steps of the process itself and the logistics of completing the process (the referral process, location of service delivery of various stages, obtaining coverage of services by public insurance, etc). The diagnosis and treatment process was confusing for patients. Furthermore, to navigate access to services and steps along the continuum of care, at-risk participants in the FGDs emphasized that populations do not know where to get information.
- Participants in the FGDs called for information about HCV to be delivered more widely. The need for information on prevention, testing and treatment was highlighted. Though at-risk populations were recognized as priorities, families and friends were also highlighted as relevant audiences for information, as they could provide support to those at-risk of HCV and/or those seeking treatment; furthermore, the importance of the general public's awareness on prevention and treatment was emphasized.
- Patients also noted that, relative to demand, there was a shortage of HCWs, both in the public or private sectors, who were eligible to deliver HCV services. HCWs indicated that much of the work must be carried out by specialists, thus limiting the pool of HCWs available to prescribe, administer, and/or refer various HCV services along the continuum of care.
- Patients also noted that they did not feel that the HCWs were well informed about the disease or about practical information on access to services.
- Patients felt very strongly that HCWs expressed stigma or poor attitudes towards HCV patients. They insisted that this contributed to lack of awareness and follow up, as patients felt that HCWs did not demonstrate a willingness to either tackle the disease itself or support individual patients. Notably, HCWs did not perceive stigma as a major issue at all.

DIAGNOSIS & TREATMENT

- Both HCWs and focus groups agreed that there was little HCW-led HCV counselling available at any stage of the patient pathway.
- Patients had to visit numerous clinics and obtain multiple referrals to progress along the pathway to treatment. The need for multiple visits—often to multiple facilities—caused confusion, delays, and led to drop outs by patients. Both HCWs and patients identified the complexity and delays in diagnosis as a serious barrier to individual treatment and, consequently, an even greater bottleneck to a scaled-up response. In turn, patients called for facilities to provide a wider range of services, thus reducing the need to travel between sites.
- Stock-outs of test led to additional delays, as it required re-booking of appointments (a process that could postpone access to tests by several weeks). Stock-outs of medicines were also reported.
- Participants reported that testing for HCV was not available at National Aids Control Organization (NACO) Targeted Intervention sites (i.e. for key populations at risk of HIV).
- Five of the seven HCWs interviewed indicated that their facility did not have a policy on which persons to screen for HCV; screening decisions were made according to doctor's individual judgment.
- Many of the participants in the focus groups are daily workers: taking a day off for a hospital appointment therefore had potentially long-term consequences for their work if they were repeatedly absent. While policymakers and HCWs may perceive diagnosis and treatment as being free, they may be under-estimating the hidden transaction costs that must be borne by the patient.
- The timelines to go through the testing process in the government hospital were particularly long. Furthermore, the cost of diagnosis or treatment in the private sector was prohibitive for most.

RECOMMENDATIONS

AWARENESS

- Explore methods for awareness-raising among healthcare workers (HCW) and methods for healthcare workers to increase awareness among patients. Such awareness-raising should be aligned with the needs/language of target populations.
- Emphasize awareness on route of transmission and information on where to get the various minimal tests/diagnostics required and where to get access for drugs.
- Develop a wider array of awareness-raising tools to inform at-risk populations about the disease, about the steps of diagnosis/treatment, and about the practical process of navigating the continuum of care (what facilities offer what services, necessary documentation, what services are covered by public insurance, etc).
- Instruct HCWs to emphasize the message that HCV is curable with simplified diagnostics and treatment with pan genotype DAAs.
- Launch HCV-focused public health campaigns to reach the general population.
- Address the workforce bottleneck by expanding the range of HCWs who can prescribe tests and support the diagnosis process. The expansion of guidelines should be accompanied by trainings. Trainings should not only educate about the disease itself, but also include instruction on how to identify risk behaviors (i.e. as part of screening algorithm) and counsel patients on the continuum of care. Trainings should also focus on the barrier that patient stigmatization by HCWs creates and should emphasize how to reduce stigma.

DIAGNOSIS & TREATMENT

- Counseling must be integrated into the provision of HCV services. This requires the allocation of resources to training for counseling and staff for counseling.
- Develop streamlined diagnosis and treatment solutions: the focus groups and HCWs provided several suggestions, including grouping services at a single site.
- Explore solutions to reduce the waiting time for delivery of test results (including the time for follow-up consultation appointments).
- Implement tools that ensure strong supply chain management.
- Make HCV testing available at all Targeted Intervention sites for key populations and PLHA.
- Develop and implement clear screening policies and train HCWs to identify patients at elevated risk of HCV.
- Ensure that policy covers all populations and that service delivery is people-centered and adapted to the constraints that patients often face in seeking health care.
- The costs of diagnosis and treatment should be covered by the public health system and the capacity at public facilities must be expanded significantly in order to reduce waiting and turnaround times.

DELHI: PATIENTS' PERSPECTIVES

SUMMARY OF DELHI FOCUS GROUP DISCUSSIONS

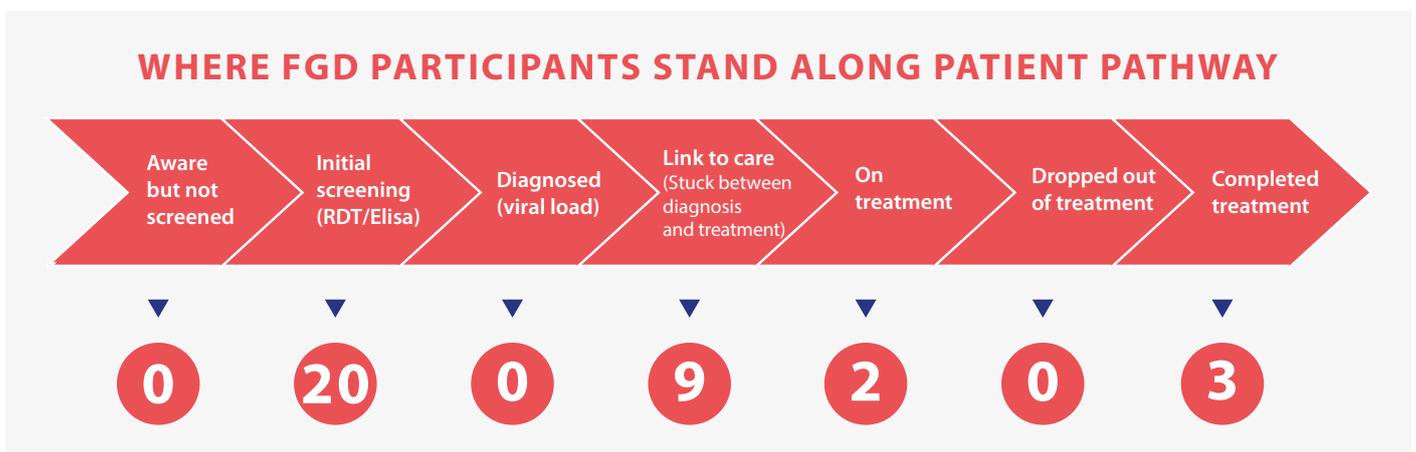
Four focus groups were held in Delhi in March and April 2018, bringing together people at-risk of HCV and those who received HCV services (i.e. screening and beyond)). A total of 34 people participated in the Delhi focus groups.

TABLE 5: DELHI FOCUS GROUP PARTICIPANTS

FOCUS GROUP 1	FOCUS GROUP 2	FOCUS GROUP 3	FOCUS GROUP 4
 9 Former PWID	 8 All screened, 2 had completed treatment	 8 All screened, none completed viral load test	 9 9 screened; 5 had viral load test; one on treatment
TOTAL : 34 PARTICIPANTS			

As highlighted in figure 17 below, the majority of participants in the Delhi study had completed initial screening, but had either not progressed to diagnosis via viral load confirmation, or had completed a confirmatory test but had not started treatment. The major bottleneck stages articulated by the Delhi patients centered on challenges in completing the various stages of diagnosis.

FIGURE 17: PROGRESS OF PARTICIPANTS ON PATIENT PATHWAY



KEY FINDINGS FROM DELHI FOCUS GROUPS

AWARENESS

The large majority of participants in the four focus groups held in Delhi had heard of hepatitis C and the majority had undergone screening. Nevertheless, the general level of awareness was still limited. A few participants, however, were extremely knowledgeable; this influenced their discussion and brought out some issues which were not touched on in other groups (e.g. the differences between Hepatitis A, B, C, D and E).

Participants in the Delhi focus groups all called for more awareness, and were grateful for the information that they had received. A small proportion among them had learned about hepatitis C through health-system based sources (e.g. through doctors recommending testing when they went for other appointments). The large majority of participants in the focus groups (85% in the case of one group) gained most of their information on hepatitis C from NGOs such as DNP+. In fact, participants were able to access testing thanks to these same CBOs, and the pairing of sensitization with testing was recognized as an important method to link awareness and practical action to initiate diagnosis and treatment.

Participants indicated that very little information is given out by government programs to the general public or at-risk populations about hepatitis C.

Focus group participants called on those who had already accessed information to share this widely in their own networks to expand the circle of HCV information. They also emphasized the use of diverse communication approaches to increase awareness: suggestions included the use of media such as street plays and puppet shows for awareness campaigns.

“SIR WE CAN SURVIVE ONLY IF (INFORMATION ABOUT HCV IS) DISCUSSED BETWEEN THE PEOPLE.” -FGD PARTICIPANT

Concerns about the reliability of information sources that were expressed by participants in the Delhi focus groups echoed concerns expressed in other countries; namely, that if at-risk populations were getting all their information from informal sources (e.g. friends, social media, etc) within their networks, there was a risk that the information was incorrect. Thus, it is important that those with expertise in the area increase information campaigns to at-risk populations, friends and family of at-risk people, and to the general population. However, they also noted the increased impact of peer experience: educators and volunteers with expertise of having gone through treatment themselves were therefore identified as the best facilitators of educational messages. In other words, while peer education was identified as a potentially valuable method, the need to ensure the peer educator is properly informed is paramount.

Furthermore, it is important that the information be clearly and fully communicated: the complexity of the disease (i.e. complexity of diagnosis in particular) and the long incubation period increased stress and anxiety among some people who had not fully understood the information they received. Many participants indicated that they do understand the information eventually but that it takes a lot of time to fully grasp. Further support in understanding the information provided was highlighted as useful.

“MORE AWARENESS CAN BE CREATED IF THERE IS FREE TREATMENT. IF THE TREATMENT IS AVAILABLE FOR FREE THEN ONE WILL SURELY COME FOR TESTING THIS DISEASE. AND IF FREE TREATMENT IS AVAILABLE THEN ONE WILL UNDERGO FREE TREATMENT. SO, MORE AWARENESS CAN BE CREATED BY THIS WAY.” -FGD PARTICIPANT

DIAGNOSIS

Almost all focus group participants had been screened and several had had viral load confirmation. However, the number who had done this on recommendation from a doctor at a government facility was very low (just under 20% in one focus group). Only one person was aware of HCV anti-body testing through the TI project, indicating that even the initial level of integration of HCV screening was limited; when asked about this, almost all participants who had engaged with the TI program indicated that testing for HCV was not available at TI sites, a point confirmed by local civil society organizations.

At least one person discovered their status after donating blood, but the individual was not provided with any guidance and support with respect to further diagnosis and treatment.

The major barriers identified at the diagnosis stage were similar across the different focus groups: the timelines, understanding where to go, getting referred between stages, test shortages, and the cost of the tests.

Several participants who had wished to undergo further tests after screening eventually stopped due to the unaffordability of diagnosis. On a related topic, several participants noted that although the tests should be free in government facilities, in practice the health workers either advised them to go to private facilities, or the government facilities did not have the equipment required to continue through the diagnostic path and they would have been obliged to go to a private facility by default.

In certain cases, the prohibitive costs associated with HCV care influenced behaviour significantly, leading those who tested positive but knew they could not afford diagnosis and treatment to turn increasingly to drugs or other substances as a coping mechanism.

PREVENTION AND RISK REDUCTION

Discussion around prevention and risk reduction tied in very closely to the discussions around awareness. Again, information about risk reduction activities were generally all sourced from NGOs and not from health services. Participants in the focus groups were linked to a specific risk reduction program (TI – Targeted Intervention under NACO), and thus had more information on harm reduction.

However, in parallel to this claim, participants also noted that increased awareness gained through the beginning of the process also led to them take more precautions to avoid infecting others.

The timelines to go through the testing process in the government hospital were particularly long; participants claimed it took up to 3 weeks to get an appointment for the tests and another 3 weeks to receive the results.

Participants reported that the diagnosis cascade was very cumbersome and dissuasive. One aspect mentioned frequently was the time impact. Availability of test kits at facilities also caused delays; however, **the most significant barrier was the logistics of getting appointments and getting referred from one stage of the process to the next.** For example, getting an appointment for a blood test and an appointment with the doctor are two separate processes which meant queueing twice in very crowded facilities where the appointment service counter had limited opening hours. Patients often did not know which referral papers they needed, making the process frustrating. A very pragmatic request was to ensure that blood tests could be taken on the same site as the doctor's clinics, thus making the process easier to link to treatment and less time-consuming.

In several cases, the test kits were out of stock when the patients went for testing. To finally get to an appointment and find out one could not get tested was described as “traumatizing and frustrating” by the participants in the focus groups.

TREATMENT

Few participants (16%) in the focus groups had started or completed treatment. Key barriers to treatment included the perception of limited urgency of care (patients only seeking treatment when they felt very ill); stock outs of test kits and DAAs in government

facilities; prohibitive cost of testing in the private sector; lack of capacity at public facilities; and poor coordination between facilities leading to delays, notably due to limited appointment slots.

Participants noted that only subsidizing one part of the process (e.g. providing free treatment) without subsidizing other stages would not solve the problem: if people cannot afford diagnosis, or are not exposed to good awareness programs, they will not take up free treatment options.

One person experienced an 8-month lag between getting screened and starting treatment. Those

who were able to shorten the timelines had done so through knowing how to actively navigate the systems well, rather than because the systems work well. For those in the most knowledgeable and articulate focus group, the time between completing diagnosis and starting on treatment was an average of 25-30 days.

Several participants mentioned a problem of stigma when they went to government hospitals: they felt that they were treated differently and that there was clearly a negative attitude from the healthcare workers, which could have influenced the providers' service delivery.

COST

As highlighted above, the cost of both diagnosis and treatment were major barriers for many participants. Several participants had dropped out of the process specifically due to the cost, while others were only able to proceed because the cost was borne by others (either family or a CBO such as DNP+).

HEALTHCARE WORKERS' PERSPECTIVES

The perspectives of healthcare workers were collected via semi-structured interviews. In Delhi, the team interviewed 7 healthcare workers in total; 5 men and 2 women. The team reached out to a considerably higher number of healthcare workers, but due to the limited number of people working on hepatitis C and their corresponding heavy workloads, it proved difficult for those contacted to find time away from their professional duties.

The healthcare workers were generally mid-career (4 people aged 30-39) with only one younger (aged 20 to 29) and one older (aged 40-49). The last participant did not provide their age. The mid-career group had the widest range of experience; two interviewees had spent less than 2 years working on HCV while another two had over 10 years.

Five of the interviewees were doctors with a specialty in infectious diseases or virology and one was a specialist nurse. The final participant had a non-technical background and was involved in outreach work to patients.

All of the interviewees in Delhi worked in a tertiary hospital. One worked in a secondary facility in addition to the tertiary-level work and one also indicated some private sector work. Three also did clinics in HIV centers and PWID drop-in centers. All of the Delhi respondents worked in urban environments (the capital or major cities).

The healthcare providers in Delhi indicated that they saw far fewer patients each week relative to the providers in Manipur: interviewees in Delhi saw an average of 2 to 5 patients per week, with a couple of outliers who saw between 10 and 20—and on occasion up to 30 patients—per week.

The most noticeable gaps in services provided by the Delhi respondents were in prevention services and liver stage testing. This might be because there are other specialists within the facilities who provide these functions; if this is not the case, it is possible that these represent bottleneck points in the system.

AWARENESS

The healthcare professionals interviewed in Delhi reported to have received most of their information from training workshops/sessions, as well as from journals and websites. Fewer than half reported to have used sources such as Government-disseminated information, WHO publications, or material from professional associations.

Half of the healthcare workers said they carry out awareness-raising activities. However, only 25% of all the healthcare workers carry out such activities in direct contact with at-risk populations

PREVENTION AND RISK REDUCTION

In terms of harm reduction activities, almost all healthcare workers identified a methadone replacement program, needle exchange program, drop-in center, or counselling as the most common.

DIAGNOSIS

All sites at which healthcare workers were interviewed offered initial screening, while about 50% offered the other stages of diagnosis. Specialist and some generalist doctors could order the initial screening, while, ordering other tests fell to specialists in most facilities. Upon further exploration, it seems the authorization framework on what generalists can and cannot prescribe is not entirely clear; in other words, lack of explicit guidelines means that many generalists operate in a sort of gray zone about what they can and cannot prescribe. This lack of clarity, combined with the limited number of specialist doctors, creates a significant bottleneck. Interestingly, at least half of those interviewed called very explicitly for a change in delivery systems to ensure that a broader range of healthcare workers could provide hepatitis C diagnosis and treatment: this included calls to take diagnosis down to a primary care level.

Five of the seven healthcare workers interviewed indicated that their facility did not have a policy on which persons to screen for HCV; the decision fell instead in the doctor's clinical decision. The patient groups most frequently seen were general population, hemodialysis patients, blood transfusion

patients, and PLHA. Other at-risk populations were only identified as priorities in fewer facilities. However, when asked who are priorities for testing or/and high-risk populations for HCV, the healthcare workers identified hemodialysis patients, blood donors, healthcare workers themselves, but also unanimously identified persons with HIV, PWID and men who have sex with men (MSM). Seventy percent of the healthcare workers interviewed also identified pregnant women and persons with chronic liver abnormalities as groups who should be monitored for HCV exposure.

It should be emphasized that both healthcare workers and the at-risk populations participating in the FGDs identified lack of awareness in the general population and at-risk populations as key barriers. However, the solutions proposed by healthcare workers do not appear to align closely with the expressed needs of at-risk populations, nor do they align with the gaps identified by the healthcare workers themselves.

Figure 18 below indicates the proportion of healthcare workers affirming that they served various at-risk populations. We have combined the graphs for Delhi and Manipur, to explore comparative service provision between the two areas. As an example therefore, it is interesting to note that 88% of the healthcare workers interviewed in Manipur indicate that they see persons who currently inject drugs, while only 43% of the respondents in Delhi indicated interaction with PWID, an observation that conforms with comparatively higher prevalence of injection drug use in Manipur.

FIGURE 18: PATIENTS SEEN BY RISK FACTOR: PROPORTION OF HEALTHCARE WORKERS INDICATING THEY REGULARLY SEE EACH CATEGORY - INDIA [MANIPUR (N=8) & NEW DELHI (N=7)]



Health professionals identified about a 2-week time lag for receiving all tests (regardless the stage). They ascribed this mainly to delays in the test centers, centers waiting to have sufficient volumes to run tests—and to a lesser degree—lack of systems for follow up to return tests. However, many in the focus group discussions identified time lags that were longer.

Healthcare workers reported that a patient who has gone further down the patient pathway is more likely to remain engaged. They specifically identified the step between screening and viral load assessment as the main drop-out point

but had few measures in place to address this or follow up with patients lost to the system.

Less than 50% of healthcare workers interviewed were able to articulate the standard algorithm for testing for HCV, indicating that there is a need for HCV protocol training among HCWs.

A common recommendation regarding diagnosis and treatment was that the system should be streamlined, especially once individuals screen positive.

TREATMENT

Healthcare workers identified a very wide range of barriers to treatment including: the availability of tests, cost and financial constraints, lack of government investment, poor follow up and referral systems; lack of awareness; and absence of counselling services.

Finally, it should be noted that healthcare workers in Delhi were not clear as to whether HCV is a notifiable disease. HCV is not a notifiable disease, according to the Indian National Center for Disease Control.

DELHI: COMPARING PERSPECTIVES



A frequently articulated concern was that the at-risk populations found it hard to receive information from healthcare workers. Participants in the focus group discussions indicated their main source of information was specialized community-based NGOs. Other sources include informal channels such as friends and family. However, several participants in the focus groups expressed concern that informal word-of-mouth communication may lead to the widespread (and circular) dissemination of incorrect information.

Only 50% of the healthcare workers indicated that they are engaged in awareness-raising and educational activities. Of these, several engaged in activities to which many of the at-risk populations had little or no access (e.g. publishing in scientific journals, speaking at conferences or publishing on the internet); in one of the focus groups, only 10% of patients had access to the internet, thus indicating that dissemination of information through the internet is not likely to reach at-risk groups.

The focus groups provided several suggestions on how to raise awareness, with street theatre being flagged as a particularly effective mechanism. Suggestions from the medical professionals on how to address the same problem included highlighting HCV in the medical student curriculum, regulating unregistered health practitioners, and building awareness among healthcare workers. It was noticeable that the responses from healthcare workers turned mainly inwards, focusing on awareness within the profession(s) rather than outreach to at-risk populations. When considered with the observation by at-risk populations about the poor quality of information exchanges with healthcare workers that they had experienced, the need to improve patient-healthcare worker interaction—i.e in addition to healthcare worker knowledge of HCV and HCV services—is an important issue to highlight.

The one common area identified by both at-risk populations and healthcare workers was the need for a national HCV program, with the HIV program cited as a model example. Furthermore, a synthesis of the feedback demonstrates that lack of awareness of HCV is an issue at all levels.

As regards harm reduction, the healthcare workers did identify facilities providing harm reduction activities. However, other than the needle exchange program, few of these were identified by the focus group participants as being high on their radar for harm reduction.

When spontaneously asked for suggestions about how to improve awareness and harm reduction, many of the healthcare workers came up with solutions which are much more closely aligned with the needs expressed by the at-risk populations. For example, the focus groups systematically identified lack of information from healthcare workers as an issue, while simultaneously

indicating that they absorbed educational and information messages if disseminated in an appropriate format. A response by one healthcare worker encapsulates the same issue:

“DESCRIBING THE RISK IN THEIR (AT-RISK POPULATIONS) OWN LANGUAGE AND CONCEPT IS REQUIRED.” -FGD PARTICIPANT

When asked about the main challenges in providing awareness and harm reduction programs, the healthcare workers identified many of the same issues which at-risk populations complained that the healthcare workers are unwilling to engage them in. For example, healthcare workers identified PWID as being unconcerned about their own health, while PWID indicated that they found it difficult to get support from healthcare workers; and that in some cases, this created such a degree of anxiety and psychological strain.

Perhaps the most frequently and vocally expressed frustration among focus group participants was the process for getting through the diagnosis pathway. Only half of the health professionals interviewed indicated that they did in fact carry out screening.

Both healthcare workers and patients identified very long timelines in getting test results back; patients estimated this at around 3 weeks, while healthcare workers estimated 2 weeks.

The main challenges which healthcare workers identified in relation to testing was lack of awareness among at-risk populations and the general population, as well as funding. This generally aligns with patient experiences, but also omits some key barriers such as the stockout of test kits, as well as the long timeline for getting appointments for diagnosis.

Both healthcare workers and focus groups agreed that there was little counselling available at any stage of the patient pathway for hepatitis C.

In relation to cost, healthcare workers perceived the patient pathway as free for key populations. However, patients experiencing the process indicated that there were a large number of hidden costs which made the ‘free’ messaging misleading. Such hidden costs included travel and lost earnings. In cases of stock outs in government facilities, patients were required to buy products in private pharmacies.

Healthcare workers and patients identified an inverse correlation between stage on the patient pathway and likelihood to continue: for healthcare workers, the further along the patient pathway an individual was, the more likely they were to complete treatment, whereas for many patients the further they were on the pathway the greater risk of dropping out unless they were well supported and provided with financial assistance to cover costs.

Major barriers identified by focus group participants and healthcare workers overlapped in many cases: these included the cost of diagnosis and treatment, long waits to book appointments and waiting times at the facility itself on day of the appointment, the number of times a patient had to return to a facility for appointments, services being split across sites, and delays in receiving test results.

INDIA: MANIPUR

CONTEXT

In parallel to the survey in Delhi, a survey was carried out in Manipur. The local investigation was led by Community Network for Empowerment (CoNE).

Manipur is located in the northeastern region of India. Lying east of Bangladesh, it borders Myanmar. It is one of the seven Indian states commonly known as the Seven Sisters. At just under 3 million people, it is among the smallest of India's 27 states. At under \$1,000 per capita per year, it is one of India's poorest states as well.¹⁴

Manipur has long faced a particularly high prevalence of injection drug use. In Manipur, some studies indicate HCV-antibody prevalence rates among PWID of over 90% in some urban settings.¹⁵ Civil society organizations—especially CBOs working with PWID—support their communities by offering free HCV rapid tests. CBOs negotiate with generic industries present in Manipur to obtain (a) free rapid screening tests, (b) free or cheap confirmation diagnostics, and (c) bulk-procurement prices for DAAs.

KEY FINDINGS

AWARENESS

- The importance of raising awareness about the disease was the most frequent and vocal theme of the focus groups and healthcare workers.
- Local NGOs, friends and family were cited as the most common source of information for at-risk populations. In common with the surveys carried out in other countries, the importance of the quality of information was emphasized. Uncertainty over the quality of information was clearly a source of anxiety for many among the at-risk populations. There was a strong call for clear, correct information.
- Participants considered that messages from doctors and experts would hold more weight in awareness-raising than communication by those affected by the disease. Participants expressed far more worry about diagnosis leading to stigma from family members than stigma from friends or healthcare workers.

DIAGNOSIS

- Completion of the diagnosis pathway was identified as a critical issue; receiving viremia confirmation without being able to complete liver staging and access treatment was identified as a major source of stress for many of the focus group participants.
- The driver for diagnosis was often a recommendation by a doctor or a local NGO; several participants in the focus groups were tested without significant awareness of the disease itself.
- Only one of the eight facilities in Manipur had a policy on screening; this facility followed NACO (the National AIDS Council) guidelines.
- Timelines for diagnosis were long, in part due to the necessity of sending samples to other parts of India for testing (as laboratory infrastructure to run HCV viral load was not accessible in Manipur). Manipur healthcare workers did not appear to be aware of delays and patients did not feel they were empowered to ask for results quickly; thus there were few advocates or catalysts to speed up the testing process.
- Fewer than half the facilities of interviewed HCWs provided confirmatory testing, creating barriers as patients would have to be referred to another facility to complete the next stage of the pathway. (Facilities “providing” testing still had to send samples to other facilities, due to absence of viral load machines.)
- Few of the healthcare workers were involved in screening. Of those who were, only around half could fully describe all stages of diagnosis.
- Healthcare workers appear to be the only ones who identified spouses and caregivers as a potential high-risk population who should be screened.
- Discount schemes are in place to encourage patients to complete diagnosis.
- The importance of counseling—both pre-/post-testing and treatment—was highlighted by Manipur participants.

TREATMENT

- It would appear that the limited number of trained healthcare workers is a significant bottleneck; at one point, patients could no longer get referred for testing and treatment because there was only one doctor for a large catchment area and he/she had limited availability; other healthcare workers may not be providing a range of services which they could be trained to provide.
- Once a patient category was identified as high-risk for HCV, they were followed through as a priority healthcare workers; however, certain categories of at-risk populations were systematically not identified as a priority for testing and were therefore not followed through for treatment.
- Some participants were obliged to stop using drugs, alcohol and tobacco as a condition for starting on treatment.

RECOMMENDATIONS

AWARENESS

- Develop mass campaigns for general population on HCV awareness. Increase use of media such as television to widen reach; complement such media with HCV-related awareness materials at the local level.
- The government should collaborate with local medical experts to increase awareness in schools and colleges; increase awareness through use of social centers such as churches; increase training of healthcare workers; increase number of healthcare workers who work directly with HCV patients.
- Increase trainings of healthcare workers to both improve knowledge of HCV services and improve their ability to communicate and counsel to patients.
- Highlight in training the extremely negative impact of patients' perception of healthcare worker stigma toward at-risk populations and/or PLHCV.

DIAGNOSIS

- Streamline the links in the testing pathway and expand capacity to evaluate liver staging.
- Screening must be paired with counseling on the meaning of test results and the next steps—if necessary—in the diagnosis pathway.
- Facilities must adopt clear policies on HCV screening and train their healthcare workers to implement these protocols.
- The program needs to develop a local laboratory infrastructure dedicated to HCV viral loads. Where there is excess capacity on multi-disease platforms used for HIV or TB (e.g. GeneXpert), HCV programs should have access. If necessary, create collaborations between public hospitals and private laboratories which are able to carry out analysis faster.
- Increase the number of sites offering diagnostic services or the number of sites linked via a sample transport network to laboratories carrying out viral load tests.
- Train healthcare workers on the identification of at-risk populations, as well as the protocol for hepatitis C testing.
- Work with healthcare workers to identify new contact points with at-risk populations, including previously un-targeted populations such as spouses and care-givers of persons infected with HCV.
- Evaluate the impact of these schemes to support further scale up.
- Train health-care workers on counselling in order to avoid loss to follow up and drop outs.

TREATMENT

- Explore the possibility of expanding the range of services provided by certain cadres of healthcare worker (i.e. task-shifting) in order to relieve workforce bottlenecks.
- Include at-risk-populations as priorities in HCV guidelines and raise awareness among healthcare workers on how to conduct HCV risk assessment
- Such restrictive treatment criteria are discriminatory and should be removed immediately.

PATIENTS' PERSPECTIVES

OVERVIEW OF FOCUS GROUPS

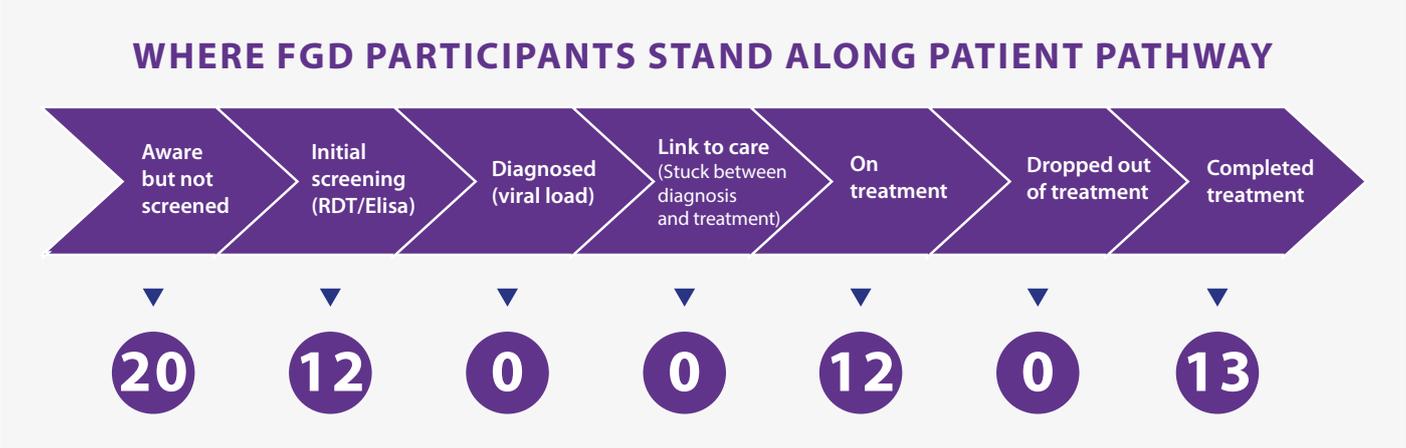
Five focus groups were held in March 2018 in Manipur, a state located in Northwest India. The focus groups were comprised of people at-risk of HCV (defined in this case as PWID, PLHA, or prisoners), as well as individuals who have undergone testing or treatment for hepatitis C. A total of 57 people participated in the Manipur focus groups. The fifth focus group was organized among inmates in a prison setting.

TABLE 6: MANIPUR FOCUS GROUP PARTICIPANTS

FOCUS GROUP 1	FOCUS GROUP 2	FOCUS GROUP 3	FOCUS GROUP 4	FOCUS GROUP 5
13	12	12	8 4 males/4females	12
Mainly PWID. All had completed treatment	Mainly PWID. All currently on treatment	All currently screened but not confirmed	Mix of MSM, IDU, sex workers, PLHIV None screened yet	All prison inmates, mainly PWID. None screened yet
TOTAL : 57 PARTICIPANTS				

The focus groups in Manipur were selectively sampled in order to coalesce around stages of the patient pathway. Thus, each group was at a different stage. A number of participants in Manipur had in fact completed treatment. Almost all participants identified awareness as a major issue.

FIGURE 19: PROGRESS OF PARTICIPANTS ON PATIENT PATHWAY



All focus groups (except the FGD held in the prison setting) were held at the CoNE office in Imphal East (Manipur). The first included 13 participants, all of whom had completed treatment. The second included 12 participants who were currently on treatment, while the third included 12 participants who had completed screening but had not yet gone for confirmatory tests. The fourth group was a mixed group including 4 men and 4 women, evenly distributed between MSM, PWID, sex workers and PLHIV who had not yet been screened. The final group in Manipur was a focus group held with prison inmates who have not yet been screened. These individuals were all former PWID.

SUMMARY OF MANIPUR FOCUS GROUP DISCUSSIONS

AWARENESS

The need to raise awareness about the disease was the central and recurrent message communicated by the focus groups.

Several of the participants explained that they were unaware of the disease until it became too serious to ignore. On discovering that they were HCV positive, some patients resumed or increased their drug abuse as a coping mechanism, especially if they were concerned that they would not be able to afford diagnosis and/or treatment. Several of those who had not yet been tested indicated that they were not aware of the seriousness of the disease and had therefore not felt an urgency to act. An important outcome of the discussion with those who were not yet screened was that at-risk participants became aware that HCV is curable and therefore they should take steps to address it quickly.

Most participants found out about hepatitis C from NGOs, the media, or friends and relatives. In common with the surveys carried out in other countries, one awareness issue discussed was the importance of ensuring that the information people received was correct. Some participants expressed concerns that some of the information provided by certain NGOs (notably those who work on HIV, but not extensively on HCV), and even some information provided by doctors (i.e. those not previously trained on HCV), was not always correct. Another issue was that the NGO information sessions were sporadic and not well publicized in advance, meaning that not all people who used the NGO services

would automatically have attended a session on HCV. Experiences with NGOs appeared to diverge significantly in terms of the quality, quantity and relevance of information provided (i.e. some NGOs were judged as very helpful on awareness, others less so).

Participants judged that messages from doctors and experts would hold more weight in awareness-raising than by peers. This feedback highlights the importance of the quality of patient-healthcare worker interaction.

A very wide range of proposals were made to increase awareness of HCV. These included mass awareness campaigns; increased awareness in schools and colleges; increased use of social centers such as churches to increase awareness about HCV; training more healthcare workers; having more healthcare workers who work directly with HCV patients; and free treatment programs. It was emphasized that awareness campaigns should not be one-off events but should be held regularly and should be disseminated through print and electronic formats. Information should be posted anywhere large crowds gather: hospitals, clinics, waiting sheds, shopping malls, schools, prisons. Teleplays or series were also recommended.

“USE THE MEDIA TO INFORM PEOPLE ABOUT HEPATITIS C THE SAME WAY YOU DID WITH HIV & ART A FEW YEARS BACK.” -FGD PARTICIPANT

Stigma was not a widely raised issue, and appeared to be more of a concern to those early in the process rather than those farther along the pathway. For example, the participants who had completed treatment did not raise this issue at all, while those still awaiting confirmation indicated that several of them are delaying confirmation due to the fear of what their family and friends might say. Participants expressed far more worry about diagnosis leading to stigma from family members than stigma from friends or healthcare workers.

Participants in the focus group also expressed concerns about relapse (in drug use), isolation from family or social networks, loneliness, and lack of access to information.

PREVENTION AND RISK REDUCTION

Suggestions about how the disease is transmitted elicited a very wide range of answers from those who had not yet completed diagnosis. Many of the answers were incorrect, indicating the need for significantly more education about the disease.

In one focus group, only about a third of participants had attended harm reduction services. In those cases, the harm reduction services were provided by local NGOs, from whom they learned about modes of transmission of hepatitis C and harm-reducing behavior such as avoidance of needling sharing. In those cases, they could also access screening services through the NGO.

DIAGNOSIS

Many focus group participants indicated that they had not started or continued on the diagnosis pathway because cost was a barrier. A few were concerned about the results, and the additional stress or mental health impact of finding out that they could test positive without any means of then addressing the disease (i.e. could not afford treatment). Several participants who had received a positive result on the screening test indicated that they were reluctant to get tested for confirmation out of fear of subsequent stigmatization.

Several of those who had not yet been tested stated that the limited information they had on the disease, especially their limited awareness of the risk, contributed to a reduced urgency to get tested. Those participants received most of their information from peers, friends and the media; none of these sources had emphasized the need or urgency to get tested. Those that had not yet been screened indicated that an absence of easily accessible testing sites in rural areas, as well as the fear of treatment side effects (due to rumors and misinformation), had led them to postpone or ignore advice to get tested.

The focus group participants who had started treatment all confirmed that they had been through all stages of testing.

The diagnosis process had been initiated in most cases by doctors / healthcare workers or NGOs. In several of the groups, only one third or half of the patients knew at the time why they had taken the test. Such cases represent missed opportunities for doctors to counsel and inform patients on the disease and patient pathway.

For participants, the diagnostic process took around 15 days to 2 months. Participants mentioned long delays in receiving test results, notably for the confirmatory test. One of the major reasons for delay was that tests had to be sent far away, i.e. to another state, to run the analyses. Patients were informed that if they took the tests at private labs, the results would be available faster, but not all had the money to do so.

Allocating time for the appointments was also a major barrier for many patients. At one point, the main doctor available to order the diagnosis and treatment in one large catchment area was temporarily unavailable, leading to additional delays.

TREATMENT

Many patients faced a delay of 20-25 days between completing diagnosis and starting treatment. This was often because they were waiting for access to free treatment from public (government) facilities or from NGOs. This delay was not the same for those who could afford to pay for the medicines themselves, thus highlighting the potential benefits of making free or subsidized treatment more widely available. Those who did not face a delay had to wait 1-5 days; this was usually until the next doctor's appointment became available. The delays in getting medical appointments was a common theme that also came up regularly in the Delhi survey.

Once patients had started on treatment, they indicated that they did not have many problems actually accessing the medicines.

**“I FELT VERY GOOD AFTER I
STARTED TAKING MEDICINES. I
FELT I AM STRONG LIKE BEFORE.”
-FGD PARTICIPANT**

Some participants found it difficult to stay off drugs during the treatment process; peer pressure and

anger management were identified as two drivers to use again.

Poor comprehension of the treatment process was highlighted in participants' concerns about possible drug-drug interactions when taking over-the-counter medicines for ailments such as cold or diarrhea. Some patients found it hard to communicate with the doctors, and indicated that they experienced negative comments or stigma from healthcare workers. However, they were much more vocal in focus groups on the issue of awareness than about stigma.

In some cases, patients expressed concerns that the healthcare workers were not able to answer questions accurately. Participants in the focus group discussed the importance of doctors and nurses being correctly trained about HCV; they also recommended that more healthcare workers should receive training and provide HCV services.

Other issues which were raised in relation to treatment – often by those who were not yet on treatment – included concerns about adherence to treatment; recommendations for free testing and free treatment; and improvements in pre- and post-diagnosis counselling.

COST

Several participants indicated that they did not receive financial support for further diagnosis or treatment beyond the initial screening stage; others received support from family or NGOs, while a few paid for their diagnosis and treatment by saving money. The issue of cost was therefore a barrier for several individuals, ultimately causing them either to stop or delay their diagnosis and treatment. Those who continued expressed stress at having to find the money somehow.

HEALTHCARE WORKERS' PERSPECTIVES

The survey also comprised individual interviews with healthcare workers. In Manipur, the teams interviewed 8 healthcare workers in total; 6 men and 2 women. In general, this survey included experienced healthcare workers; 4 mid-career (3 people aged 30-39 and 1 aged 40-49), and 4 aged 50-59 years old. This group was relatively well-versed in clinical experience with hepatitis C, with three participants having 3-5 years of direct experience with HCV clinical work and another four having 6-10 years or more.

Five of the interviewees were medical doctors (three specialists and two in general medicine), one was a nurse, and the remaining two focused on laboratory work.

Interviewees showed a wide range of work sites, with 7 of the 8 interviewees working in both government and private sector facilities, while around half also

worked for non-profit facilities. However, most focused their work in hospitals or clinics, rather than specialist reference sites such as HIV-clinics or PWID drop-in centers. This range of sites highlights the potential importance of reaching out to key healthcare providers; the overlap also offers the potential to consolidate messaging and training / outreach opportunities towards healthcare workers in Manipur.

All of the Manipur interviewees worked in the capital city (State level). The average number of patients seen per week ranged from 15 – 30, with most interviewees seeing 20 – 25 patients each week. **The laboratory-focused interviewees had very different workloads, with one seeing around 35 patients per week, while the other saw around 140 patients.** The nurse saw significantly fewer patients, only 5-6 per week: this raises a question as to whether nurses could play a larger role to relieve some of the pressure on long waiting times for appointments.

It is noticeable that respondents in the Manipur survey indicated that they engage heavily in testing activities. This highlights the importance of the diagnosis process in addressing the hepatitis C burden.

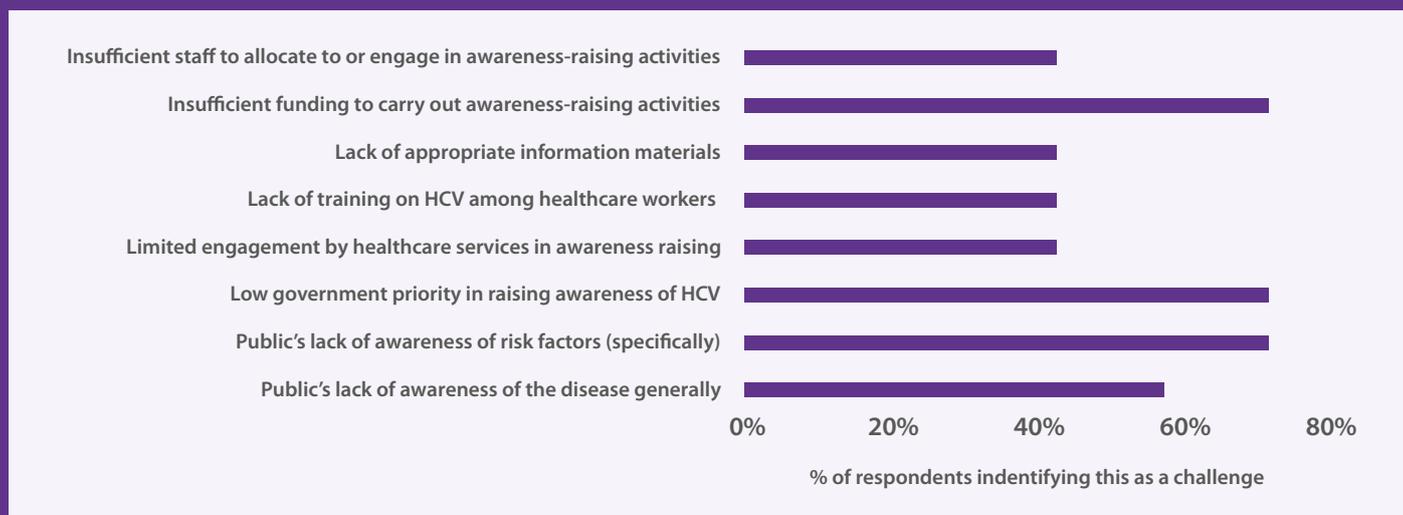
AWARENESS

Healthcare workers unanimously identified trainings and workshops as a key source of information. Two thirds of them also gathered information from WHO publications, and professional associations, while around half sought information from journals.

Just over half of the healthcare workers interviewed for the Manipur survey were involved in HCV education activities. These activities included: screening for HCV; carrying out awareness programs in association with NGOs; carrying out awareness programs in association with pharmaceutical companies; patient counselling sessions; education for patients at hospitals and clinics; education to healthcare workers; serving as a resource person for NGOs; delivery of talks at conferences and symposia; and appearances on TV shows or in public discussions.

When asked to identify the main challenges in providing awareness-raising activities, there was no dominant theme offered by healthcare workers.

FIGURE 20: MAIN CHALLENGES IN PROVIDING AWARENESS RAISING SERVICES (HEALTHCARE WORKERS RESPONSES, MANIPUR) (N=8)



Healthcare workers suggested that new ways of increasing awareness could be: to carry out mass awareness programs at the local level in both urban and rural settings; to establish free screening and education centers in every district; to increase awareness programs on electronic and print media; to carry out advocacy vis-à-vis stakeholders and funding agencies; to implement better awareness through educational curricula, professional bodies etc; to propose new legislative approaches and additional government funding; to increase funding for awareness-raising activities ; to train healthcare workers on HCV.

PREVENTION AND RISK REDUCTION

Only one of the eight healthcare workers interviewed in Manipur was involved in providing harm reduction services in any way (through an opioid substitution program). The biggest challenges that this person faced in providing harm reduction services was that some PWID were not implementing recommendations to avoid needle sharing, and communication challenges related to the educational levels of some PWID.

DIAGNOSIS

There appeared to be significant gaps in diagnosis services. While all the facilities offered initial screening and fibrosis (liver stage) testing, very few offered viral load testing. Participants highlighted that in order to bridge the existing gap in far flung areas, there is the need for doctors in remote areas to be trained on HCV as it would reduce the need to travel long distances for HCV diagnosis services. Furthermore, the trained GP could play an important role in explaining the necessary diagnosis steps. Moreover, it was noted in Manipur that patients don't usually go for diagnosis without the prescriptions of treating doctors. Of course, to compliment such decentralization, there needs to be a robust mechanism in place to transport samples and communicate results; or, even better, for there to be placement of viral load diagnostic capacity closer to local clinics.

Consensus around which populations should be considered 'high-risk' was less clearly identified. Thus, healthcare workers may benefit from additional training on identifying and reaching out to high-risk populations. In addition to PWID and PLHA, populations identified as possible at-risk groups to screen included the spouse / caregiver of an infected patient, female sex workers, tourists, and frequently transferred officials. Those patients who were identified as high-risk and therefore as a priority for diagnosis also appear to be identified as a priority for treatment.

Only one of the eight facilities in Manipur had a policy on screening; this facility followed NACO (the National AIDS Council) guidelines. The other facilities had no policy. Those who are involved in screening identified a common testing algorithm

as standard: screening by RDT or EIA, followed in antibody-positive cases by a RNA test and liver staging.

Around 60% of respondents in Manipur were involved in screening services. Of these, almost all could name the different stages of diagnosis correctly, while only around 50% could describe the different stages.

Healthcare workers all indicated that counselling was widely available, either directly through their own facility or through an associated facility.

Healthcare workers confirmed that out-of-pocket payments were the most common source of funding for almost all diagnosis and treatment for hepatitis C in Manipur. They indicated that initial screening may be obtained for free from government facilities or through some NGOs in certain cases. But for other tests, the healthcare workers understood that the individuals must pay. Discount schemes are in place to encourage patients to complete diagnosis but there was no indication or feedback concerning the impact or effectiveness of these.

Feedback from healthcare workers about follow up along the diagnosis-

treatment pathway were extremely diverse and no discernable trend could be found. It would appear therefore that follow up by both patients and healthcare workers was very inconsistent; this perhaps indicates opportunities to learn lessons about reasons for drop out and solutions for patient retention in the continuum of care. Healthcare workers identified the stages after initial screening, after viral load and during treatment as being the key times at which patients drop out of the system. However, they did not explore what makes a patient drop out or what may encourage them to continue.

Only one of the eight healthcare workers interviewed indicated that they follow up with NGOs or through other relevant channels if a patient drops out of the system during diagnosis or treatment.

Interestingly, when asked at the end of the interview for any additional comments, all the healthcare workers focused on diagnosis. Comments included the need for: better (simpler) diagnostic tools; free diagnosis programs; improved reporting on tests; reductions in the costs of ancillary services; and availability of quality test kits and reagents.

TREATMENT

Discussion over the main challenges in providing treatment raised a surprising degree of consistency, more so than other countries participating in this survey. The challenges identified by healthcare workers include lack of awareness / education about HCV and financial constraints. These two were mentioned as the key issues by all respondents. Only one respondent also indicated that stigma from healthcare workers may be an issue.

Most of the healthcare workers had no idea whether HCV is a notifiable disease, and did not know how it could or should be notified. One suggested that patients are sent to a senior medical officer, and only one identified a standard reporting system for notifiable diseases. It was subsequently confirmed upon follow up that HCV is not a notifiable disease in India.

COMPARING PERSPECTIVE

While both healthcare workers and focus group participants put a very heavy emphasis on awareness raising, it was noticeable that not all of the solutions proposed and activities undertaken by the healthcare workers aligned with the needs expressed by the patients in focus groups. In general, the healthcare workers focused on more academic approaches, while at-risk populations requested more direct outreach and communication. However, one major point of alignment was on the importance of local awareness campaigns to complement regional or national-level campaigns.

The reasons given for delays in testing were remarkably consistent between healthcare workers and focus group participants; these were identified as the time required for sending samples to testing centers in other parts of the country, as well as delays in waiting for enough samples to run a test. However, healthcare workers did not appear to know the actual turnaround times for tests, while at-risk groups did not feel empowered to chase tests results: thus, there was no one to serve as an advocate for reducing timelines through the diagnosis process.

Healthcare workers indicated that counselling is available, while at-risk populations put a strong emphasis on having more access to counselling; there is clearly a gap in perspective between service provider and patients about the availability or sufficiency of existing counseling services.

Interestingly, while healthcare workers believed that out-of-pocket payment was the main source of payment, the issue of cost was not the top priority for focus group discussants in Manipur, who seemed more concerned about awareness-raising. A number of patients in Manipur received support from their families to access diagnosis and treatment, while others received support from NGOs. Thus, cost was clearly a decisive factor for at-risk populations at the start of the diagnosis pathway, leading some of them to put off testing, but once they had started on the pathway the issue of cost seemed to decrease as a concern.

INDONESIA

THE SURVEY IN INDONESIA WAS LED BY PKNI (PERSAUDARAAN KORBAN NAPZA INDONESIA), A COALITION PLUS PARTNER. PKNI IS A NETWORK OF DRUG-USER ORGANIZATIONS; IT WAS ESTABLISHED TO ADDRESS THE IMPACT OF HARSH DRUG POLICIES—STIGMA, VIOLENCE, DISCRIMINATION AND VIOLATIONS OF HUMAN RIGHTS—UPON PEOPLE WHO USE DRUGS.¹⁶

CONTEXT

Indonesia has a population of 261 million with a per capita Gross National Income (GNI) of USD 3,846; it is therefore classed as a lower middle-income country by the World Bank.¹⁷

Indonesia is part of the WHO South-East Asia Region (SEARO). With a total of approximately 1.8 million estimated HCV cases (estimated antibody seroprevalence of 0.8-1%)¹⁸ and around 14,000 incident (new) cases per year.¹⁹

TABLE 7: EPIDEMIOLOGY OF HEPATITIS C IN INDONESIA

2015 ESTIMATES	INCIDENCE	ESTIMATED NUMBER OF PLHCV
INDONESIA	14,000	1,800,000

As a lower middle-income country, Indonesia was included in the voluntary license that Gilead Sciences issued in 2014, and also in the BMS voluntary license (via the Medicines Patent Pool) on daclatasvir in 2016. However, access to DAAs remained limited until quite recently. Sofosbuvir was only made available in hospitals in 2017 and daclatasvir remains scarce, as it was restricted until very recently to a special access scheme, due to registration difficulties and subsequent procurement delays.

Until 2015, the Ministry of Health's hepatitis plan did not provide for systematic HCV testing for HIV-infected patients and opioid substitution therapy clients, nor did it include mention of key populations to screen, diagnose or educate. However, in 2015, the Ministry of Health revised the plan, a move that reflected the input of multiple key actors—local civil society organizations, the Ministry of Health's hepatology committee, and international institutions. Subsequently, the Ministry of Health decided to elaborate a new National Strategic Plan (2016-2021), as well as documents outlining an action plan, guidelines that included available DAAs, screening strategies, and protocols for diagnosis and treatment.

However, until 2016, hepatitis C was not considered a top health priority for the Ministry of Health, due in part to a lack of epidemiological data on HCV and to the lack of awareness concerning hepatitis C within the Ministry of Health. This was partly attributable to a high rate of turnover among HCV-related staff within the Ministry of Health, which contributed to a lack of internal stability and continuity that, in turn, slowed efforts to develop robust HCV data and elaborate further policies. This situation was improved by the creation of a sub-directorate dedicated to viral hepatitis, in 2016.

Currently, the budget allocation for the hepatitis sub-directorate is approximately USD 9 million (123 billion Rupiah), with approximately 75% of that budget (90 billion Rupiah) allocated to procurement of sofosbuvir for the treatment of 6,000 patients—the target of the Ministry of Health over a two-year window. There is no public

coverage of diagnostic costs, and current prices for all the needed tests to access treatment can run up to USD 500.

Moreover, healthcare workers are not trained to assess which population to prioritize for HCV testing. Even blood donors identified as HCV antibody-positive via blood donation are only notified that their blood donation has been destroyed and that they should seek a general bloodwork check by themselves. While updated Hepatitis C Treatment Clinical Management guidelines have been published and healthcare workers and providers are starting to be trained, few of the PLWHC that have been diagnosed have accessed treatment.

The challenges of the HCV response are manifold. These include: structural challenges in the Indonesian health system, the lack of HCV awareness among key populations and healthcare workers, and the fact that the high cost of diagnostics is still borne by the patient. Those obstacles are particularly strong beyond the capital of Jakarta. In fact, a survey of at-risk populations and healthcare workers from more distinct provinces and/or rural areas would likely yield a far more critical profile of awareness and access to services. Moreover, it should be noted that 25 of 32 focus group participants involved in the study had started or completed treatment. This was the highest of all the study sites; thus, the participants' own awareness of HCV and their success in accessing services is likely skewed to be over-optimistic in its reflection of the experience of a PLHCV in Indonesia, a country where less than 1% of the estimated HCV population has initiated treatment. More specifically, participants were all sampled from HIV and HCV referral services in the Jakarta area, a fact that is likely to introduce toward an excessively optimistic evaluation of the HCV response, as Jakarta has the greatest concentration of HCV services in Indonesia.

Finally, the public health impact of repressive drug polices in Indonesia cannot be underestimated: the government position concerning the war on drugs (the largest present driver of the HCV epidemic in Indonesia) is a fundamental impediment to the response to HCV

KEY FINDINGS

AWARENESS

- Patients expressed concern about the very limited awareness surrounding hepatitis C. One patient pointed out that although there are many times more PLHCV than PLHA, the disease does not have the same support, investment or awareness. Healthcare workers also called for better training and awareness of HCV among healthcare workers
- Hepatitis C patients in Indonesia were very concerned about transmission of the disease to family members (e.g. between spouses). Participants expressed this concern much more vocally than the focus groups in other countries in the study. However, patients in Indonesia did not express major concerns about stigma.
- Information about HCV was not systematically provided to PLHA as part of their treatment for HIV. They were also not systematically offered testing for HCV.
- Very few participants got information about HCV from health services; those who did usually received this as part of the process of starting on DAA treatment and not as a process to encouraging them to get diagnosed or consider treatment. Some indicated they had received information about HCV from the health services when they were hospitalised for opportunistic infections related to their HIV status. Healthcare workers identified patients' lack of care-seeking behavior as a major challenge.

DIAGNOSIS

- Those who had been screened and actively sought information had more knowledge; in most cases, the screening led to greater awareness, rather than vice-versa.
- Patients called for a simplification of the referral system. The complexity of the patient pathway leads to long delays, creates confusion, and can impose important indirect costs on patients. Healthcare workers also called for more affordable and less time consuming diagnostic solutions.
- The time requirement to complete tests was also considered burdensome. As not all patients understood the purpose of the tests, it was not clear to them why they were asked to invest so much time in taking different tests. Several participants highlighted the limited availability of counselling in Indonesia.
- Mobile testing services was highlighted as a potential solution for decentralization of HCV services for certain populations.
- Services (diagnosis and treatment) must be available across the whole country, not just in Jakarta or limited to major cities.
- Stock-outs of test kits and reagents was highlighted by both focus group participants and healthcare workers.
- High out-of-pocket costs of testing stages was highlighted a major barrier to completing diagnosis.

TREATMENT

- Focus group participants who had started on treatment did express concerns about the availability of medicines and possible stock-outs. Stock-outs had indeed caused delay in starting treatment for a few participants in the Indonesian survey. (Note: this concern arose in the capital city, where access to HCV services are strongest.)
- Patients indicated that they had to make multiple return trips to the healthcare facilities during their treatment. One specific issue mentioned in Indonesia which was not articulated as explicitly in other countries was the requirement to bring the latest completed blood test results when seeking to re-fill a prescription.
- Healthcare workers raised the issue of sustainable funding for HCV programs.

RECOMMENDATIONS

AWARENESS

- The government should promote HCV-related information more actively; information campaigns are needed that target at-risk populations, the general public and healthcare workers. Such campaigns should be as widely disseminated as possible, particularly in public spaces. Awareness raising and screening programs should also be integrated with other existing key programs implemented by the government such as harm reduction centers, HIV centers, and the Maternal and Child Health program, as this last could reach and screen pregnant women.
- Information should be available for family members and sexual partners of PLHCV regarding testing and treatment. It should also be highlighted that treatment of PLHCV is a form of prevention of further transmission to peers.
- CV awareness-raising should be promoted at HIV-focused clinics, and screening tests should be made offered free-of-charge to PLHA. More broadly, testing should be offered to all PLHA who are not aware of their HCV status. Information should cover both HCV prevention and treatment.
- Healthcare workers should demonstrate greater initiative in HCV awareness-raising. This means that not only must healthcare workers receive training on HCV, training on viral hepatitis must be better integrated into the study curriculum of healthcare worker education. The Ministry of Health must allocate resources for such training and to improve health campaigns to inform the public of risk reduction behaviors.

DIAGNOSIS

- Awareness-raising campaigns must be scaled up significantly, and these campaigns must link to practical information about access to screening. Outreach systems for high-risk populations should be implemented and expanded; communication between health services and NGOs must be better integrated.
- Individual facilities should aim to develop the capacity to implement the full protocol, in order to limit the complexity of the referrals. The diagnostic process should be simplified in terms of the tests and time required. References should be available—via internet or call centers—to obtain information about location and hours of HCV services.
- Ensure that counseling accompanies testing. An important part of this counseling should explain the stages of testing and treatment.
- Explore the feasibility of providing mobile testing services.
- Increase nationwide investment in HCV capacity, access to treatment and investment in health facilities; services for HCV should be expanded across the whole country, not just centralized in a few areas. Decentralization of care could be obtained by setting up a system such as ECHO clinics.
- Eliminate stock-outs of diagnostics (kits, reagents) through more efficient supply chain management.
- Testing should be covered by the public insurance system and hidden costs of testing should be minimized.

TREATMENT

- Stock-outs of medicines should be eliminated. In order to do so, a system should be in place for anticipating low inventories that triggers renewal of stocks before it is too late and registration of new generic drugs should be simplified to expand treatment options. Planning and estimation of PLHCV in need of treatment should be based on current data on volumes of viral load tests, not only antibody test.
- Re-fills should be streamlined, and blood test results should not be required for a prescription re-fill.
- HCV services should be covered in full by national insurance.

PATIENTS' PERSPECTIVES

OVERVIEW OF FOCUS GROUPS

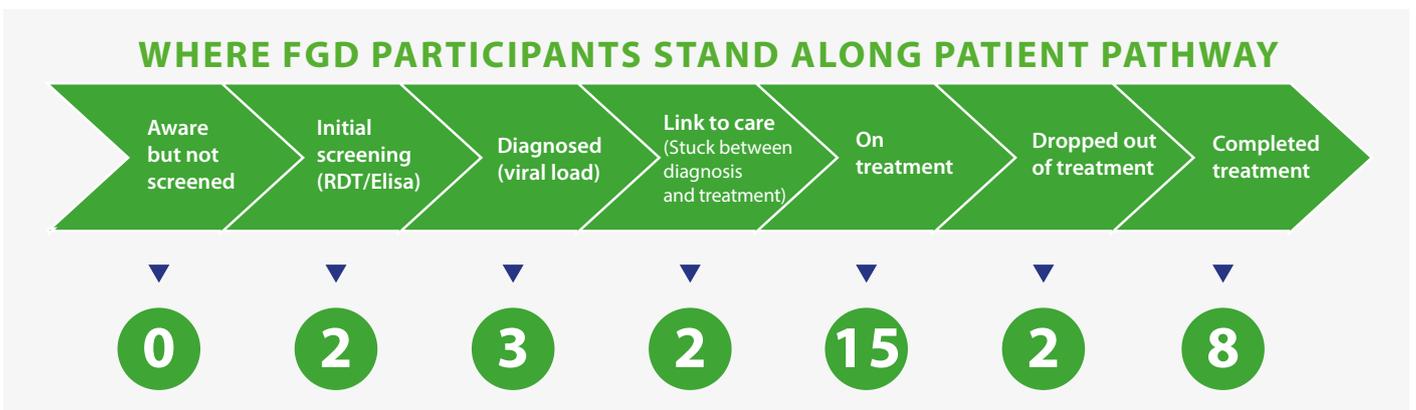
Four focus groups were held in Indonesia in April 2018, bringing together people at risk from, screened for, diagnosed with or under treatment for Hepatitis C. A total of 32 people participated in the Indonesian focus groups.

TABLE 8: INDONESIA FOCUS GROUPS

FOCUS GROUP 1	FOCUS GROUP 2	FOCUS GROUP 3	FOCUS GROUP 4
 8 7 men, 1 woman A mix of PWID and PLHA Mainly not yet started treatment	 8 6 men, 2 women A mix of PWID and PLHA Most participants were currently in treatment	 8 7 men, 1 woman Almost all PLHA; one prison inmate Many participants had completed treatment	 8 6 men, 2 women All on methadone replacement therapy Many participants had completed treatment
TOTAL : 32 PARTICIPANTS			

As highlighted below, the majority of participants in the Indonesian study were either on or had completed treatment.

FIGURE 21: PROGRESS OF PARTICIPANTS ON PATIENT PATHWAY



The first focus group was held in at the Fatmawati Hospital, and included a mix of participants who were HIV positive and PWID. The second group included 6 men and 2 women, also a mix of people who are HIV positive and PWID. It was held at Rumah Makan Karawaci, Cengkareng. Six of the group were on treatment, one had been screened and one had had a viral load test. The third group was held at the Pengayoman Hospital which serves both general public and prison services. The final focus group was held in a PWID hotspot in the community, it included 8 people on methadone replacement therapy.

SUMMARY OF INDONESIA FOCUS GROUP DISCUSSIONS

AWARENESS

Most of the participants in the focus groups had heard about hepatitis C and were aware of their own personal risk of contracting the disease. Some were aware that PWID have a higher risk of contracting HCV. However, they indicated that the general level of knowledge was initially very low. Those who had been screened and actively sought information had more knowledge; the screening led to greater awareness rather than vice-versa.

Once patients had decided to seek out more information, they generally had a fairly high level of knowledge about the whole patient pathway, from transmission through to diagnosis and treatment; these participants were aware about the diagnostic and treatment options and implications; they discussed different treatment options available, side effects etc. It should be noted that most of the individuals in the focus groups had already started treatment; their advanced awareness may be both a cause and result of their progress on the pathway. On the other hand, participants with very little information also expressed concerns about side effects and interaction with other treatments, and their lack of knowledge proved a barrier in taking informed decisions on how they should proceed.

Participants in the focus groups expressed concern about the lack of HCV information targeting the general population or other at-risk populations. They called for an increase in broader awareness-raising activities.

The most knowledgeable participants in the focus groups obtained information from PKNI awareness-raising activities or through friends and family. The information-dissemination activities conducted by NGOs were appreciated and applauded by at-risk populations; these activities included community training and information sessions, as well as dissemination

of information and education materials. Focus group participants considered these to be helpful in raising awareness of HCV and reducing misleading information about the disease.

Information dissemination by peers was considered very helpful in Indonesia. The participants who highlighted this point did not articulate the same concerns highlighted by focus group participants in other countries about the poor quality of information from friend networks.

Very few participants got information about HCV from health services; those who did usually received this as part of the process of starting on DAA treatment and not as a process to encouraging them to get diagnosed or consider treatment. Some received information about HCV from the health services when they were hospitalised for opportunistic infections related to their HIV status. This indicates that HCWs missed opportunities to inform at-risk patients.

Most participants in the focus groups assumed that they would not have access to more information and services until there is free treatment available for hepatitis C in Indonesia. This was borne out by the experience of the HIV-positive participants in the groups, who had been attending harm reduction services for many years but were only given information about HCV once the free treatment program had started. Information about HCV was not systematically provided to PLHA as part of their treatment for HIV, and they were also not systematically offered testing for HCV.

Focus group participants were not clear whether they should be pushing healthcare workers for more information or if the onus was on the professional to provide information regardless of expressed demand.

PREVENTION AND RISK REDUCTION

Prevention and risk reduction were not really addressed by participants but many of them indicated that they did not disclose their HCV status to sexual partners, thus highlighting the importance of awareness-raising among other at-risk groups and the general population to stimulate a wider discussion around HCV. However, several participants also expressed concern about transmitting the disease to people close to them (e.g. their spouse). This was a theme which appeared several times in the Indonesian discussions, far more so than in other countries.

DIAGNOSIS

Several patients faced barriers during the diagnostic stage, as full diagnosis was a pre-requisite for treatment. This led to challenges or drop-out for those without insurance coverage as cost was a major barrier to completing diagnosis if the tests had to be paid for out-of-pocket.

A few participants had carried out a viral load test which proved inconclusive or negative, causing confusion for those patients as to their HCV status.

Many had completed the full diagnosis pathway but did not have detailed information or understanding of the tests which had been performed; thus there is a concern about awareness and consent as the patients did not understand the process sufficiently. In other words, focus group discussions highlighted a clear need for counseling by healthcare workers providing HCV services to patients.

The time requirement to complete tests was also considered burdensome. As not all patients

understood the purpose of the different procedures, it was not clear to them why they were asked to invest so much time in taking different tests.

In some cases, stock-outs of key diagnostic equipment (tests, cartridges, etc) had caused delays for those seeking to complete the diagnosis requirements for treatment; in some cases, the combination of stock-outs of diagnostics and the lack of availability of free treatment options led to a one-year delay between starting diagnosis and starting treatment.

Referral times between one step in the patient pathway to the next was frequently raised as a bottleneck in the system, causing long delays in getting to the point of starting treatment.

In certain cases where patients were likely to be HIV and HCV co-infected, some patients did not follow doctors' recommendations to get a HCV test as they wished to prioritize getting onto HIV treatment first.

TREATMENT

Participants indicated concerns about shortages or stock-outs. Indeed a few participants had had to postpone the start of treatment due to stock-outs. Those focus group participants who had already started on treatment said that the services were easy to access and that it would be easy for them to complete the treatment and be HCV-free. Granted these individuals were from the Jakarta area, which has the greatest access to HCV services.

A few participants in Indonesia indicated they were still on sofosbuvir and ribavirin, a suboptimal regimen.

The advocacy work and patient support provided by NGOs was clearly acknowledged as having had an impact on making services more accessible, more convenient, cheaper and faster.

For those who had started treatment, it had taken 2 to 4 months to initiate. Those who had experienced a delay in the start of treatment attributed this to one of two reasons: the cost of diagnosis, especially for those who did not have insurance; and the lengthy timeline and logistical complexity of completing diagnosis. Some patients experienced much longer delays but in almost all cases this was due to their own decisions, e.g. not being up to date on their health insurance payment, deciding if they wanted to go forward with treatment, taking time to absorb the diagnosis etc.

Some patients on methadone maintenance therapy experienced delays in accessing treatment because they prioritized access to the methadone first. To avoid such delays, information about the safety of DAA and methadone medication should be disseminated to patients (i.e. they are not contra-

indicated), as several expressed concerns about possible interactions.

Only one person in the Indonesia focus group made reference to concerns about drug-drug interaction (i.e. between DAAs and drugs other than methadone); this person had had to delay the start of treatment for HCV as they were being treated for another condition which may cause interactions.

Patients indicated that they had to make multiple return trips to the healthcare facilities during their treatment, even though the medication itself was free of charge. Thus, while there was no specific barrier to accessing treatment, the process was

COST

The cost of treatment (before the free program had started) had been a barrier for several people and had caused them to delay the start of treatment.

The major out-of-pocket cost which patients faced during treatment was the registration fee at health services. Some patients faced additional costs for direct payment of tests if they were not covered by health insurance – in such cases, costs often led to drop-out from the system. The out-of-pocket costs for testing in Indonesia can run up to hundreds of dollars.

considered time-consuming and onerous. This was particularly true for people who live far from major treatment centers. One specific issue mentioned in Indonesia which was not articulated as explicitly in other countries was the requirement to bring the latest completed blood test results when seeking to refill a prescription.

There were several questions about the possibility of treatment failure, and the efficacy rates of the different treatment regimens. This was a much bigger issue in discussion in Indonesia than in the other focus groups.

HEALTHCARE WORKERS' PERSPECTIVES

In Indonesia, the team interviewed 8 healthcare workers in total; 4 men, 3 women, one individual who did not specify. This was the only country to have a relatively even male – female healthcare worker perspective. Only two of the interviewees had experience of over 10 years working clinically on hepatitis C. Five of the respondents had less than 2 years working on this specific disease.

Four of the eight Indonesian interviewees were specialist medical doctors, one generalist doctor and two were nurses. The last had a general healthcare management background. Six of the eight interviewees work mainly in HIV-focused clinics, with the two others working in tertiary-level hospitals. Only two worked specifically in HCV-focused clinics. Two of the interviewees also worked in the private sector and one worked with a not-for-profit in addition to their public sector work. All of the Indonesian respondents worked in the capital city or the immediate surroundings.

Healthcare workers indicated that the number of patients they see varies considerably over time. At the end of 2017, they were seeing around 10-20 or up to 30 per week, whereas in early 2018 this had dropped to around 5 per week. (Further correspondence confirmed that, following a near stock-out in 2018, the number of patients receiving treatment has been limited.) One person estimated that he regularly saw around 50 patients per week, while others only see around 5 HCV patients per week, despite offering specialist HCV services.

Treatment was clearly indicated as a key service among healthcare providers. Fewer participants in Indonesia identified testing as being a significant part of their job, when compared to other countries.

The services provided in hospitals offering HCV diagnosis and treatment were fairly complete. They included screening, viral load test and treatment. Some facilities have not been offering services for very long as they had only expanded their HCV services once the DAA became available in Indonesia.

AWARENESS

Healthcare workers in Indonesia clearly and almost unanimously identified training sessions, workshops and health-sector journals as being their primary source of education and information. Around half turn to government sources and to professional bodies for additional information, while colleagues or the WHO do not appear to be significant references for accessing information.

The healthcare workers interviewed indicated that they are involved in raising awareness through direct educational activities with patients and patients' families. Some healthcare workers are involved in outreach initiatives to prison inmates. However, healthcare workers identified patients' lack of care-seeking behavior as a major challenge.

Although the healthcare workers interviewed do provide various services such as harm reduction services, counselling, and links between the HIV and HCV services, a lack of information/education materials was seen as a challenge in promoting awareness of HCV, especially for reaching out to the general public. Finally, healthcare workers also called for more peer advocates and patient advocates, to raise a joint voice for hepatitis C awareness and investment. One doctor highlighted the problem of specialists' lack of opportunity/time to share expertise.

Healthcare workers would also like to get more involved in raising awareness among colleagues, highlighting as potential targets the staff working in the emergency room or with dialysis patients.

DIAGNOSIS

The limited availability of testing capacity, notably due to the lack of test kits or reagents, was identified as a major barrier to diagnosis. Several healthcare workers noted this issue in Indonesia; it was not mentioned nearly as often by healthcare workers in other countries carrying out this survey.

The healthcare workers were generally familiar with the different stages of diagnosis, both in terms of the stages and methods used. However, challenges in accessing the equipment meant that an APRI score, as opposed to a FibroScan, was the common method for liver staging test.

Test results often took over 2 days to return. This was due to limited staff in the laboratory unit, lack of funding for tests, lack of reagents and kits, and not being able to get back in touch with patients to provide results.

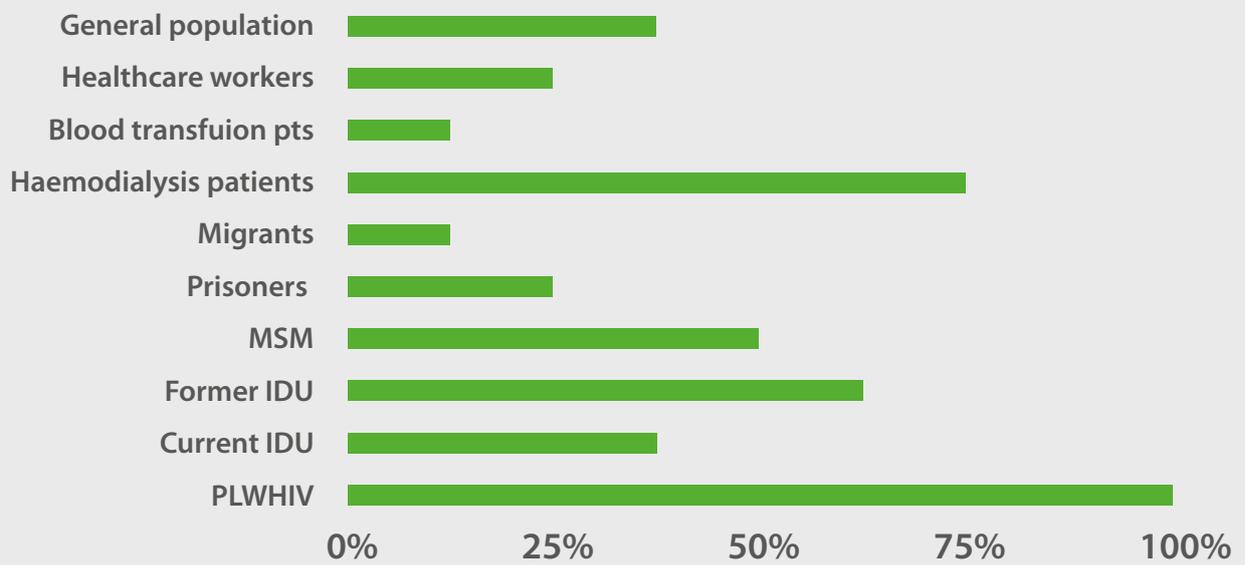
Not all facilities had systems to follow up with patients who dropped out of the system. Some healthcare workers followed up on a personal basis, calling patients at their own expense or on

their own time. Most of the interviewees claimed that, once patients started on the pathway, their facilities did not have a problem with patient drop out.

The interviewees claimed that cases of HCV are recorded and ultimately reported to the provincial health office.

Figure 22 below indicates the proportion of healthcare workers indicating that they serve the various at-risk populations identified in the questionnaire. All of the healthcare workers interviewed in Indonesia indicate that they see people living with HIV, and 75% see hemodialysis patients. Migrants and prisoners, however, do not feature highly despite being an important risk group. It should be emphasized here that the sample sizes are very small and results should therefore be read with caution. Healthcare workers indicated that they would ideally also like to prioritize healthcare workers and HCV patients' partners / spouses as a priority for screening and testing if testing capacity allows.

FIGURE 22: PATIENTS SEEN BY RISK FACTOR: PROPORTION OF HEALTHCARE WORKERS INDICATING THEY REGULARLY SEE EACH CATEGORY - INDONESIA



TREATMENT

The treatment phase was not particularly addressed by healthcare workers in Indonesia.

COMPARING PERSPECTIVES



The challenges and opportunities identified by patient and healthcare workers in Indonesia were surprisingly aligned. The most significant challenges included: increasing awareness of HCV; government investment and support, especially funding; the limited availability of services across the country, as well as stock-out of diagnostic materials and medicines.

The Indonesia study identified several barriers and bottlenecks which were not raised to the same degree by the surveys carried out in other countries. The most important of these was the lack of diagnostic capacity (stock out of reagents, RDTs etc). Stock outs were raised frequently—by both healthcare workers and patients—as a key reason for delays in progressing along the diagnostic pathway.

Both parties identified that a limited numbers of patients were entering the pathway. Those focus group participants who did go through the system appeared to have completed the full patient pathway without too many issues. However it is quite possible that the selection process (i.e. the high number of participants who were on or had completed treatment) in Indonesia might have skewed results, given both the limited number of persons receiving treatment nationwide and the concentration of HCV services around the capital and major cities.

Indonesian participants in both parts of the survey called for partners and spouses of HCV patients to be prioritized for screening: it was the only country which put so much emphasis on this group and was noticeable in the consistency of messaging between the patient population and healthcare workers.

While patients did not identify major gaps in healthcare workers knowledge, they did indicate that healthcare workers did not pro-actively engage patients with information about HCV; instead patients indicated that they had to push for information. This might relate to the concern that healthcare workers expressed about colleagues not being very well trained on HCV and requesting further training to facilitate their work. Notably, the healthcare workers interviewed indicated that they had been active in educating patients.

Neither at-risk populations nor healthcare workers identified stigma as a major concern.

MALAYSIA

THE SURVEY IN MALAYSIA WAS LED BY COALITION PLUS PROJECT PARTNERS, THE POSITIVE MALAYSIA TREATMENT ACTION AND ADVOCACY GROUP (MTAAG+) AND THE MALAYSIAN AIDS COUNCIL (MAC). IN ADDITION TO THEIR ADVOCACY ACTIVITIES, THESE ORGANIZATIONS COLLABORATE WITH LOCAL SERVICE PROVIDER GROUPS THAT WORK DIRECTLY WITH PERSONS AT-RISK OF HCV, HCV PATIENTS, AND HEALTHCARE WORKERS INVOLVED IN HCV SERVICES. MTAAG+ AND MAC WORKED WITH PARTNERS TO CARRY OUT THE DATA COLLECTION IN MALAYSIA. THIRD WORLD NETWORK ALSO PROVIDED SIGNIFICANT TECHNICAL AND ADMINISTRATIVE SUPPORT TO THE SURVEY.

CONTEXT

Malaysia has a population of 31.2 million with a per capita Gross National Income (GNI) of USD 9,994; it is therefore classed as an upper middle-income country by the World Bank.²⁰

Malaysia is part of WHO's Western Pacific region (WPRO). An estimated 400,000 Malaysians are living with chronic HCV.²¹

TABLE 9: EPIDEMIOLOGY OF HCV IN MALAYSIA

2015 ESTIMATES	INCIDENCE	ESTIMATED NUMBER OF PLHCV
MALAYSIA	2,000	400,000

An estimated one in every 63 Malaysians is infected with hepatitis C and this figure reaches 2.5% of the population aged 15 – 64 years.²² Many more—as family members and other social networks of those infected—are affected by the disease. Given the high burden and the long-term consequences of the disease, hepatitis C represents a major public health concern in Malaysia.

The recent availability of generic DAAs has significantly changed the dynamics of the HCV response. Malaysian public health actors are now considering routes towards HCV elimination.

The feasibility of HCV elimination received a massive boost when—in mid-2017—the Malaysian government became the first government to issue a compulsory license for sofosbuvir. Prior to this move, negotiations with originator companies over the procurement of DAAs had made insufficient progress, and prices demanded by monopoly-holders were so expensive that the Malaysian government could not reasonably afford to launch a major HCV treatment program. Since March 2018, the combination of generic sofosbuvir and generic daclatasvir are now available in 18 public hospitals in Malaysia for about USD 300 for the 12-week full course.²³

A broad coalition of over 21 civil society organizations is continuing to work with key government departments to maintain and expand access to DAAs.

Given rapidly changing political and access dynamics around treatment for hepatitis C in Malaysia, a key question of interest to the research team was the extent that patients and healthcare workers were familiar with the various changes. While the evolving scale-up of access to treatment should be kept in mind, it should be emphasized that many elements captured here may not be immediately influenced by the arrival of significant price reductions: these include, among others, low levels of HCV awareness and the diverse barriers in the diagnosis process.

KEY FINDINGS

AWARENESS

- The focus group participants expressed the need to increase awareness on hepatitis C among HCWs and at-risk populations.
- All the healthcare workers indicated that they were engaged in some form of health education activities targeting both at-risk populations and other healthcare workers.
- At-risk populations generally felt they did not have enough information about hepatitis C and were eager to have more information on diagnosis and treatment. When they did get information, they found the information easy to understand.
- Healthcare workers perceived that the attitude of healthcare workers and the experience of stigma (from healthcare workers or others) is an important but not critical issue influencing a patient's decision to engage with HCV services.
- Patients perceived healthcare workers as having the knowledge to advise correctly. However, in practice, at-risk populations generally got information through informal sources (social networks, social media) or from organized information sessions run by NGOs.
- Only 1 of 11 of healthcare workers interviewed believed that the lack of awareness was the result of low government prioritization of HCV.

PREVENTION AND RISK REDUCTION

- Only 2 of 11 of the healthcare workers interviewed in the Malaysia study were engaged in providing harm reduction services. However, they also called for more accessible needle exchange programs, indicating that there was an awareness of the need for good harm reduction services.

DIAGNOSIS

- Healthcare workers suggested that all Malaysians should get tested for HCV as a way of removing the taboo and stigma of testing, as well as a way of increasing awareness about HCV in the general public.
- Professionals serving as gatekeepers to the healthcare system (general practitioner doctors / family physicians, nurses, health-focused social workers) saw very few HCV patients. Health professionals called for certain components of HCV awareness, diagnosis and treatment to be brought down to facilities at the primary healthcare level.
- All the facilities interviewed offered initial screening. Subsequent tests were offered in only around half the facilities. Where these were offered, they were offered to everyone and not a sub-set of patients.
- Tests normally had to be ordered by a specialist; for tests beyond initial screening (e.g. viral load confirmation, fibrosis testing), general practitioner doctors could order these in only around 20-30% of facilities of interviewed HCWs. Thus, given the limited number and availability of specialist doctors, restrictions on who may prescribe/administer testing creates a potential bottleneck for diagnosis.
- Healthcare workers interviewed claimed that almost all their facilities use the standard algorithm for the diagnostic pathway. Yet only about 50% of healthcare workers interviewed indicated that all tests are performed at their facilities, only about 30% could correctly name and describe all the stages of diagnosis for HCV.
- Patients faced long delays in linkage to confirmatory testing and subsequently to treatment. When asked about time to receive results, the lag was either unknown or varied significantly.
- Healthcare workers were not certain of how diagnosis services are paid for. In the FGDs, at-risk populations clearly articulated diagnosis costs as an important barrier to progress along the continuum of care.

TREATMENT

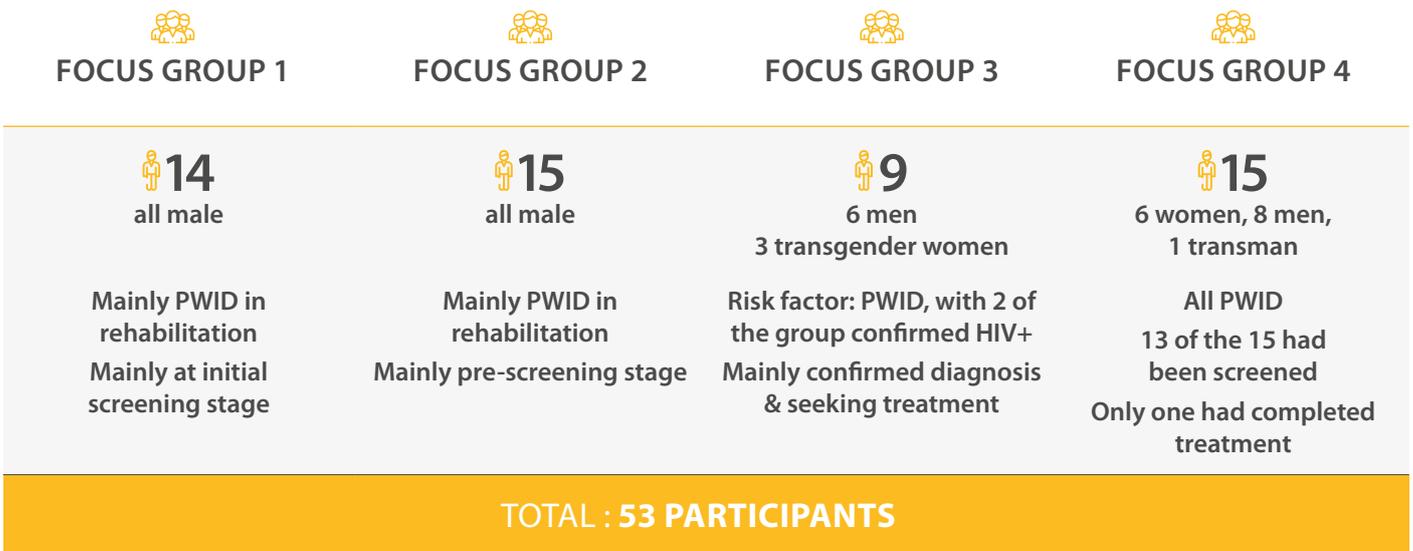
- Participants were not clear on how to access treatment through the public sector. Participants indicated that treatment was very expensive (prior to arrival of generic DAAs) and that the cost of treatment had caused patients to drop out of treatment. While cost was a critical factor, the presentation and information about treatment was also identified as being an essential component to expanding availability and accessibility of treatment. Information about the treatment should be client-friendly and easy to understand.
- If patients did drop out, this was normally between completion of the diagnosis process and start of treatment. In addition to historical barriers of treatment cost, participants cited the inconvenience of getting to healthcare services (time and cost) and the side-effects of the treatment.
- For those seeking treatment or on treatment, peer support groups were important.
- Less than half of healthcare workers interviewed indicated that their facility provides treatment.

PATIENTS' PERSPECTIVES

OVERVIEW OF FOCUS GROUPS

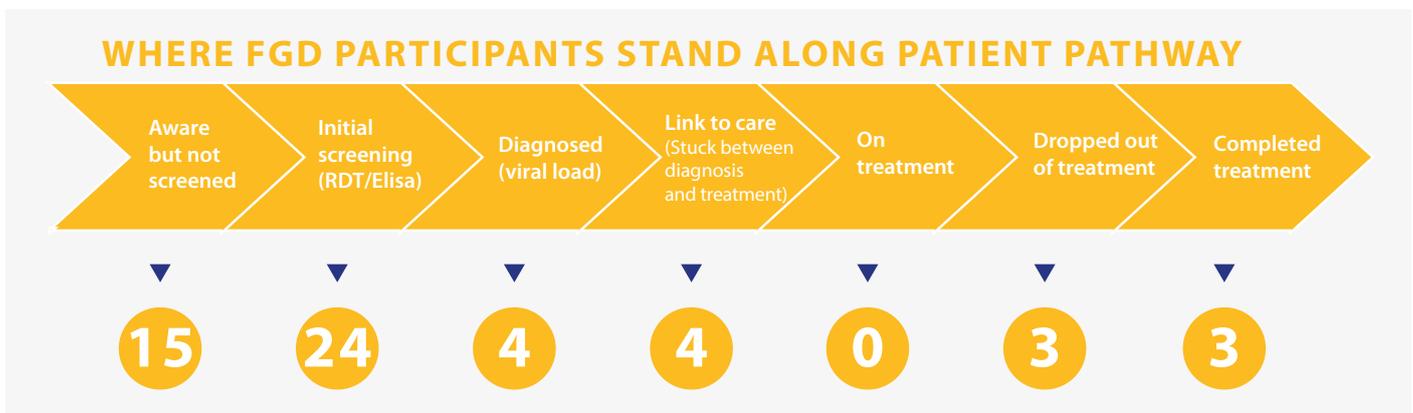
Four focus groups were held in Malaysia in March 2018. The focus groups brought together people at risk of hepatitis C, as well as those who had been tested for HCV.

TABLE 10: PROFILE OF FOCUS GROUP PARTICIPANTS



As highlighted below, the majority of participants in the Malaysian study were still early in the continuum of care, with many of them not yet screened or screened but without confirmation. Correspondingly, most of the barriers were identified at the awareness and screening stages.

FIGURE 23: PROGRESS OF PARTICIPANTS ON PATIENT PATHWAY



The first focus group was held in the state of Negeri Sembilan. It involved 14 participants from around Pedas Linggi and Rembau, two small towns in the West region of the Malaysian Peninsula. Participants were all men, aged in their 20s to 40s. The focus group was held at a residential drug rehabilitation center where most of the participants are staying (funded either by themselves or by the church organization which runs the center). This group focused PWID and individuals in drug rehabilitation. The concentration of most participants at the start of the continuum of care influenced the scope of the discussion. This focus group clearly demonstrated the need to raise awareness and disseminate information on HCV.

The second was held in Hulu Langat, a small town in the state of Selangor; it included 15 people. It was organized jointly by the Cure and Care Service Centre (CCSC) and MTAAG+. CCSC is a government-funded organization for rehabilitation of PWID. The group was also comprised exclusively of men, aged in their early 20s to 40s.

Focus group 3 was carried out in Alor Setar, a town in the state of Kedah. It was organized in collaboration with Cahaya Harapan. They had good access to information, a factor that might have influenced the level of knowledge about the disease. All had advanced to screening and confirmation. Three participants were on treatment at the time of the survey and two had dropped out of treatment for financial reasons. One participant in this group

was still on an interferon-based regimen.

Group number 4 included 15 people; it was held in Kuala Lumpur (the capital city of Malaysia), and was organized by the Malaysian AIDS Council (MAC). It included 6 women, 8 men and one transman; participants ranged from 30 to 64 years old. All participants are connected with local NGOs, which focus on harm reduction or drug rehabilitation centers. All participants were aware of HCV and 13 of them already knew their HCV status. Only one participant had completed treatment. Almost all this group was stuck at the referral stage, having been screened and identified as antibody positive but waiting to be referred on to the next stage for confirmation of their diagnosis.

SUMMARY OF MALAYSIA FOCUS GROUP DISCUSSIONS

The following analysis considers participants of all the focus groups together, with key group-related distinctions highlighted where relevant.

AWARENESS

It became very clear through the focus groups that while people believed that they had some information, they were unclear as to exactly what level of information they had (e.g. with some issues being wider health issues and not HCV-specific). It also became quickly apparent that the information was often obtained through informal sources, and therefore may not have been correct or up-to-date. Participants were clearly extremely anxious to access quality information and clarify core concepts.

Focus group participants were generally very vocal on the need for a scale up in awareness. A key take-away from the discussion on awareness was the gaps in knowledge about

hepatitis C and the treatment itself.

On the issue of discrimination, respondents were again almost evenly split on whether persons suffering from hepatitis C faced similar levels of discrimination as people face when affected by other diseases. The issue of discrimination came up more frequently in the context of discrimination against PWID. Those who had completed treatment became a focus of attention for the group, with other members seeking to learn from their experience to facilitate their own paths. This peer-to-peer learning theme was a recurrent feature of the focus groups and can have either positive or negative consequences, depending on the quality.

PREVENTION AND RISK REDUCTION

The issue of prevention and risk reduction was not raised in the focus groups.

DIAGNOSIS

Patients experienced very different situations when moving through the diagnosis stage. When seeking further clarification from participants, it seemed there was in some cases, participants were not able to articulate exactly what tests they had had, what the results of these were or what stage of testing they had reached. This made it very difficult then for moderators or the HCV experts to provide detailed guidance in the short time allocated for the focus groups.

Responses to a further exploration about whether it was clear to them what would happen next in the process further highlights this issue. Unlike on certain other topics, there was no clear consistency among participants' views on the issue. This certainly raises interesting questions about how information is processed at different stages along the patient pathway and why some people found it easier to access and understand information than others. Further probing and understanding of this issue would be of great use for ensuring patient-focused advocacy is optimized and has the greatest impact.

The participants expressed strong views that the main bottleneck for diagnosis was not cost or access but rather the confusing nature of the diagnosis process. Recognizing this, patients made a strong plea for simplification of the testing process, as reduction in the length and complexity of the

process (in terms of turnaround time, number of visits, and number of facilities visited) could have a big impact on retention and follow up for patients. For example, taking time off work or finding family care was a challenge for at least half of the participants in the discussion groups, indicating that such indirect costs can be a fairly significant barrier throughout the diagnosis and treatment process.

Participants generally had a very positive attitude towards getting more information. This was especially evident during the discussions on experiences accessing information. Many were not aware that the diagnosis process for HCV involves more than one stage of testing; in such cases, a patient who has been tested once and then faced challenges in referral along the treatment pathway may not have even been aware that they have not completed the diagnosis process (and may not ultimately have chronic HCV).

Experiences with access to counselling was also very mixed. It was clear from the discussions that those who had had counselling, mainly from doctors, had a higher comfort level and understanding of the diagnosis and treatment process. These individuals were more articulate and confident in their knowledge, while those who had not received counselling were clearly much more confused and were actively seeking more information.

TREATMENT

One focus group had some understanding of where and how to get hepatitis C treatment, and several participants were aware of the difference between the older and new treatment regimens. One participant in this group was still on an interferon-based regimen. These experiences raised a discussion on the importance of peer support in continuation along the patient pathway to treatment completion.

COST

The cost of the medicines was a very clear barrier articulated in the focus groups, with an overwhelming majority of participants agreeing that the cost of medicines was a barrier. At least 4 people had either not started or stopped treatment because of the cost of medicines. This demonstrates the historical impact of price as a barrier to accessing DAAs. As the focus groups were held the same month that the government launched access to generic treatment in 18 public hospitals, one may anticipate that the cost barrier will fall drastically. Therefore, it is crucial to spread awareness of the fact that the treatment is both new and free.

However, the cost of medicines was not the only major financial barrier that was flagged. The overall cost of the pathway, including healthcare service visits, was also identified as a major financial barrier for many of the participants.

Finally, other indirect costs such as time off work or covering family care were also highlighted as important barriers, although perceived to be of lower impact than the direct out-of-pocket costs.

HEALTHCARE WORKERS' PERSPECTIVES

The survey also comprised individual interviews with healthcare workers. In Malaysia, the teams interviewed 11 healthcare workers in total; 8 men and 3 women. The healthcare workers included 4 at the start of their careers – aged 20 to 29, 5 mid-career (3 people aged 30-39 and 2 aged 40-49), and 2 with more experience aged 50-59 years old.

Six of the interviewees were medical doctors, including two hepatologists, one was a nurse, four had social care / counselling background and one had a background in healthcare management. Nine of the eleven HCWs work mainly in urban environments (the capital or major cities).

The number of patients per provider in Malaysia proved surprisingly diverse. It was further parsed that the first point of contact in many healthcare systems are seeing few HCV patients, while those with a more intensive socio-medical support role (such as nurses and counsellors) see a far higher number of patients – up to 25 patients per week for this latter category.

AWARENESS

All 11 Malaysian healthcare workers interviewed indicated that they carried out some form of health education activities. These included: information for PLHA and PWID; participation in hepatitis C support groups; education at opioid replacement therapy / methadone patient sessions; health education, counselling and screening of at-risk patient groups; performance of risk assessments; provision of information to at-risk groups on modes of transmission and treatment; engagement on HCV during World AIDS Day; delivery of public talks and lectures to other doctors.

The healthcare workers interviewed consistently identified the following sources of information as important for their own education on hepatitis C: government sources (e.g. publications by the Ministry of Health), trainings and workshops, journals and WHO materials.

When asked to identify the main challenges in raising awareness about HCV, the healthcare workers were remarkably consistent despite the fact that the interviews were carried out individually. Seventy-

seven percent indicated that key problem was the public's lack awareness of the disease. Forty-five percent agreed with the statements that there was limited engagement by healthcare services in awareness-raising and that there was a lack of training about HCV among healthcare workers. A particularly interesting finding from the Malaysian healthcare workers was that only 14% believed that the lack of awareness was the result of low government prioritization of HCV, thus raising the question whether existing information campaigns and investments might benefit from a change in approach to awareness-raising.

When asked what could be done to help improve awareness, healthcare workers responded that the government's leadership was seen as crucial. They also called for greater training of fellow healthcare workers and indicated that the initial response should be taken down to primary levels of healthcare services. Finally, they recommended that hepatitis C dialogue and testing should not focus only on at-risk populations.

DIAGNOSIS

Healthcare workers suggested that all Malaysians should get tested for HCV as a way of removing the taboo and stigma of testing, as well as a way of increasing awareness about HCV in the general public. HCV was identified as a notifiable disease, and is notified through standard forms.

All the facilities interviewed offered initial screening. Other tests were offered in only around half the facilities. Those facilities which did offer tests beyond initial screening generally offered the full range of tests, and where these were offered, they were offered to everyone and not a sub-set of patients. Tests normally had to be ordered by a specialist; for any test beyond initial screening, general practitioner doctors could order these in only around 20-30% of facilities. Thus, the number and availability of specialist doctors creates a potential bottleneck for diagnosis. Almost all the healthcare workers interviewed are engaged in some part of the diagnosis process. Although about 50% of healthcare workers interviewed indicated that all tests are performed at their facilities, only about 30% could correctly name and describe all the stages of diagnosis for HCV.

Almost all facilities used the standard algorithm for the diagnostic pathway – only one indicated that they must use ELISA rather than rapid diagnostic tests and one indicated that they should carry out genotyping

as part of the algorithm. In relation to diagnosis, healthcare workers echoed at-risk population calls for simpler screening and diagnosis processes.

A wider range of patients were seen for screening and diagnosis: all categories of patients were seen in at least one third of the facilities represented. Around 75% of facilities offered services for key populations such as PLHA, PWID (current and former), MSM and the general population. At least 80% of the facilities had a HCV screening policy or standard operating procedure. These policies included persons attending methadone clinics; persons recently diagnosed with HIV; MSM; patients with abnormal liver function; other high-risk persons; and blood transfusion patients receiving blood before 1992. In some clinics, there was a policy of recommending screening for the general public too. Healthcare workers emphasized that the decisions ultimately lay with the attending doctor and the patient. In general, healthcare workers believed that the policy is followed.

Migrants and the general population were identified as a high priority by about half of the healthcare workers. Other priority populations identified for screening included: pregnant women; persons with chronic or unexplained liver disorder; sex workers; transgender persons; persons living with a HCV-infected person.

PREVENTION AND RISK REDUCTION

In terms of prevention, fewer than 20% of the healthcare workers interviewed were engaged in providing harm reduction services. Nevertheless, they called for more accessible needle exchange programs, indicating that there was an awareness of the need for good harm reduction services.

The following challenges to providing information to people who attend harm reduction services were identified: difficulties in accessing at-risk populations unless they present to healthcare facilities; gaps in the knowledge of healthcare workers about harm reduction and the need for further training on harm reduction; good communication and outreach

skills to initiate a dialogue; the need for more networks and platforms for at-risk populations to communicate and share information. Healthcare workers also noted that stigmatization of at-risk populations by some healthcare workers may be a problem.

When asked what they thought might have the greatest influence on a patient's decision to engage with HCV services, healthcare workers were almost unanimous in identifying the following the most important influences: public information campaigns and integration of awareness campaigns in support services for at-risk populations.

TREATMENT

Approximately 1 in 3 of the healthcare workers interviewed provided treatment services. Those who do provide treatment claimed for all at-risk populations without discrimination certain groups. They indicated that once patients start on treatment, they normally come back for follow up as required. If patients did drop out, this was normally between completion of the diagnosis process and start of treatment. If patients dropped out, healthcare services generally did try to follow up to find out why.

COMPARING PERSPECTIVES

The perspectives from at-risk populations and healthcare workers in Malaysia were surprisingly aligned, much more so than in the other countries surveyed. The importance of increasing awareness among the general population was a very significant theme for both groups.

Both at-risk populations and healthcare workers indicated that they have some knowledge, but it became clear on digging into the details of knowledge that other than very specific specialist doctors, all the other persons interviewed – whether patient or provider – lacked knowledge and were very eager to address this problem. This confusion was demonstrated most clearly on the topic of diagnosis: almost all participants were aware that diagnosis involved several stages, but once the discussion turned to specifics of each stage, it became clear that they were gaps in their knowledge.

One notable difference to this common perspective was the question of clarity on the steps through the diagnostic and treatment pathway. While healthcare workers perceived that information was clearly provided on where to go next and how to get diagnosed or treated, at-risk populations identified this as a barrier, mainly in terms of accessing treatment.

There was consensus that diagnostic and treatment steps need to be simpler, and that they should be made available at much lower levels of service provider. Both patients and healthcare workers expressed concern at how few people currently have access to DAAs and called for DAA treatment to become more widely available.

MOROCCO

THE SURVEY IN MOROCCO WAS LED BY COALITION PLUS MAIN PARTNER ALCS (ASSOCIATION DE LUTTE CONTRE LE SIDA), A NATIONAL ORGANIZATION FOCUSED ON PREVENTION OF HIV/AIDS AND HCV, ACCESS TO TREATMENT, AND PROVISION OF MEDICAL & SOCIO/ PSYCHOLOGICAL SUPPORT TO PLHIV. ALCS CARRIED OUT THE DATA COLLECTION IN MOROCCO.

CONTEXT

Morocco had a population of 34 378 000 inhabitants in 2015 with a per capita Gross National Income (GNI) of USD 3,007 in 2016; it is therefore classified as a lower middle-income country by the World Bank.²⁴ Morocco is part of the Regional Office for the Eastern Mediterranean (EMRO). Estimations of people living with HCV vary, with one widely-referenced figure placing the number at approximately 400,000.²⁵ The Center for Disease Analysis estimated an incidence of 9,216 new infections per year.²⁶

TABLE 11: EPIDEMIOLOGY OF HCV IN MOROCCO

2015 ESTIMATES	INCIDENCE	ESTIMATED NUMBER OF PLHCV
MOROCCO	9,216	Approximately 400,000

The Ministry of Health has drafted a National Strategic Plan (NSP) to fight viral hepatitis. The proposed draft contains ambitious targets, but its finalization hinges on the allocation of a significant budget to the hepatitis response. In addition, since the epidemic is not concentrated in a specific population, the government needs to set up a prevalence study before launching its program in order to identify the areas (or people) where the epidemic is distributed. This study was planned in the National Strategic Plan but has not yet been carried out.

The ability of the Moroccan healthcare system to diagnose hepatitis C remains very limited. It is estimated that, until 2013, less than 1,000 patients were treated per year (with pegylated-interferon), and 100% of those were in the private sector.

The Ministry of Health aims to publish updated guidelines and protocols for HCV screening, diagnostics and treatments in 2018. They have been receptive to civil society's request to include (a) outreach testing among at-risk populations, as well as (b) integration of the offering of tests during patients' visits to their general physician and (c) a simplification of the confirmation test for diagnosis and follow up.

In Morocco, neither sofosbuvir nor daclatasvir are under patent. Local generic companies are commercializing the combination of sofosbuvir and daclatasvir at 1350 USD per 12-week treatment.

KEY FINDINGS

AWARENESS

- There appeared to be much less public discussion on hepatitis C in Morocco relative to other countries; this absence of public debate made it more difficult for those infected or affected to engage pro-actively in the response.
- Patients in Morocco had much less difficulty accessing information than those in other countries; they felt that healthcare workers were relatively well-informed and communicative. However, healthcare workers interviewed indicated that more trainings were needed.
- Stigma and fear of humiliation was a barrier which prevented at-risk populations from coming forward and engaging with services; counselling was not widely available and was not widely discussed as a major topic by any respondent.

DIAGNOSIS

- Only two of the nine healthcare workers interviewed indicated that they provided screening.
- Healthcare workers highlighted the need for increased training and human resources to address HCV. Healthcare workers called for more HCV capacity, decentralized testing and access to services for at-risk groups.
- Although diagnosis should be available free of charge for certain at-risk groups, both healthcare workers and patients indicated that this was not widely the case and that in practice patients should expect to pay for diagnosis out-of-pocket.

TREATMENT

- Seven of the twenty-seven participants had accessed treatment.
- Cost was recognized as a problem for almost all respondents (at-risk populations and healthcare workers).
- Patients who had started on the pathway indicated that many of their greatest barriers related to logistics; reinforcing this point, the healthcare worker interviews highlighted a fragmented approach to service delivery.
- Capacity of HCV services at all levels (awareness, prevention, diagnosis, and treatment) needs to be strengthened.

RECOMMENDATIONS

AWARENESS

- Launch public dialogue and awareness campaigns on HCV.
- Expand trainings of healthcare workers, as healthcare worker awareness of the protocol and service pathway are essential to patient-level experience and scale up.
- Address discrimination, stigmatization and isolation of HCV patients. This sensitivity must be included in trainings.

DIAGNOSIS

- Increase the number of healthcare workers trained/eligible to provide screening services to ensure HCV is more widely diagnosed and therefore patients can start on the patient pathway. In turn, tests must be accessible in a wider range of facilities.
- Ensure that policies around hepatitis C are clear, more widely disseminated, more widely known and followed by healthcare workers. Increase training of healthcare workers on different aspects of hepatitis C.
- Eliminate the out-of-pocket cost of diagnosis and treatment for HCV to ensure wider uptake.

TREATMENT

- Ensure that DAAs are widely available and promoted as the first-line treatment; the price of DAA treatment needs to be significantly reduced.
- The costs of the diagnosis-to-treatment pathway should be covered by both publicly funded insurance and private insurance.
- Address the logistical barriers faced by patients seeking treatment. Services need to be simplified and streamlined, while counseling services for navigating the pathway to treatment need to be readily available.
- Increase resources (human, material, and financial) for awareness raising, harm reduction, diagnosis & treatment; increase service provision to address hepatitis C.

PATIENTS' PERSPECTIVES

OVERVIEW OF FOCUS GROUPS

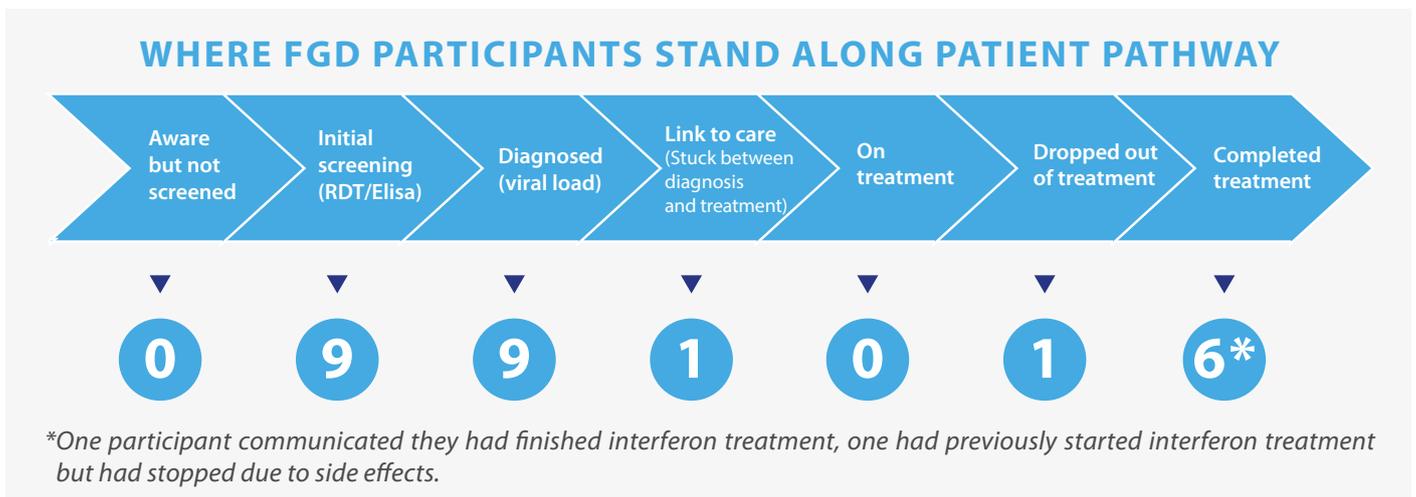
Two focus groups were held in Morocco in April - May 2018; participants who had been scheduled to participate in the remaining focus group were interviewed on an individual basis to avoid logistical delays. A total of 27 individuals from at-risk populations participated in the study, which was carried out in Casablanca and Tétouan. The survey was managed by ALCS.

TABLE 12: PROFILE OF FOCUS GROUP PARTICIPANTS



As indicated below, all participants in the Moroccan study had at least been screened: around one-third had only received screening and had not yet progressed to viral load; 7 of the 27 participants had completed HCV treatment (1 of whom had completed interferon treatment). These figures suggest that the participants represent a comparatively well-informed sample of the population; furthermore, the relatively high proportion of participants who have engaged with community-based organizations also suggests the group had comparatively strong support in accessing HCV services.

FIGURE 24: PROGRESS OF PARTICIPANTS ON PATIENT PATHWAY



SUMMARY OF MOROCCO FOCUS GROUP DISCUSSIONS

AWARENESS

There appeared to be limited public discussion on hepatitis C in Morocco; this absence of public debate made it more difficult for those infected or affected to engage proactively in the response. When asked if the general public is generally aware of hepatitis C, 26% disagreed and 67% strongly disagreed. Two-thirds of respondents found that, in their own experience, it was easy to get information about the disease; nevertheless, nearly half of respondents felt strongly that the general public does not have access to information about HCV.

Two-thirds of respondents indicated that people with HCV have very little social support and 63% strongly agreed people with HCV face stigma as a result of the disease. Focus group participants in Morocco expressed more sentiments of isolation and fear than participants in other study sites. Participants described their situation as

“fearful”, “humiliated” and “stigmatized”. They expressed concerns about infecting others, and wanted to avoid further transmission of the disease.

Participants called for healthcare workers to put themselves in the shoes of at-risk and diagnosed populations to help understand the challenges and communicate solutions. Knowing how to navigate the system was identified as the biggest challenge for all. Most respondents did, however, feel that healthcare workers have the knowledge to advise them correctly.

When asked what could be done to address hepatitis C, focus group participants called for the Ministry of Health to increase efforts to fight against this disease, in order to make rapid progress and avoid new infections.

DIAGNOSIS

All of the participants in the Tétouan focus group had attended harm reduction services. Those who attended a harm reduction service had been offered, and had taken, a screening test for hepatitis C.

A number of people in the Moroccan group had been tested many years before, several indicating that they had been tested in the 1990s. Some people had taken a viral load test abroad.

Accessing information was less of a problem in Morocco than in other countries: 81% of respondents indicated that they found it easy

One participant described the process of diagnosis and treatment as a marathon, requiring a lot of preparation, a large investment of time, energy and organization. Focus group participants highlighted that they did not have to go to several facilities to complete the pathway, but they did indicate that they

to access information about HCV testing, a figure reflecting the access of participants (notably those from Tetouan) to high-quality harm reduction services. 59% of respondents found that information easy to understand.

Barriers in Morocco centered mainly around logistical obstacles, financial barriers, and social attitudes; these barriers were clearly and consistently identified by patients with the following issues identified by at least 85% of respondents: logistical challenges (e.g. waiting time at facilities, distance of facilities from home or work, number of visits required) and cost of diagnosis.

could not choose which facility to go to, thus adding time and cost to the process. Taking time off work and finding family care were important barriers (nearly 90%). Furthermore, it was noted that there was not enough staff to address demand (56%) and it took a long time to receive test results (80%).

TREATMENT

Seven participants indicated that they had completed treatment. One of these individuals had completed interferon treatment. 100% of participants agreed that the cost of medicines was a barrier to treatment.

COST

Many of the participants had to pay for diagnosis out of pocket, and affordability of diagnosis was clearly identified as a problem. 100% of the participants indicated “strong agreement” that the cost of healthcare and medicines was a barrier. There was also a clear call for the price of medicines to be reduced. Many at-risk persons also called for greater government engagement in the process, to support greater access, and ultimately to reduce the risk of more people requiring treatment in the future.

HEALTHCARE WORKERS’ PERSPECTIVES

The survey also comprised individual interviews with 9 healthcare workers; 4 men and 5 women. Seven of the healthcare workers had provided hepatitis C services for over 10 years. There were two gastroenterologists, three infectious diseases specialists, three nurses and one health-focused social worker. Five described their facility as public sector; the other four as a university hospital center. All nine individuals interviewed worked in urban centers.

Several of the doctors interviewed indicated that they see only 1-3 HCV patients per week. Furthermore, the range of services provided by the healthcare workers in Morocco appeared more fragmented than in other countries; one facility covered the full spectrum of services from awareness raising to post-treatment follow up; the others generally only provided one part of the patient pathway. Five of the healthcare workers claimed to provide some awareness-raising through patient counselling and workshops targeted for at-risk populations, while only four offered screening tests. Only one of the nine interviewed claimed that their facility can perform viral load testing. The fragmentation of number and range of services provided indicates that there might be some opportunity to consider grouping services in a more consolidated approach.

The main challenges identified in providing educational or awareness-raising activities was limited information about the disease among the healthcare workers themselves, lack of education materials, and insufficient funding for trainings. Addressing these gaps was seen as important to improved awareness among healthcare workers.

Healthcare workers interviewed in Morocco indicated that they received information about HCV mainly from training sessions/workshops, professional associations and health sector journals. Only the healthcare workers who collaborate with non-governmental organization benefited from training sessions/workshops, the Ministry of Health have not yet organized any training for them. WHO, Ministry of Health, or colleagues were not widely accessed for information by those interviewed.

Only one healthcare worker was involved in providing harm reduction services. The main challenges identified here was the limited capacity dedicated to this service; absence of specific offices or space to carry out awareness raising activities; and the lack of trained personnel to carry out awareness-raising activities.

Only two of the healthcare workers were involved in any part of the diagnostic pathway. As in many countries, the rights to order tests are centralized with medical doctors and many services are limited to specialists. This therefore highlights the importance of ensuring a high degree of awareness among these groups and wide-spread adoption of screening policies to avoid a ‘gatekeeper bottleneck’ as has also happened in other countries.

The populations most frequently seen for tests are PLHA and PWID, with hemodialysis patients and the general population also featuring in early stages of screening. A nationwide policy on screening does not exist; instead, each medical center has its own recommendations; even then, it seemed these

more ad hoc screening recommendations were not widely known and not always followed. As indicated above, only one healthcare worker was involved in screening and none of the interviewees could clearly articulate the diagnostic algorithm, nor could they clearly identify whether and how HCV should be notified to the authorities. (Further correspondence clarified that HCV is not currently a notifiable disease.) Similarly, several HCWs did not clearly identify high-risk populations; training might be useful to address this gap.

Healthcare workers indicated that initial screening, confirmatory diagnosis and genotyping should be available free of charge to the general population, and in particular to at-risk populations. However, it appeared that this was not widely considered to be available in practice and that de facto most patients would be obliged to pay for diagnosis in the private sector. The main populations identified for treatment were PLHA, PWID, and the general population.

The main drop-out points along the continuum of care were identified as after screening or diagnosis and before treatment. The main reasons identified were challenges in accessing confirmatory testing and the cost of treatment; cost was identified as the over-riding barrier by all interviewees.

When asked what impacts an individual's decision to access or follow through with services for HCV, healthcare workers were unanimous in identifying cost and attitude of healthcare workers as the two key drivers. Morocco only recently stopped providing interferon in public hospitals (November 2017), though DAAs are not yet available in public facilities (as of June 2018). One specialist doctor noted that one historical barrier of HCV treatment has been the harsh side-effects of interferon-related treatments. The single driver which most influenced healthcare workers' engagement was education designed specifically for service providers. Better guidelines, improved policies, and access to more information sources were also identified as important for increasing engagement by healthcare workers.

When asked what could make the most impact for healthcare workers to improve services, the theme of increased training and human resources were identified as key. Healthcare workers called for more specialist services for HCV, decentralized testing, and access to services for at-risk groups. Finally, the cost of diagnosis and treatment was considered to be the most significant long-term barrier to expanding access.

COMPARING PERSPECTIVES



Key among the emerging themes was the very limited public discussion and engagement of multiple stakeholders on hepatitis C in Morocco. Despite actively reaching out to those engaged in the field, it was difficult to identify participants for the survey in Morocco – whether from at-risk populations or healthcare workers. Those who did participate indicated limited engagement with the disease, suggesting that the general profile of the disease and investment in addressing it as a priority health burden is limited.

Awareness among the general public was assumed to be very low, and the number of healthcare workers who might serve as gatekeepers and advocates for screening was also extremely limited. Low awareness and low capacity can create a circle of limited engagement that continues to depress demand for diagnosis and treatment.

Patients indicated a much greater ability to access and absorb information than in some

other countries, indicating that there may be a latent opportunity to expand awareness. Interestingly, patients in Morocco identified healthcare workers as being well-informed and able to assist them in accessing information, while healthcare workers themselves identified lack of training, information materials, and policies / guidelines as being the biggest barrier they face.

Patients who had started on the pathway indicated that many of their greatest barriers related to logistics; reinforcing this point, the healthcare worker interviews highlighted a fragmented approach to service delivery. There may therefore be an opportunity to identify areas of simplification and streamlining in service provision.

Finally, cost and availability of diagnostic services and treatment was clearly highlighted as a barrier by all interviewees.

THAILAND

THE SURVEY IN THAILAND WAS LED BY THAI AIDS TREATMENT ACTION GROUP (TTAG) AND OZONE FOUNDATION. AS AN ADVOCACY GROUP RUN BY PLHA, TTAG WORKS AT BOTH THE GRASSROOTS AND ADVOCACY LEVEL TO PROMOTE THE RIGHTS AND VOICES OF PEOPLE LIVING WITH HIV/AIDS. OZONE FOUNDATION TARGETS SUSTAINABLE COMMUNITY-BASED SERVICE DELIVERY AND THE EXPANSION OF HEALTH SERVICE ACCESS FOR PEOPLE WHO USE AND INJECT DRUGS IN THAILAND. BOTH ORGANIZATIONS WORK DIRECTLY WITH PEOPLE LIVING WITH HIV/AIDS AND ALSO PARTNER WITH LOCAL SERVICE-PROVIDER GROUPS.

CONTEXT

Thailand has a population of 68.8 million with a per capita Gross National Income (GNI) of USD 6,593; it is therefore classed as an upper middle-income country by the World Bank.²⁷

Thailand is part of the WHO South-East Asia region (SEARO). With a total of 450,000 estimated HCV cases and around 10,000 incident (new) cases per year.²⁸

TABLE 13: EPIDEMIOLOGY OF HCV IN THAILAND

2015 ESTIMATES	INCIDENCE	ESTIMATED NUMBER OF PLHCV
THAILAND	10,000	450,000

Despite the arrival in most high-income countries of key DAAs in 2014, the unreasonably high prices demanded by originator pharmaceutical companies meant the Thai Ministry of Health was not able to provide DAA treatment through national health insurance until 2018. In fact, until very recently, Thai HCV patients were still being treated with Pegylated-Interferon and Ribavirin, despite crippling side effects and its inferior cure rate.

In December 2016, the Ministry of Health published a national viral hepatitis strategy. However, due to price barriers to the scale up of DAA access, the official program was not launched. In August 2017, Thailand was finally included in the Gilead Sciences voluntary licence for its HCV and HIV products. Since then, generics of sofosbuvir and sofosbuvir/ledipasvir have been registered, while sofosbuvir/velpatasvir registration is still on progress.

The budget has now been raised to THB 400 million (approximately USD 12.5 million). With the goal of elimination, Thailand is planning a major scale-up of its program. It aims to treat 20,000 patients in 2018, and up to 50,000 per year from 2019 forward. The fixed-dose combination of sofosbuvir/ledipasvir has been chosen as the main treatment option in the guidelines; sofosbuvir and sofosbuvir/ledipasvir have also been included in the national essential drug list, which means they are reimbursed under the national health security system.

However, several challenges remain. At the time of writing this report, pegylated-interferon is still prescribed to patients with genotype 3, who represent almost 50% of the infected population. This is because generic DAAs that work on GT3 are not available in Thailand as Thailand is excluded from BMS's generic license for daclatasvir. As the originator for sofosbuvir/velpatasvir only received regulatory approval recently, generics of the combination are expected to reach the market soon.

Beyond access to medicines, there are several issues in the healthcare system itself, with lack of knowledge among healthcare workers about the disease and the testing/treatment protocol, a theme that will be addressed in the chapter below. Furthermore, the guidelines have not been updated to match WHO recommendations and guideline implementation is irregular. This also means that key populations are not targeted, their needs are not recognised, and they are even often excluded from the program.

In short, DAA access is finally feasible in Thailand. In turn, access to generic DAAs has led to ambitious treatment targets in the coming years. As the chapter below describes, now that this key barrier has been significantly reduced, many other challenges remain.

KEY FINDINGS

AWARENESS

- Overall, HCV awareness of FGD participants was very low and patients were keen to access more information.
- Healthcare workers identified low awareness as part of a vicious circle. Lack of minimum level of awareness was seen as fostering lack of engagement, while lack of engagement has contributed to lack of awareness.
- A low level of general knowledge exacerbates risk for at-risk populations. They do not know where to turn to for services, what questions they should be asking and how to interpret the information they are given. It is critical to ensure that information is of high quality, easily accessible, and easily digestible.
- The healthcare workers interviewed indicated that they carry out awareness-raising, but highlighted that more needs to be done. However, the methods and media identified by healthcare workers were very different to the needs expressed by the focus group participants.
- FGD participants expressed that counselling is not widely available or offered at any stage in the patient pathway, although it was perceived by healthcare workers to be widely available
- Some of the issues which were most frequently articulated by patients and at-risk populations figured lowest on the list of barriers cited by the healthcare workers; the divergence was especially important on the following themes : fear of stigmatization; absence of systems for referrals from one facility / service to another; failure to refer from one stage to the next; results taking too long to process; and patients not receiving their results.
- Healthcare workers indicated that they generally have very few contact points with at-risk populations, which restricts their ability to carry out awareness-raising or educational activities.
- The at-risk populations interviewed in the focus groups identified one very clear area of interest: how to get diagnosed.
- At-risk populations generally gathered their information from NGOs and support services, not from healthcare workers; they indicated that healthcare workers rarely or never spontaneously discussed HCV with them. In the interviews with healthcare workers, only one person identified NGOs / CSOs as an opportunity for collaboration and increasing awareness.
- The importance of information sources was another theme: in many cases, focus group participants identified other patients, social networks or family as key sources of information. This raises potential concerns about the quality of information being accessed, as informal channels of information are often—despite the best intentions— unreliable or outdated.)

DIAGNOSIS

- Delays in diagnostic processes were identified by many as the highest barrier to on the path to treatment. FGD participants emphasized the length of time to complete diagnosis, the limited understanding of the diagnosis process, and the number of steps on the pathway between screening and treatment.
- The healthcare workers indicated that people always or frequently come back at each stage of the process to move on to the next stage. This does not appear to be borne out by the statements made in the focus groups. Focus group participants indicated that in very many cases, they never receive the results of tests. In those cases, some FGD participants reported that they had dropped out of pathway due to lack of information.

TREATMENT

- Cost of treatment was an important concern. With the arrival of generic medicines in Thailand, price concerns on medicines should be reduced.
- Doctors and health professionals in Thailand often imposed a requirement that patients should be “clean” (not consuming recreational drugs) for 6 months before they could start treatment. This requirement sometimes went beyond the use of narcotics and included the use of alcohol, tobacco and similar substances. Similarly, patients were required by some clinics to be screened for HCV as a condition for receiving methadone treatment. 50% of the healthcare workers identified the burdensome criteria for treatment as the major challenge (this includes the requirement to be clean from drug and substance abuse for 6 months before treatment is offered). This problem was also raised in the focus groups, where patients indicated that it was one reason for drop-out.
- Distance from the facility/clinic was a very significant barrier articulated by participants in focus groups held in areas further from the capital and large health facilities; this was an important dissuasive factor in seeking diagnosis and treatment, as patients weighed travel time and likelihood of accessing treatment against the ‘silent’ nature of the disease, an aspect that some participants suggested made HCV easier to ignore.
- Healthcare workers pointed out the need for increased availability of quality medicines.

RECOMMENDATIONS

AWARENESS

- Mass awareness campaigns are needed that target both general population and at-risk populations.
- Explore new options for awareness raising by and among healthcare workers, which are better aligned with the target populations needs. Need for investment in new communication solutions to transmit information about HCV outside of the technical, medical language spoken by doctors.
- Better alignment between what healthcare workers communicate and what at-risk populations absorb may be useful. Further training for healthcare workers on sensitivity to stigma may therefore be beneficial.
- Provide training to healthcare workers in how to reach out to and interact with key at-risk populations in an effective manner; a starting point for this could be to explore and open a dialogue on divergence between issues identified as highest priority for healthcare workers and those identified by at-risk populations.
- Information about diagnosis could be used as an entry theme for discussion in order to create a bridge between health workers and at-risk populations; this could also address the issue of patients not receiving results or not following up on tests.
- Explore opportunities for collaboration between healthcare workers and CSOs to increase awareness about HCV. Integrate educational activities related to HCV with services on harm reduction and HIV services.
- Develop a mass campaign to educate the public on HCV (e.g. billboards/TV ads on test-and-cure) that encourages public to seek further HCV information and services.

DIAGNOSIS

- Develop streamlined diagnosis and treatment solutions: the focus group participants provided several suggestions, including grouping services at a single facility. Make greater use of existing voluntary services (i.e. NGO drop-in clinics etc) and increased use of mobile clinics.
- Conduct further research on when and why people drop off the patient pathway might be useful; such information should be provided to healthcare workers in order to target retention interventions as they have little information on this at present.

TREATMENT

- It will be important to monitor prices paid in the public sector to assure that the impact of generic competition has been maximized.
- Eliminate the treatment criteria of substance abstinence.
- Expand the range of healthcare workers who can prescribe tests and support the diagnosis process (e.g. provision of testing and treatment in centers that provide ARVs). This expansion must be accompanied by trainings.
- Facilitate registration of new drugs and advocate for the Inclusion of Thailand in BMS's voluntary license for daclatasvir.

PATIENTS' PERSPECTIVES

OVERVIEW OF FOCUS GROUPS

Four focus groups were held in Thailand in April 2018, bringing together people at risk from, screened for, diagnosed with or under treatment for Hepatitis C. A total of 36 people participated in the focus groups from Thailand.

TABLE 14: PROFILE OF FOCUS GROUP PARTICIPANTS

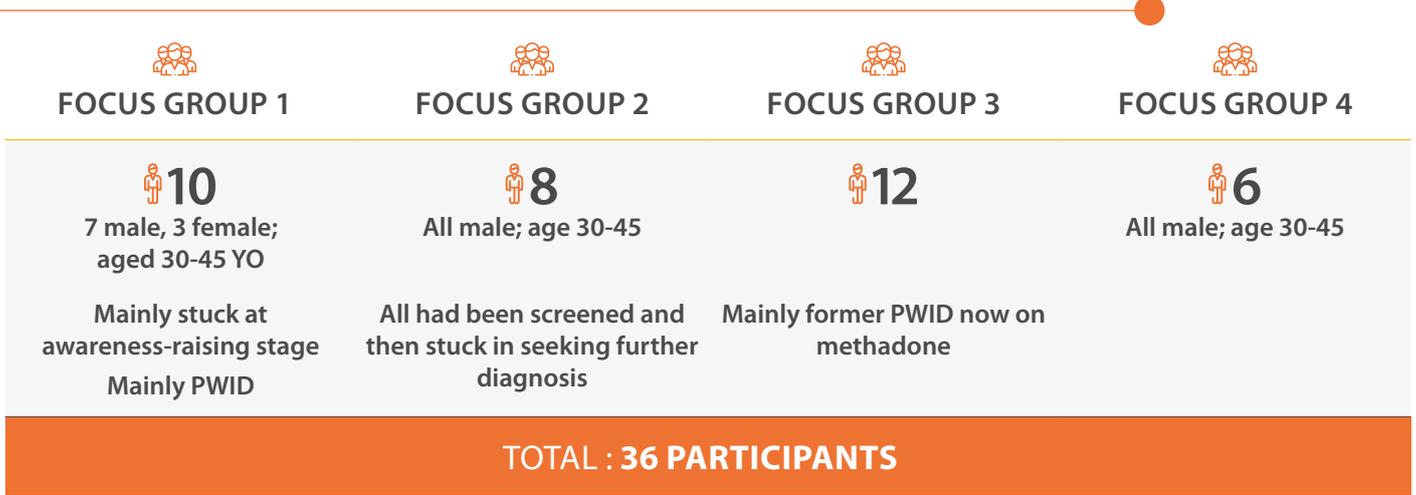
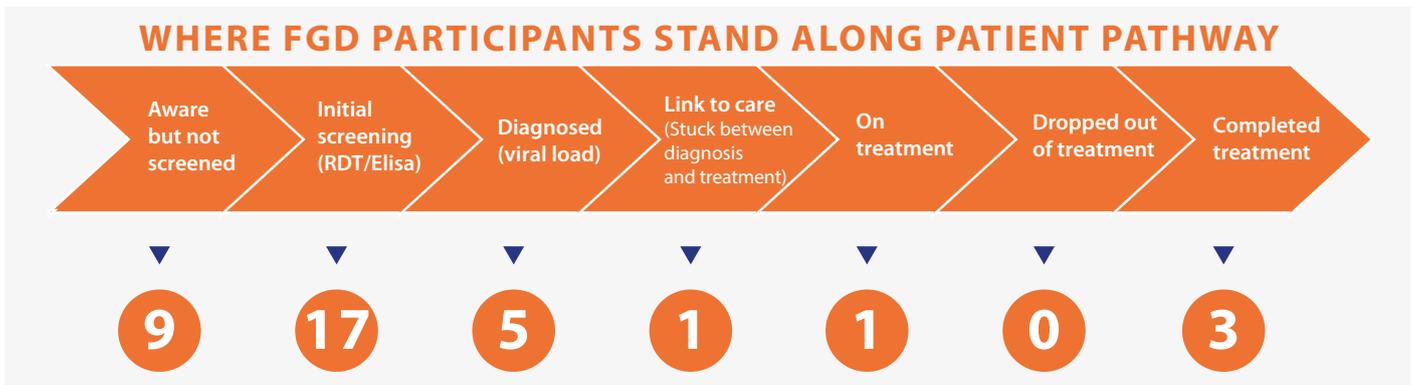


FIGURE 25: PROGRESS OF PARTICIPANTS ON PATIENT PATHWAY



As highlighted below in figure 25, the majority of participants in the Thai study were concentrated in the early part of the patient pathway, with the bulk gaining some awareness of HCV but not having completed the diagnosis process. Correspondingly, the most significant barriers were identified at the awareness stage, impacting on access to screening.

The first focus group was held at the TTAG and RakThai Drop-in Office in Onnuch (Bangkok). It included 10 participants in total, 7 men and 3 women all aged around 30 – 45 years old. One of the participants worked at the drop-in center. Many of the participants were illiterate.

Basic awareness of HCV was a challenge: participants indicated that their main source of information was the Raks-Thai drop-in center and that they did not receive information from healthcare workers. The level of knowledge about the process for diagnosis was very limited, thus creating a barrier to accessing further treatment steps. Most participants did not even have enough basic knowledge to be able to suggest ways of increasing awareness for themselves and others. Despite the fact that all participants knew that they were in a high-risk group, seven of the participants had never been screened for hepatitis. Nobody in the group had progressed beyond the initial screening stage. The

main topic raised during the discussion was access to services, particularly access to services after the initial screening process. Participants wanted to access better services, but the very low level of knowledge limited discussion as there was not sufficient time to explain even the most basic concepts such as modes of transmission.

The second focus group in Thailand was held in Bangkok, organized by TTAG and OZONE and held at the OZONE drop-in at Songkla, Jana. It included 8 participants in total. Participants in this focus group had advanced much farther in the diagnosis process. All of them had completed viral load diagnosis, one person claimed to be stuck in linkage to treatment, 1 was currently on treatment, and three in the group had completed treatment. This group was significantly more informed than group 1, with detailed knowledge of different treatment options, why and how treatment was started or stopped etc.

In the third group, all participants were stuck near the beginning of the process. All participants sought more information to increase their awareness of the disease.

Although they had received HCV screening tests, very few had received their results. When asked why they had not received results, participants explained that they had not asked the doctors for results, despite seeing those doctors on multiple other occasions for other examinations (i.e. facilities/doctors did not appear to be actively informing patients on test results). This group included 12 participants in total, mainly former PWID who are now on methadone.

The fourth and final focus group in the Thai survey included 6 participants in total, all men. It was held in Chang-Rai at the Chang Rai Drop-in center; it was organized by TTAG and Ozone. Participants in this group were spread over the early part of the patient pathway, giving a more diverse perspective. All, however, were stuck at some point leading up to treatment, with none in this group having started on treatment. The most important topic of discussion in this group was to understand how to get onto treatment: patients indicated very clearly that they did not understand the criteria for starting treatment and could not get referred along the system by healthcare workers.

SUMMARY OF THAILAND FOCUS GROUP DISCUSSIONS

AWARENESS

Awareness about the disease itself and the diagnosis-to-treatment pathway was a major barrier for many participants in Thailand. The discussion on awareness highlighted a strong thirst for more information; participants suggested that centers provide presentations/talks on a range of important topics, as such sessions would promote more understanding of these issues.

The low level of general knowledge meant that most of the representatives of at-risk populations lacked knowledge about where to turn to for services, what questions they should be asking, and how to interpret the information they were given.

However, in some cases, participants were significantly more educated about the disease and more engaged with health professionals, notably doctors. The group with higher knowledge levels also noted that it is very important to increase knowledge among the general public [e.g. through media campaigns (radio, television), pamphlets etc]; the high-awareness group acknowledged that they themselves received information through NGOs, but suggested that

public education campaigns were needed in order to reach those who do not connect with HIV/HCV/PWID-focused organizations. Just under half the participants in the focus groups thought that the general public were informed about the disease, while the rest had either no opinion or no strong negative opinion. However, participants also clearly identified greater awareness as a high priority – both for at-risk populations and the general population.

Those who had managed to access and assimilate information were noticeably more articulate on many issues: for example, on the point of risk reduction, they noted the importance of using clean needles (as did the other groups), but followed up with a comment that it was the use of infected needles which was problematic – ‘drug users who inhale drugs were therefore not exposed to the same risks’.

The importance of information sources was another theme: in many cases, focus group participants identified other patients, social networks or family as key sources of information. This raises potential concerns about the quality of information being

accessed, as informal channels of information are often—despite the best intentions—unreliable or outdated. In particular, one point where updated information is very relevant: the recent arrival of generic DAAs in Thailand will make HCV treatment far more affordable and far more tolerable than the previously available treatment.

NGOs were judged a very important source of information and appeared to be a very trusted source. Focus group participants did not perceive healthcare workers as a good source of information: they indicated that healthcare workers rarely or never spontaneously discussed HCV with them. All groups, whether well informed or not, indicated that they would probably not have continued through the patient pathway without support from specialized support groups such as TTAG and Ozone.

All focus groups highlighted the very important role of ‘volunteers’ (i.e people connected with NGOs) in sharing information. Volunteers were asked to provide information about the disease itself, and also about the diagnostic pathway and treatment options.

PREVENTION AND RISK REDUCTION

Although many of the participants in the focus groups identified as being in at-risk groups, it was clear that several did not fully understand why they were at risk, what hepatitis C is, or the process for diagnosis and treatment. Reasons for not continuing with diagnosis included: “not feeling sick”, a response that captures the misconception that the “silent” nature of the disease means it is not particularly serious; not knowing where to go to access services; and concerns about cost. Most participants had received information from volunteers and NGOs. The most common risk reduction message absorbed by participants was to use clean needles; this information was obtained from presentations/talks and outreach activities.

DIAGNOSIS

“I HAVE NEVER HAD AN EXAMINATION, BUT I KNOW ABOUT HEPATITIS C. I JUST DON’T KNOW WHAT TO DO NEXT” -FGD PARTICIPANT

Delayed diagnostic processes were identified by many as the highest barrier to access to treatment. The length of time to complete diagnosis, combined with limited understanding of the diagnosis process, represented a major barrier. More precisely, the number of steps along the diagnostic pathway was clearly articulated as a key problem.

For diagnosis, the focus groups highlighted the importance of awareness as a major barrier, as it limited individual initiative to get tested. For example, there was a very clear indication of confusion around basic details of the disease in group 1. Much of the information sought in all the focus groups centered on how to get diagnosed. The diagnosis pathway was confusing for all, even for those who were most familiar with the disease and HCV services. It should be noted that there was also some degree of confusion on the two-test sequence of screening test and viral load confirmation.

Beyond awareness of the disease (i.e. modes of transmission, health risks, new treatment, etc) limited awareness of practical information was also a concern (e.g. the locations of services and/or the exact steps required by local testing guidelines). Suggestions to

improve access to diagnosis recommended greater use of existing voluntary services (i.e. NGO drop-in clinics etc) and increased use of mobile clinics. Other factors which influenced diagnosis included: cost, distance to facilities and ease of access (in terms of travel time, access to transport etc). The combined impact of cost, the time factored for getting to and attending appointments, and the absence of symptoms created a dissuasive combination for many – but not all – patients; some patients across the focus groups very clearly indicated that the number of visits and time for hospital appointments was not a significant barrier, while it was one of the most critical factors for others, especially those who were farther from the capital.

Distance from the hospital was raised as a critical barrier; in one case a travel time to facility of up to 6 hours was cited. Uncertainty of results, lack of understanding of the system and having to go to different locations for different tests led some patients to drop out of the process.

Lack of follow up on tests was highlighted several times in the discussions in the Thai focus groups: in several cases individuals were not given the results of

initial screening tests. Many individuals noted that they themselves had not requested the results of tests either. They expressed some concerns about long term cost if they were to complete diagnosis and start treatment. However, the main reason for their lack of personal

follow-up on their test results appeared to be the lack of confidentiality in busy hospital settings (they did not always see the healthcare workers in private settings) and a sense that the healthcare worker was too busy to provide results and follow-up.

TREATMENT

Few of the participants in the Thai study had experience of treatment for the reasons mentioned above. Those who had already started on treatment, or were better informed generally, had a very different set of questions. Their issues related mainly to the difference between the old and new treatment regimens, side effects of the new medicines, etc. This group also raised issues around readiness to start treatment and how this impacted them. Readiness was defined as both the individual patient's readiness to accept treatment and the doctor's readiness to prescribe.

Stigma was a factor which played into the unwillingness to seek diagnosis and treatment among PWID. The main feedback around this was with respect to the attitude of healthcare workers. Participants indicated a lack of respect from the healthcare workers and that they felt the doctors were concerned about becoming infected themselves. When asked what could be done to incite them to engage more with health services, one message was clear:

“DON'T TREAT US AS SECOND-CLASS CITIZENS. DON'T GIVE US THE LOOK”. -FGD PARTICIPANT

References to healthcare workers during the focus groups were almost unanimously neutral or negative (i.e. a lack of support from healthcare workers). Where healthcare workers were judged to have offered limited support a range of reasons was given: they were too busy, they had limited knowledge (“not enough doctors know about HCV”), they displayed stigma toward drug users.

In very practical terms, participants also suggested reducing the number of steps required to access treatment, reducing the number of trips, and improving the attitude of healthcare workers toward at-risk populations.

Participants in all the Thai focus groups confirmed that drug users are required to stop using for 6 months before being eligible for treatment. This requirement was applied to a wide variety of addictive substances, including drugs, alcohol, cigarettes etc. Similarly, patients were required by some clinics to be screened for HCV as a condition for receiving methadone treatment. These requirements were perceived as problematic by both at-risk populations and by healthcare workers.

COST

Cost was clearly a factor. One participant claimed:

“(OUT-OF-POCKET) WAS A HUGE BARRIER TO RECEIVING TREATMENT....IF EVERYTHING WAS OUT-OF-POCKET, NO ONE WOULD HAVE GONE”. -FGD PARTICIPANT

However, direct out-of-pocket costs were not the only barrier. A related barrier was the lack of information and certainty around costs: what will be the costs for certain steps, as well as what steps will be covered by the health insurance system and what will be out of pocket. Concerns about understanding the total cost were frequently raised in the Thai focus groups.

The opportunity cost of seeking treatment was often raised as well. These indirect “hidden” costs include the cost of transportation, as well as the loss

of income as a result of missed work for a day spent travelling to and attending an appointment. In some cases, these costs were judged to be as important as the direct expenses of the diagnosis or treatment. This was true for all focus groups, irrespective of the level of education or knowledge about the disease. Suggestions for addressing this include greater use of mobile clinics; streamlining the patient pathway; and making diagnosis and treatment more widely available in more clinics (i.e. not just specialized centers or tertiary hospitals).

HEALTHCARE WORKERS' PERSPECTIVES

The survey also included individual interviews with healthcare workers. In Thailand, the team interviewed 8 healthcare workers in total (1 man and 7 women). This was the only country to have a greater representation of female healthcare worker perspectives.

The healthcare workers interviewed in Thailand represented the most diverse group of all 6 sites. There were 2 specialist doctors, 2 generalist doctors, 1 clinical officer and 3 nurses. Most were in their 30s (4 respondents) or 40s (3 respondents), with one in her 50s. Thus, this group represented experienced health professionals with several individuals possessing over 10 years' experience working on hepatitis C; the minimum experience level was 3 years.

All the interviewees in Thailand worked at least part-time in the public sector, though many also worked for private and not-for-profit clinics. Over half worked in secondary-level hospitals or specialized clinics such as PWID drop-in centers or HIV clinics (5/8). One worked at a tertiary-level hospital and 2 worked at a primary-level facility. Two worked in the private sector in a private hospital and a PWID drop-in clinic. Another

two participants complemented their public sector work with outreach through not-for-profit clinics.

The healthcare workers interviewed all worked in urban environments, with an even split of 50% in the capital (Bangkok) and 50% in other major cities.

Similarly to the situation in Malaysia, the number of cases seen by different providers in Thailand varied significantly, from 3-5 cases per week up to around 20 cases. We therefore examined the number of cases with respect to professional background and came to a similar conclusion as in Malaysia: the cases cluster into two major groups, with generalists such as General Practitioner doctors and nurses seeing few patients, while specialist doctors and specialized nurses seeing significantly more cases per week. While expected, the clustering of cases for specialists raises the question as to whether there are bottlenecks in the early awareness raising and information components, and whether generalist healthcare providers could contribute their skills to help increase access to information.

Interviewees worked in facilities providing a wide range of services on hepatitis C: this finding correlates with the fact that around half of those interviewed work in specialist clinics of some kind which deal specifically with hepatitis C. Of greater interest is the fact that interviewees generally identified as providing a wide range of services themselves, including most stages of testing.

AWARENESS

The healthcare workers interviewed in Thailand turned almost exclusively to government sources for their own education on hepatitis C. Around half of those interviewed also identified training sessions and workshops as being important. Other sources — such as journals, WHO publications, colleagues, the general media—were not identified as particularly relevant sources of education and information for these healthcare workers.

Three quarters of healthcare workers in the Thai survey indicated that they carry out awareness activities; of these about half indicated that they serve as guest lecturers while about 25% mentioned direct outreach to at-risk populations.

In terms of awareness challenges, healthcare workers identified low levels of knowledge of the disease

and risk factors among the general public as being a barrier. Lack of engagement from healthcare workers themselves was also seen as a challenge. This therefore becomes a circular problem: lack of awareness and lack of engagement result in lack of engagement and lack of awareness. Proposed solutions for increasing awareness included increasing training among healthcare workers, and the organization of out-reach activities with at-risk populations. Only one of the healthcare workers suggested increasing collaboration with NGOs / CSOs.

Most of the interviewees claimed that their facilities provide some kind of risk reduction services, but it did not appear from the feedback from focus groups that healthcare workers capitalize on these interaction points to transmit education about HCV. That the provision of harm reduction services is limited (at

facilities of interviewees) was reinforced by the fact that healthcare workers indicated that they have very few contact points with at-risk populations, which they highlighted as a restriction on their ability to carry out awareness raising or educational activities.

Healthcare workers also noted the importance of good communication and avoiding stigmatization of at-risk populations. Further training for healthcare workers may therefore be beneficial.

DIAGNOSIS

Most of the interviewees claimed that their facilities offer all stages of diagnosis. The initial screening stage could be carried out by specialist or generalist doctors and by nurses. Fibrosis testing had to be carried out by a specialist in half of the facilities, while genotyping was normally carried out by a specialist; in only 25% of facilities a general doctor could offer genotyping.

The population seen for HCV diagnosis was very much dominated by PLHA and PWID (current and former). In half of the facilities, the population seen included MSM while only one in the eight identified the general population as being seen regularly for HCV. Hemodialysis patients and healthcare workers only registered as being seen for HCV in 25% of the facilities while none of the facilities indicated that they saw migrants for hepatitis C.

Responses to the question about who are high risk populations who should be screened for HCV followed a very similar pattern to those who are currently screened with one major difference: none of the healthcare workers identified MSM as a key population, but 90% identified migrants as a key population (migrants did not appear at all on the list of those being screened or treated). When asked who else should be offered the test, in addition to the standard high-risk categories suggested, 25% of respondents replied that the test should be offered to everyone (60% of respondents did not answer this question).

Two thirds of the interviewees worked at facilities with a policy on which patients to screen for HCV: yet few of the healthcare workers could articulate

the policy; those who could identified HIV patients as priority populations for screening. Healthcare workers from those facilities with policies felt that the facility did indeed follow its policy. In sum, these responses indicate that too few facilities are aware of the existence of diagnosis and treatment guidelines they should be applying.

Two-thirds of the healthcare workers interviewed carried out some stage of the diagnosis process; all of them could name the different stages of the diagnosis pathway correctly. Only one of the eight respondents indicated that the initial screening results are provided within 30 minutes; the rest indicated that tests were generally available between 2 hours to the following day. In all other stages, respondents indicated that the tests would take longer than 24 hours without giving a specific timeline. There was no consensus as to the reasons why it took so long to get test results. Reasons provided included limited staff numbers; delays at testing centers; delays due to waiting for enough samples to run test; lack of system for rapid follow up to return test results. In addition to delays in the determination of results, an important follow up question concerns how results are communicated. For example, participants in the FGDs suggested that many facilities do not actively contact patients to inform them of the results.

There was little consensus around the funding sources for HCV services: around 50% of healthcare workers interviewed thought that the initial screening and viral load tests are free for high-risk individuals. For the rest, it was assumed that patients pay out-of-pocket.

TREATMENT

The profile of people seen for treatment and test of cure aligned extremely closely with the profiles seen for diagnosis: 75% of healthcare workers mentioned people living with HIV, 50% indicated PWID (current or former), while only 25% mentioned MSM and general population.

When asked what the main challenges are in ensuring access to treatment for HCV, 50% of the healthcare workers identified the criteria for treatment as the major challenge (i.e. the requirement to be clean from drug and substance abuse for 6 months before treatment is offered).

COMPARING PERSPECTIVES



Both groups – at risk populations and healthcare workers – expressed concern about the low level of awareness and information about HCV at every level: at-risk populations, general public and healthcare workers.

Based on interviews with healthcare workers who did possess high levels of awareness, feedback suggested that they did not have frequent opportunities for communication with at-risk populations. It would appear that even where those opportunities do exist, e.g. at harm reduction sites, opportunities to raise awareness on HCV are not being maximized.

Through discussion with dozens of individuals from at-risk populations, there was strong feedback suggesting that most healthcare workers do not provide any HCV education.

The healthcare workers indicated that people typically come back if they are already in treatment, but frequently drop out during the diagnosis pathway. This does not appear to be borne out by the statements made in the focus groups. Healthcare workers also indicated that if patients do not attend scheduled appointments, the facility will follow up, often through the intermediary of an NGO. This suggests that there is some contact between the facility and relevant NGOs which could further be developed.

At-risk populations identified a number of very clear and specific concerns and barriers which prevent them from continuing along the patient pathway. Among these were issues of getting appointments, as well as the indirect costs such lost wages (as appointments often consume several hours) and travel costs to a hospital. While healthcare workers also identified the lack of resources as a barrier, they did not position this in the context of patients' needs. Although the drivers were different, both groups identified the need to expand or clarify the policy on who can diagnose and treat HCV in order bring services closer to populations. This is an idea which could be further explored by a cross-sectional group.

Similarly, many of the issues most frequently articulated by study participants were not recognized as major concerns by HCWs. This dissonance extended to issues such as: fear of stigmatization; absence of systems for referrals from one facility / service to another; failure to refer from one stage to the next; results taking long to process, and people not receiving their results.

Poor communication and dynamics between the two groups were raised as a major challenge by both parties; this is clearly problematic and is limiting the ability to scale up services for HCV.

STUDY LIMITATIONS

As an exploratory design, the site samples sizes were small and we advise readers to consider this when interpreting results. The number of participants does not allow statistical extrapolation to national level findings. However, the study results provide relevant exploratory findings for further discussion and further evaluation of the HCV response. Feedback from lead and local investigators will be synthesized at the end of the study and integrated into future iterations of the methodology.

REFERENCES

- 1 WHO. Available from: <http://www.who.int/news-room/fact-sheets/detail/hepatitis-c> (June 2018)
- 2 The global burden of viral hepatitis from 1990 to 2013: findings from the Global Burden of Disease Study Stanaway, JD, Flaxman, AD, Naghavi, M et al. *Lancet*. 2016; (published online July 6.) DOI: [https://doi.org/10.1016/S0140-6736\(16\)30579-7](https://doi.org/10.1016/S0140-6736(16)30579-7)
- 3 Global Hepatitis Report 2017. Geneva: World Health Organization; 2017.
- 4 Polaris Observatory. Center for Disease Analysis. Available from www.polarisobservatory.org (Accessed 2017).
- 5 Platt L, Easterbrook P, Gower E, McDonald B, Sabin K, McGowan C et al. Prevalence and burden of HCV coinfection in people living with HIV: a global systematic review and meta-analysis. *Lancet Infect Dis*. 2016;16 (7):789–808. DOI: [https://doi.org/10.1016/S1473-3099\(15\)00485-5](https://doi.org/10.1016/S1473-3099(15)00485-5)
- 6 Global Health Sector Strategy on viral hepatitis, 2016–2021. Geneva: World Health Organization; 2016 [WHO/HIV/2016.06]
- 7 Progress report on access to hepatitis C treatment: focus on overcoming barriers in low- and middle-income countries, March 2018. Geneva, Switzerland: World Health Organization; 2018 (WHO/CDS/HIV/18.4).
- 8 WHO Global Hepatitis Report 2017.
- 9 WHO Progress report. March 2018.
- 10 World Hepatitis Alliance Press Release. Available from: <http://www.worldhepatitisalliance.org/news/nov-2017/nine-countries-now-track-eliminate-hepatitis-c> (checked August 2, 2018)
- 11 The World Bank. Available from: <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD> (Accessed August 8, 2018)
- 12 Polaris Observatory. Center for Disease Analysis. Website: <http://polarisobservatory.org/polaris/dash.html> (Accessed 2017)
- 13 World Health Organization, Regional Office for South-East Asia. Report on People who inject drugs in the South-East Asia Region. 2010. Available from :: http://www.who.int/hiv/pub/idu/people_who_inject_drugs_searo_010.pdf
- 14 Press Information Bureau, Ministry of Statistics and Programme Implementation, Government of India. Data for 2014-2015 incomes.
- 15 Devi KS, Singh NB, Mara J, Singh TB, Singh YM. Seroprevalence of hepatitis B virus and hepatitis C virus among hepatic disorders and injecting drug users in manipur - A preliminary report. *Indian J Med Microbiol* 2004;22:136-7
- 16 PKNI website. Available from: <http://korbannapza.org/en/aboutus>. Accessed April 18, 2018.
- 17 The World Bank. Available from: <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD> (Accessed August 8, 2018)
- 18 Indonesian Association for the Study of the Liver. Konsensus Nasional. Penatalaksanaan Hepatitis C di Indonesia. 2017.
- 19 Polaris Observatory, Center for Disease Analysis. Accessed in 2017.
- 20 The World Bank. Available from: <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD> (Accessed August 8, 2018)
- 21 Center for Disease Analysis. Figure cited by Ministry of Health documents as well.
- 22 Raihan, Ruksana. Hepatitis in Malaysia: Past, Present, and Future. *Journal of Euroasian Hepatogastroenterology*. Jan-July 2016. doi: 10.5005/jp-journals-10018-1167
- 23 Fong, Loh Foon. Hope for Hepatitis C Patients. *The Star Online*. Available from: <https://www.thestar.com.my/news/nation/2018/03/02/hope-for-hepatitis-c-patients-18-state-hospitals-offering-treatment-through-affordable-medicine/> (Accessed August 3, 2018) World Bank. Available from: <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD> (Accessed August 6, 2018)
- 24 World Bank. Available from: <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD> (Accessed August 6, 2018)
- 25 Baha, Warda et al. "Prevalence and Risk Factors of Hepatitis B and C Virus Infections Among the General Population and Blood Donors in Morocco." *BMC Public Health* 13.1 (2013) doi: <https://doi.org/10.1186/1471-2458-13-50>
- 26 Polaris Observatory. Center for Disease Analysis. Available from: <http://cdafound.org/polaris/> (Accessed 2017)
- 27 World Bank. Available from: <https://data.worldbank.org/indicator/NY.GDP.PCAP.CD> (Accessed August 8, 2018)
- 28 Polaris Observatory. Center for Disease Analysis. Available from: www.polarisobservatory.org (Accessed 2017).

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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.

ANNEX: Survey Tools



An annex of protocol documents will be made available online on the Coalition PLUS webpage (www.coalitionplus.org/mindthegap). A copy of this report will also be available at the same address.

- Survey protocol (in English)
- Focus Group discussion guide (in English)
- Focus Group invitation letter to participants (in English)
- Focus Group consent form (in English)
- Healthcare worker questionnaire (in English)
- Healthcare worker consent form (in English)

Additional materials can be requested by email to:

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