**JUNE 2022** 

ANALYSIS OF COMMUNITY TREATMENT **OBSERVATORY** DATA FOR HIV AND **HEPATITIS C VIRUS** SERVICES IN INDIA AND **INDONESIA** 

TREATASIA \_\_\_\_\_amfAR We sincerely acknowledge and appreciate the time and effort of care recipients, service providers, HIV and hepatitis C treatment centers, and community networks in the data collection and advocacy processes shared in this report. Without their assistance, this work would not have been possible.







Photography courtesy of Community Network for Empowerment (CoNE) and Yayasan Peduli Hati Bangsa

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# **ACRONYMS**

ARTC	Antiretroviral Treatment Center
CBC	Complete Blood Count
CHC	Community Health Center
CLM	Community-Led Monitoring
CTO	Community Treatment Observatory
FBO	Faith-Based Organization
HCV	Hepatitis C Virus
ICTC	Integrated Counseling and Testing Center
JNIMS	[India] Jawaharlal Nehru Institute of Medical Sciences
KFT	Kidney Function Test
LAC	[India] Link ART Center
LFT	Liver Function Test
MSACS	[India] Manipur State AIDS Control Society
MSM	Men who have Sex with Men
MTC	[India] Model Treatment Center
NACO	[India] National AIDS Control Organization
NGO	Non-Governmental Organization
NHI	National Health Insurance
NVHCP	National Viral Hepatitis Control Program
OPD	Outpatient Department
PHC	Primary Health Center
PWID	People Who Inject Drugs
RIMS	[India] Regional Institute of Medical Sciences
SACEP	[India] State AIDS Clinical Expert Panel
SNO	[India] State Nodal Officer
SVR	Sustained Virologic Response
SW	Sex Worker
TC	Treatment Center
TG	Transgender
TLD	Tenofovir, Lamivudine and Dolutegravir
TND	Target Not Detected

- VL Viral Load
- VLT Viral Load Testing



# BACKGROUND

amfAR's TREAT Asia program worked with partners to initiate two Community Treatment Observatories (CTOs) in two sites in India and Indonesia. The two national partners are the Community Network for Empowerment (CoNE) in India and Peduli Hati in Indonesia. The project has been implemented with the International Treatment Preparedness Coalition (ITPC) as a technical partner, which assisted in training the national partners in India and Indonesia and TREAT Asia staff, and currently hosts the CTO databases of the two sites on its online portal.

In collaboration with TREAT Asia, ITPC organized and led trainings on the CTO model, including indicator development, CTO/ Community-Led Monitoring (CLM) principles and the CLM cycle from data collection to advocacy. Country-specific quantitative and qualitative indicators on HIV and hepatitis C virus (HCV) services were developed for the CTOs of CoNE and Peduli Hati.

Each organization carried out data collection from February/March to December 2021 for their selected health facility sites and entered the data into the databases hosted by ITPC. This report presents the findings and analyses of the data to help guide the ongoing implementation of the CTOs and to inform advocacy for HIV and HCV service improvements for people living with HIV (PLHIV) and people who inject drugs (PWID).

Project implementation and data collection were conducted during the COVID-19 pandemic. The consequent restrictions on clinical care and transportation proved difficult both for service providers and recipients, and impacted the quality and continuity of services. The CTO staff and service providers put in extra efforts to ensure continuity of CTO data collection and service provision. The program partners are grateful for the time and effort provided to the CTOs by all health care providers, data collection sites, key population representatives and government departments.

# **CTO Program**

Community Treatment Observatories in Manipur state in India and in Indonesia were aimed at documenting the availability, continuity, and quality of local HIV and HCV services. CLM data collection was guided by a set of country- and disease-specific quantitative and qualitative indicators. For India, a total of six sites were selected for quantitative and qualitative data collection for both HIV and HCV (see Table 1). For Indonesia, quantitative data for HIV and HCV were collected from two Ministry of Health (MOH) websites, and from interviews and focus group discussions (FGDs) for qualitative data (see Table 1). The primary target populations for qualitative data collection for both countries were health service providers, PLHIV and PWID. In Indonesia, services for children living with HIV were also explored (see Table 2).

The implementation of the proposed CTOs followed the ITPC model, which includes four components: 1) *Education* enabling communities to identify barriers to accessing and shortfalls in the quality of HIV and HCV services; 2) *Evidence* of the identified issues provided through the collection and validation of relevant community-level data; 3) *Engagement* with partners representing a variety of stakeholders; and 4) *Advocacy* to encourage all engaged partners to work together to address the identified gaps in HIV services.

Each CTO was supported by a data supervisor and two data collectors who each had direct experience working with local communities, including key populations (i.e., PLHIV and PWID) who are at highest risk for HIV and HCV. The data collected focused on the state of HIV and HCV programs, treatment procurement systems, drug stocks, and diagnostics facilities that test for viral load and for common co- and opportunistic infections.

## Table 1. Selected monitoring sites and data sources for data collection for HIV and HCV

MANIPUR STATE, INDIA	
MONITORING SITES FOR QUANTITATIVE & QUALITATIVE DATA	FACILITY LOCATION
Jawaharlal Nehru Institute of Medical Sciences and Hospital HIV – ART Center, HCV – Model Treatment Center	Imphal East District
Regional Institute of Medical Sciences and Hospital HIV – ART Center	Imphal West District
Chandel District Hospital HIV – ART Center, HCV – Treatment Center	Chandel District
Ukhrul District Hospital HIV – ART Center	Ukhrul District
Community Health Center Link ART Center	Saikul, Kangpokpi District
NGO implementing the Targeted Intervention project	State-wide
INDONESIA	
MONITORING SITES / DATA SOURCES	TYPE OF DATA
Ministry of Health Hepatitis Information System, official website	Quantitative HCV
Ministry of Health HIV Sub-Directorate website	Quantitative HIV
Ministry of Health Hepatitis Sub-Directorate staff	Qualitative HCV
Lentera Anak Pelangi - NGO representing children living w/HIV in Jakarta who were accessing ART and HIV viral load testing from the following hospitals: - Koja Hospital - Sulianti Saroso Infectious Diseases Hospital - Tarakan Hospital - Cipto Mangunkusumo Hospital - Puskesmas (Community Health Center) - Cengkareng Hospital	Qualitative HIV

- Dharmais Hospital

Focus group discussion participants accessing HIV and HCV services from the following health facilities

City/Province	Facility	Services discussed
West Kalimantan	Dr. Soedarso Hospital	HIV and HCV antibody tests, HIV and HCV viral load tests, ART, direct-acting antivirals (DAAs)
Bogor, West Java	Bogor Regional Hospital	HIV and HCV antibody tests, HIV and HCV viral load tests, ART, DAAs
Jakarta	Pengayoman Hospital	HIV and HCV antibody tests, HIV and HCV viral load tests, ART, DAAs
	Fatmawati Hospital	HIV and HCV antibody tests, HIV and HCV viral load tests, ART, DAAs
Bekasi, West Java	Bekasi Regional Hospital	HIV antibody tests, HIV viral load tests, ART
North Sulawesi	Kandou Hospital	HIV and HCV antibody tests, HIV and HCV viral load tests, ART, DAAs
	Bhayangkara Hospital	Buprenorphine
	5 Puskesmas (Community Health Center): Tikala Baru, Bahu, Teling Atas, Sario, and Tuminting	HCV antibody tests (note: HIV services can be accessed in all Puskesmas)
North Sumatra	Bhayangkara Hospital	HCV antibody tests, DAAs
	Adam Malik Hospital	HIV and HCV antibody tests, HIV and HCV viral load tests, ART, DAAs
	Pringadi Hospital	HCV antibody tests, DAAs
West Nusa Tenggara	West Nusa Tenggara Provincial Hospital	HIV and HCV antibody tests, HIV and HCV viral load tests, ART, DAAs
Aceh	Dr. Zainoel Abidin Hospital	HIV and HCV antibody tests, HIV and HCV viral load tests, ART, DAAs

Table 2. List of interviews and focus group discussions (FGDs) by country, viral infection and type of interviewee

Type of interviewee	India HIV	India HCV	Indonesia HIV	Indonesia HCV
Health Service Provider	3 interviews	2 interviews	1 interview (services for children)	1 interview (MOH Hepatitis Sub-Directorate staff) 1 FGD
PLHIV	12 interviews 4 FGDs	1 interview		2 FGDs
PWID	4 interviews	14 interviews 5 FGDs		

# DATA ANALYSIS METHODOLOGY

Analysis of data as presented in this report was carried out by an external consultant under the guidance of TREAT Asia. The consultant conducted a desk review of country indicator frameworks and data collection tools. The consultant also reviewed and analyzed country indicator data for the period of 1 March 2021 through 31 December 2021 for India and 1 February 2021 through 31 December 2021 for Indonesia, which country CTO implementers had uploaded to a virtual project database.

Data on the virtual database were in the form of Excel-based indicator tracking sheets for the quantitative data for both countries. For qualitative data, each country uploaded a master Excel-based tracking sheet with details on date and time, facility code, type of qualitative data collection method (interview or FGD), infection (HIV or HCV) and type of interviewee (health service provider [HSP], PLHIV, PWID) and reporting period. Qualitative data included scanned copies of completed paper questionnaires, typed transcripts and audio recordings of interviews and FGDs. Findings under the sections on qualitative data for HIV and HCV capture main (frequent) responses that were raised by each type of interviewee and by participants in FGDs. Responses were not extensively edited in order to retain the voice of the respondent. Where relevant, these responses were further organized by the Availability-Accessibility-Acceptability-Quality (AAAQ) framework areas.



# **SUMMARY OF MAIN FINDINGS**

Tables 3 and 4 below summarize the main findings from reported country data for HIV and HCV. Findings are organized by the AAAQ framework<sup>1</sup> for assessing health services. It should be noted that the indicators and associated data collection tools were not the same across the two countries; rather, they were CTO-specific. Therefore, there are variations in the data presented.

## Table 3. Main findings from India CTO data

AAAQ category	HIV	нси
Availability	Insufficient number doctors or staff to provide services, including for regular health check-ups	Not all services are available due to broken down machines, staff shortage
	Not all services are available due to broken down machines	
Accessibility	Financial barriers due to services not consistently available for free at the government facilities and so people have pay for the services out of pocket at private facilities; additional out of pocket costs to travel a long way to reach facilities	Financial barriers due to services not consistently available for free at the government facilities and so people have pay for the services out of pocket at private facilities; additional out of pocket costs to travel a long way to reach facilities
	Physical barriers due to ART centers not being a close distance for some people to access conveniently	Physical barriers due to services not being a close distance for some people to access conveniently
	Administrative barriers such as the requirement to obtain an outpatient department (OPD) ticket in order to access services resulting in long queues and waiting times; working hours not long enough to accommodate all the patients; some lack a government ID card which is required for ART initiation	Administrative barriers such as the requirement to obtain an OPD ticket in order to access services resulting in long queues and waiting times; working hours not long enough to accommodate all the patients; some lack a government ID card which is required to access services at the government facilities
Acceptability	Health facility staff not always community-friendly – instances of PLHIV being teased, humiliated and scolded for missing appointments	Health facility staff not always community-friendly – instances of PWID not feeling comfortable with treatment by staff because of possible stigma and discrimination for being a person who uses/used drugs, missing appointments (drug use habits as a main reason for this)
Quality	Weak referral system between Integrated Counselling and Testing Center (ICTC) and ART center	It takes one week to over a month to receive a HCV confirmatory viral load test result
	Poor quality of counselling in some health facilities	
	Health facility infrastructure is inadequate due to lack of drinking water, proper waiting rooms, seating arrangement and toilet facilities	
	Staff not always on time or punctual which creates overcrowding and unnecessary waiting	

<sup>1</sup> World Health Organization Availability, accessibility, acceptability and quality infographic can be accessed here: https://www.who.int/gender-equityrights/knowledge/aaaq-infographic/en/. For **India** for HCV, in addition to the AAAQ issues listed in Table 3, the following issues facing PWID also created barriers to their accessing HCV services:

- Low HCV literacy among PWID related to different steps from screening to treatment to sustained virologic response (SVR; marker of cure and treatment success)
- o Drug use habits can lead to relapses for those on treatment and prevent PWID from testing and initiating treatment
- Misinformation among PWID regarding taking HCV treatment and using drugs at the same time, including around whether it is required to stay at a drug rehabilitation center while on HCV treatment

For **Indonesia**, out of 12 HIV quantitative indicators monitored by the CTO, data for only seven indicators were available. Quantitative data of the indicators related to access to HIV viral load testing, monitoring and dolutegravir use (DTG) were unavailable.

AAAQ category	HIV	нси
Availability	Not all Community Health Centers have HIV testing linked to HIV treatment services	The 2020-2024 Hepatitis National Plan has been disseminated to all 34 provinces, but only implemented (i.e. services available) in 18 priority provinces – the government plans to add four more provinces for a total of 22 in 2022
		HCV antibody screening is available in community health centers and hospitals, but confirmatory viral load testing is only available at facilities in the 18 provinces
		Services are sometimes not available due to HCV testing machines being used for COVID-19-related testing
Accessibility	No major issues were raised related to HIV testing, as respondents shared that the testing procedure is simple HIV testing is offered for free at the community health	Barriers related to accessibility include: 1) limited operating days; 2) not all HCV services are covered by the National Health Insurance program, resulting in the need to pay for some services out of pocket which creates
	center Access to multi-month supply of antiretrovirals (ARVs) varies across provinces	a financial barrier; for those without insurance, the out of pocket costs are higher and differ based on location and type of service needed
	Viral load testing is not available to all due to differing guidelines where if you have National Health Insurance some locations cover it and others do not	
	Viral load testing for children is not covered by the National Health Insurance program and the price varies by location	
Acceptability	None noted	None noted
Quality	HIV test results are received within a day Regarding HIV treatment, the combination of tenofovir- lamivudine-DTG (TLD) is offered to those who are newly initiating ART or suffering side effects from a different regimen	Stock-outs in recent years created treatment interruptions, but also created reluctance by those on treatment because a viral load test is required for re- treatment and some did not want to pay the cost if not covered by National Health Insurance or they did not have insurance
	Quality of services is compromised due to the additional responsibilities placed on health facility staff to carry out Covid vaccination and Covid testing	
	For children living with HIV, national guidelines have not been updated since 2014; information on pediatric drug formulations and dosages are only available via webinars and not from a national guideline	
	Pediatric formulations are unavailable, resulting in having to use crushed tablets and smaller doses of adult formulations; application in the field varies by doctor	

# **DETAILED FINDINGS**

The following data are presented by country and by infection/virus. For India, the data cover the period of March through December 2021 for Manipur state. For HIV, issues monitored included access to HIV treatment, baseline tests (complete blood count, kidney and liver function tests) and viral load testing. For HCV, issues monitored focused on access to HCV antibody testing, treatment and HCV confirmatory RNA viral load testing. For Indonesia, the data are from February through December 2021. For HIV, issues monitored were access to HIV testing, treatment and routine viral load testing. For HCV, issues monitored included status of national viral hepatitis plan, access to HCV antibody testing, HCV confirmatory RNA viral load testing, treatment and HCV drug stock-outs.

Quantitative data are presented per indicator. Qualitative data are summarized per type of interviewee (HSP, PLHIV, PWID, NGO) and per FGD. Where possible, issues raised are further categorized by the AAAQ framework for assessing health services.



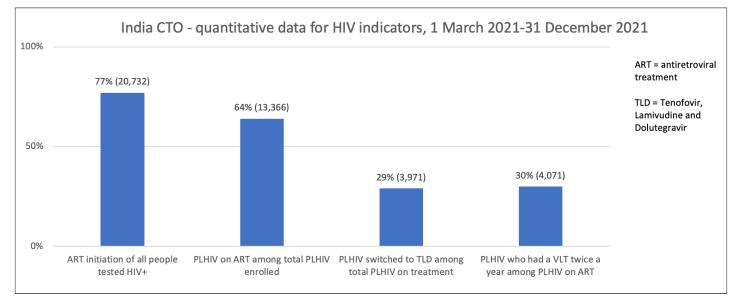
# INDIA

#### **HIV QUANTITATIVE RESULTS**

Summary points:

- The quantitative data for HIV for the period March-December 2021 are reported as total figures. The Manipur State AIDS Control Society (MSACS) could not provide monthly or quarterly data by indicator to be able to assess for changes. The MSACS informed CoNE that data are updated annually.
- The percentage of ART initiation of all the people who tested HIV-positive was 77% (equivalent to the number of PLHIV on treatment of 20,732 divided by the total number of PLHIV of 26,795).
- The percentage of PLHIV on ART out of the total PLHIV enrolled in ARTC was 64% (13,366 / 20,732).
- The percentage of PLHIV switched to an appropriate regimen (i.e., TLD) out of the total PLHIV on treatment was 29% (3,971 / 13,366).
- The percentage of PLHIV who had an HIV viral load test twice a year among PLHIV on ART was 30% (4,071 / 13,366).
- Data were not available for specific key populations.
- No stock-outs of medicines and diagnostics were reported.

## Figure 1. India CTO – quantitative data for HIV indicators for the period of March 2021 thru December 2021



## Table 5. Quantitative data on access to HIV services

			Access to	o HIV trea	tmen	t	
Indicators	ators Target Population*						
	TOTAL		Total Male	Total Fen	nale	Transgender	COMMENTS FROM DATA COLLECTION
1. Number of PLHIV in the state	26,795		14,994	11,662		139	
2. Number of PLHIV who are on treatment	20,732		11,462	9,146		124	
3. Number of PLHIV known to be continuing treatment 12 months after initiation	13,366		6,495	6,786		85	
4. Number of people tested positive at Integrated Counselling and Testing Centers	1,756		999	634		NA	
5. Number of people referred to ART center for treatment initiation or pre-ART registration	1,809		NA	NA		NA	There is lack of coordination between the counselling and testing centers and the ART centers with regards to referral of people testing HIV-positive and needing treatment. As a result, accurate data of the people tested HIV-positive at the testing centers and referred for treatment initiation are not available.
6. Number of people on TLD	3,971		NA	NA		NA	
			Access t	o baseline	e tests	;	
		Total	sites in the state	9	CON	MENTS FROM	DATA COLLECTION
7. Number of health sites providing baseline investigation needed for treatment initiation		Not a	vailable		All three baseline tests (complete blood count, kidney and liver function tests) are available at the government health sites when an ART center is attached except in some health sites (e.g., community and primary health centers). However, PLHIV canno always access them due to limitations in working hours, lengthy visit process, overcrowding and transportation requirements. The three tests are available at private labs at a total cost of ~\$30. The tests are more easily accessible at the private lab, bu patients have to pay out of pocket; no provision is available for reimbursement from the government.		vailable at the government health sites where ched except in some health sites (e.g., nary health centers). However, PLHIV cannot due to limitations in working hours, lengthy owding and transportation requirements. vailable at private labs at a total cost of more easily accessible at the private lab, but out of pocket; no provision is available for
			Access to	viral load	testir	ıg	
Indicators						Target Popul	ation*
		ΤΟΤΑ	L		CON	MENTS FROM	DATA COLLECTION
8. Number of PLHIV on ART who received a 4,07 viral load test twice a year		4,071	They do not maint		do not maintai	cted by manually sitting with MSACS officials. n updated data in their computerised formation system.	
9. Number of PLHIV on ART who did not receive viral load test		1,949					
10.Number of PLHIV who had viral load testing per NACO guidelines		11,417		This number includes the total number in Indicator no. 8.			

 $^{\ast}\mbox{Data}$  not available for individual key populations or disaggregated by sex.

Type of Interviewee	Barriers to accessing HIV treatment	Barriers to accessing baseline tests (complete blood count, kidney and liver function tests)	Barriers to accessing viral load testing
Health service provider	Low numbers in pre-ART registration and ART registration compared to the total number of PLHIV in the state due to: 1) many people are going to the private lab for HIV testing (Availability) 2) fear of social stigma and self-stigmatization of PLHIV (Acceptability) 3) lengthy process to enrol (administrative Accessibility) 4) privacy issues because Aadhar card (govt ID card) required for ART initiation or people without Aadhar card - contradicts Supreme Court verdict that an Aadhar card not needed for free ART (Acceptability, Accessibility) 5) weak referral mechanism between the counselling and testing centers and the ART centers (Quality) 6) negative attitudes of health staff discouraging PLHIV from coming (Acceptability) 7) possible technical errors or double counting in that some PLHIV enrolled but dropped out of treatment, then repeat their HIV test in different counselling and testing centers to facilitate re-linkage to treatment (and then counted again) (Quality) 8) unavailability of medicines for opportunistic infections particularly for cryptococcal meningitis, as the cost is no longer supported by MSACS (Accessibility)	Availability: Some tests not available or machines not functioning so people go to private diagnostic centers Financial Accessibility or Affordability: Some cannot afford the test at private centers (USD 30 for all three tests) Quality: Some get tested, but then do not return to pick up their medicines/treatment because the testing canters do not provide the test report ** ART Center at Jawaharlal Nehru Institute of Medical Sciences (JNIMS) has started providing ART after completion of a physical examination without requiring CD4 count tests and other baseline investigations, though PLHIV are asked to come back to the ART center with the testing documentation within 15 days from the date of initiation	Quality: Doing a better job of following the NACO viral load testing guidelines (i.e., doing viral load testing as part of routine monitoring rather than just for the purpose of screening for failure before switching to DTG; blood sample collection daily vs weekly; partnership with Regional Institute of Medical Sciences (RIMS) when their laboratory is overloaded with blood samples) Financial Accessibility: Some prefer to pay out of pocket to go to the private clinic for viral load testing to avoid busy clinics Quality: Most patients at ART centers are on DTG, however, some are still on different regimens (e.g., that include efavirenz or nevirapine) due to clinics wanting to use up existing drug stocks, based on NACO's instructions. After stock is finished, they will be switched to DTG.
People living with HIV and people who inject drugs	Health facility infrastructure: -PLHIV experience challenges when going to the ART center to collect ARVs, due to lack of drinking water, washroom/toilet facilities, proper waiting room (exacerbated by large numbers of clients who have to stand, or end up waiting some distance away from the ART Center) -Takes almost a full day to collect monthly doses; long queues Availability: -Access to proper health check-ups by the doctor at the ART center is challenging - consultations with the doctor are difficult due to overcrowding of patients; sometimes contact private doctors for consultation -Ratio of counselling staff to clients is inadequate Accessibility (administrative): -Working hours of the ART center is a problem with closing time being fixed, whereas the opening hours are not consistent/haphazard -PLHIV are inconvenienced while trying to get their ARVs after travelling long distances due to fixed closing timing (limited working hour) of the ART center	Availability: -Baseline clinical tests not available at the government hospital so went to the private lab and paid out of pocket -Routine investigation is supposed to be provided free of cost by the hospital, but most of the time clinical test was done at private diagnostic center either at own cost or supported by the NGO due to frequent machine breakdown -Process is very lengthy and time consuming since the counter also serves general patients and sometimes staff are discriminatory towards PLHIV	Availability: -Asked to come for viral load testing after given an appointment but staff in the laboratory refused to collect the blood sample giving the reason that there were no more slots for the day (16 had been completed already), so told to come on the next blood collection day Accessibility (administrative): -A viral load test is only offered on Wednesday, which is inconvenient

# Table 6: Summary responses from interviews with HSP, PLHIV and PWID on barriers to accessing HIV services

Type of Interviewee	Barriers to accessing HIV treatment	Barriers to accessing baseline tests (complete blood count, kidney and liver function tests)	Barriers to accessing viral load testing
	Accessibility (financial, physical): Travel allowance of Rs.150 which was previously given to PLHIV has stopped for many years; was helpful for PLHIV coming from long distances; told to give a photocopy of government ID card and bank account number for transferring the travel allowance but it never worked Acceptability: -Reluctant to visit ART center because humiliated by health facility staff due to frequent interruptions in treatment due to drug habits -Teased and scolded by ART center staff when appointments missed -Attitude of ART center staff not community-friendly- give more support to patients they know; some staff are very friendly and some were very rude Quality (ART center): -Was not given treatment until CD4 count was 260 despite being diagnosed HIV-positive for several years - Was advised to start ART without doing a CD4 count test by a PLHIV-friendly doctor - Several years after stating ART, transferred from a clinic to a hospital to access free service under the national program, but tenofovir (TDF) was not available there so referred elsewhere; the medical officer advised to switch from efavirenz to DTG, but the patient requested to transfer back to the other hospital due to unfriendly attitudes of the staff - One time, only received sufficient supply of second- line ART for 5-7 days due to shortage of medicine stocks, so had to visit the ART center numerous times from a long distance - Staff are not punctual so have to wait a long time at the ART center - Was told to take a TB test before ART initiation but blood sample misplaced so did not receive test result - While going to collect monthly ART doses was given Isoniazid 300mg without any proper counselling on why it was given and how it might interact with ART; experienced side effects Quality (NGO Targeted Intervention program): -NGO accompanied PLHIV to the ART center to support ART initiation and follow-up visits; provided vitamins -NGO program helped re-start ART after starting at another hospi	Accessibility (administrative): -Difficult to keep the date and time of appointments for routine investigation especially for people from far-off places – if an appointment is missed, need to reschedule -For routine investigation, need outpatient department ticket and wait a long time in a crowded queue and then the laboratory is closed when it is the PLHIV's turn -Very poor experience at one hospital to get routine investigations done as the procedure was very lengthy and time consuming, standing in a long queue to get a ticket without which the clinical tests cannot be done (sometimes arriving at 7:30 am and counter doesn't open until 9:30am); after getting the ticket, need to go to the ART center to get a requisition form for the clinical investigations, and then have to rush to get the blood drawn before they stop taking samples due to large volumes of patients - once was denied at the laboratory and had to repeat the process all over again; after all that was given a supply of ARVs for 15 days, on three different instances, for not bringing my clinical investigations report	Quality: -Did a viral load test three times, the first two were part of routine monitoring (the first was not done for some reason by the laboratory, and a second sample had to be obtained); was advised that the third time would help decide whether or not to switch the ART regimen to DTG, however there was an error in the report so was asked to test a fourth time in May 2021, but due to the COVID-19 pandemic, the test was not done; remains on the same regimen -Supported by the NGO to do viral load testing which resulted in the switch to TLD -Staff advised to repeat the viral load test to see if suitable to switch to DTG, but since then no one has followed up to remind to come for the test (could be because of the COVID-19 situation) nor has the interviewee followed up to make an appointment

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# Table 7: Summary findings from FGDs with PLHIV on barriers to accessing HIV services

Type of Interviewee / Site	SUMMARY FINDINGS
People living with HIV FGD 1 Sites: ART Center JNIMS and ART Center RIMS	<ul> <li>Under the national ART program, ART Center at RIMS is better than ART Center at JNIMS in terms of accessing routine investigation or viral load testing</li> <li>Negligence and lack of concern from the government to ensure consistently functioning testing machines for clinical investigations and appropriate infrastructure at the ART Center (i.e. waiting room, seating arrangement, toilet facilities, proper drinking water facilities)</li> <li>Huge gap in the ratio of patients to counsellors in both the ART Center RIMS and JNIMS which results in patients having to spend more time at the ART Center at JNIMS</li> <li>ART Center staff are not always friendly and welcoming of PLHIV</li> <li>Capacity building of ART Center staff is needed to avoid perpetuating myths and misconceptions about the PLHIV community</li> </ul>
People living with HIV FGD 2 Sites: ART Center JNIMS, Link ART Center Community Health Center Saikul	<ul> <li>Referral mechanism for viral load testing for PLHIV accessing ARVs from Link ART Center is a big challenge; PLHIV have to visit the main ART Center first to book their appointment instead of the ARTC staff facilitating this and booking for them</li> <li>Existing system makes PLHIV have to repeatedly visit the ART Center and spend more than the cost of the ARV drugs for traveling to and from the ART Center (e.g. 300 INR per visit)</li> <li>Due to recruitment of staff at Link ART Center at the Community Health Center, irregular attendance of staff has hindered PLHIV in accessing services available specifically for referrals for viral load testing</li> <li>ARTC is congested due to the late arrival of staff and limited working hours</li> <li>Community Health Center, an important government health care service center, has no basic testing facilities (LFT, KFT, CBC) and no ARVs; PLHIV have to travel long distance to access ARV drugs at the ART Center in JNIMS</li> <li>Despite the ART program being rolled out for nearly two decades, still huge gaps in access to clinical investigation for PLHIV at ART Center in JNIMS and Link ART Center</li> </ul>
People living with HIV FGD 3 Sites: ART Center Ukhrul District Hospital, NGO TI project, Ukhrul District	<ul> <li>HIV treatment literacy among PLHIV is very poor</li> <li>Process to switch to second line ART for PLHIV accessing medicine from the ART Center Ukhrul District involved cost to travel to the tertiary hospital</li> <li>Transportation for PLHIV from the fringe of Ukhrul district is a barrier as the district comprises of four sub-divisions with diverse topography</li> <li>Access to regular health check-up by the doctor in the ART Center is difficult as the doctor is always unavailable</li> <li>NGO staff working in the field of HIV/AIDS is very supportive to the PLHIV community of the district</li> <li>Quality of counselling services available at the ARTC Ukhrul District Hospital needs to be strengthened</li> <li>PLHIV in the district need to be empowered to help themselves monitor their HIV treatment and know their basic rights per national guidelines</li> </ul>
People living with HIV FGD 4 Sites: ART Center JNIMS	<ul> <li>Stigma and discrimination towards PLHIV within the staff of ART Center in JNIMS is a reason that prevents PLHIV from accessing free testing services</li> <li>Lack of concern from the government regarding irregularity in the functioning of clinical investigations testing machine, strengthening of the ART Center infrastructure including sitting arrangement, proper drinking water, not sufficient waiting space etc.</li> <li>PLHIV who were from far flung areas do not want to receive their ART services at the nearby Link ART Center due to fear of disclosing their identity, therefore resulting in overcrowding at ART Center JNIMS</li> <li>There is still a problem in dolutegravir (DTG) transition as many patients are still not yet switched to DTG at ART Center at JNIMS</li> <li>Lack of knowledge among the staff at the ART Center on the benefits and importance of Isoniazid Preventive Therapy resulting in low coverage of the same among PLHIV</li> </ul>

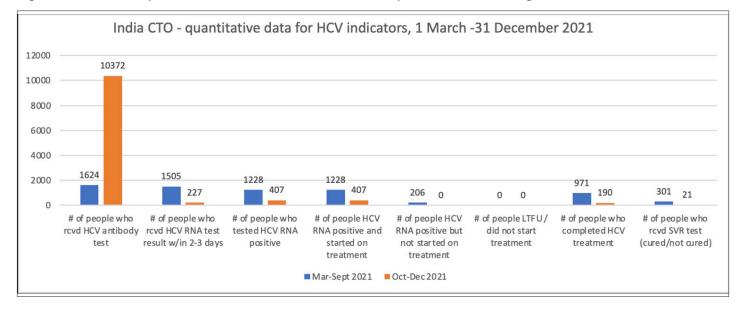


#### **HCV QUANTITATIVE RESULTS**

Summary points:

- The State Nodal Officer of the National Viral Hepatitis Control Program, Manipur, clarified that the data reported are only for two Model Treatment Centers (MTC) – JNIMS and RIMS.
- The National Viral Hepatitis Control Program, Manipur does not maintain separate aggregated data for Male, Female, TG people, PWID, SW or MSM.
- The data collectors observed that overall, the National Viral Hepatitis Control Program, Manipur does not maintain data systematically.
- During the Mar-September 2021 reporting period,
  - o Out of 1624 people screened for HCV, 1619 (99%) people were found to be HCV antibody reactive.
  - Out of the 1619 people found to be HCV antibody reactive, 114 (7%) did not return for their test result.
  - 1299 (80%) people were confirmed to have HCV chronic infection, but only 1228 (75%) were initiated on HCV treatment, as 71 (4%) people did not turn up for their HCV treatment.
  - 301 (24%) people had their HCV sustained virological response test at 12 weeks, out of whom 258 (21%) achieved HCV sustained virological response at 12 weeks, which is considered a cure, and 43 (2%) of them were found to have treatment failure. The National Viral Hepatitis Control Program does not have any specific data for retreatment of those who had primary HCV treatment failure.

- During the Oct-December 2021 reporting period,
  - The number of people screened with HCV antibody tests was 10,372, which includes hospital ward patients, referrals from NGOs and self-walk-ins. The facilities could not provide the numbers of people who tested HCV antibody positive.
  - o There were 227 people who had a HCV viral load test; however, some of the reports took nearly one month to be returned.
  - The number of people initiated on HCV treatment was more 0 than the number of people who had undergone HCV viral load testing under the national program. Many people had their HCV viral load tests from private labs, but the labs cannot share data on how many were found non-viremic or had a result of "Target not detected," nor how many individuals have done a viral load test at their labs. There are large communications gaps between the District Viral Hepatitis Management Unit, the Microbiology department where HCV diagnostics are conducted and the State Viral Hepatitis Management Unit in terms of sharing the data of people who have had HCV antibody tests and RNA tests. Due to delays in receiving a HCV viral load test under the national program (sometimes more than one month), many people visited private labs for their HCV viral load test, resulting in inconsistencies between the number of people on treatment and the number of people who had a HCV viral load test at the Model Treatment Center.
- No stock-outs were reported.



#### Figure 2. India CTO – quantitative data for HCV indicators for the period of March through December 2021

Type of Interviewee	Barriers to access to HCV testing (antibody test)	Barriers to access to HCV treatment	Barriers to access to HCV RNA viral load test
Health service provider	The small numbers of direct walk- in patients for HCV testing could be due to the lack of awareness, especially among people who are at the highest risk; are not aware of the benefits of early diagnosis and treatment of HCV like how it's done for HIV Most people coming to Model Treatment Center at JNIMS are those who are already tested HCV antibody reactive. Despite of HCV testing kits being provided by National Viral hepatitis control program, screening is not happening; people hardly come to undergo HCV antibody test at Model Treatment Center	Expressed the need to decentralize HCV services of HCV - most patients referred from far flung districts refuse to go back and collect their medicine from their respective district once they are confirmed HCV RNA positive, which results in unnecessary increase in the number of patients at the Model Treatment Center and hampers tracking the patients who are lost to follow- up Need to establish mechanism for close coordination among various hospital departments such as blood bank, ART Center, surgery and gynaecology etc. for referral of HCV antibody reactive patients to Model Treatment Centers Out Patient Department (OPD) ticket being made mandatory for HCV screening has been identified as one of the barriers	During COVID-19 time, it takes nearly one month or even more to provide the HCV viral load test report; situation has improved and now are able to give the viral load report in one week, but trying to give the report in 2-3 days is still very challenging as they have only one staff in the laboratory Not able to track systematically the patients who drop out and those not turning up for their SVR testing due to lack of peer support staff The number of people coming back to the Model Treatment Center for their SVR test at 12 weeks is comparatively less – reasons given include COVID-19-related issues, having personal work conflicts, not being aware about the need of doing SVR, patient themselves being negligent on the need of
	- B surface antigen reactive and those tested hepatitis - C antibody reactive, are referred to either a private diagnostic center or the Model Treatment Center at JNIMS for HBV DNA and HCV viral load confirmation tests; but once confirmed by HCV viral load test, they are not willing to return back to the Treatment Center at their districts for HCV treatment; rather, they will insist the Model Treatment Center in Imphal allows them to continue their treatment there	allowing many people to put off treatment Gap between demand and supply of the medicine – example given of 90 bottles each of sofosbuvir and daclatasvir tablets that were collected from the National Health Mission as an allocation for Chandel District Hospital when National Viral Hepatitis Control Program was launched in January 2020, but only 15 bottles each of sofosbuvir and daclatasvir were utilized for 5 patients and all the remaining medicine was thrown away due to reaching their expiration dates	the test Number of missing people can be reduced if HCV viral load testing facilities are made available at the district hospital (e.g., could have helped the 5 patients treated for HCV who have not turned up for their SVR 12- week test) Manpower in the Treatment Center is low; peer support staff is yet to be recruited

# Table 8: Responses from interviews with HSP, PLHIV and PWID on the barriers to accessing HCV services



People living with HIV and people who inject drugs	Availability: -Received an HCV antibody test at a screening camp supported by a local NGO – got the result the same day or the next day -Was about to undergo surgery at the RIMS and both HIV and HCV tests were mandatory; conducted his HIV and HCV tests at the RIMS and at a private lab (Babina Diagnostics Center); during the process of undergoing surgery, found out was HCV reactive but HIV-negative; was advised by the doctor at both the government and the private labs to obtain an HCV viral load test Accessibility (physical, administrative): -Travelled quite a long distance to JNIMS and then had to get the HCV antibody test; took 30 minutes to get his OPD ticket and report was received the next day Accessibility (information): -Aware of government free hepatitis C programme available at JNIMS but felt uneasy to access the services because limited knowledge on whether to start	Availability: -Faced challenges getting clinical investigation tests done – able to get all but one test (Prothrombin Time and International Normalized Ratio) at the Primary Health Care center located nearby, then visited the hospital at tertiary level where MTC are attached but unfortunately the needed test was also not available, so ended up getting it done at the private laboratory and paid out of pocket -Machine broken down so could not get baseline investigation tests done and cannot afford to get them done at a private facility so have not started HCV treatment Accessibility (information): -PLHIV and PWID has a lot of myths and misconception such as it will be less effective to start HCV treatment while using drugs -PWID peers say that treatment is not needed and HCV will go away on its own -Was offered help by an NGO to start HCV treatment, but refused because thought that the time at the drug rehab center would be extended until completed treatment Accessibility (financial): -Even though the interviewee left the rehabilitation center, they followed up and called to tell to collect medicines for HCV treatment at the center; they charged money for the medicines so from the 2nd month on,	Availability: -NGO helped to do the baseline clinical investigation -At the screening camp, blood was collected for HCV viral load test for confirmation at the Model Treatment center; report was received after 15 days Accessibility (information): -Did not get HCV confirmatory test due to lack of knowledge in the HCV diagnosis process -Did not do the SVR 12-weeks test due to lack of knowledge and relapsing into drugs Accessibility (financial): -Went to a private diagnostic center (Babina Diagnostics Center) for HCV viral load test paying around 240 USD but did not collect the report due to relapse in drug using habits and remain without knowing HCV confirmatory test status -Did not do viral load testing because not offered for free at the testing facility and could not afford to get it at a private facility Accessibility (administrative), Quality: -Went to get viral load test but had to wait in long queue for the out-patient ticket and when finally got the ticket and arrived at the department providing free viral load testing, could not get it done due to Covid-19 outbreak; went back again after
	HCV treatment when into drug habits -Unaware that after testing reactive to an HCV antibody test, need an HCV viral load test to confirm active HCV infection before starting on treatment	got help from the NGO to get the medicines at the MTC which are free Accessibility (administrative, physical), Acceptability: For enrolment at Model Treatment Center for initiation of HCV treatment, was declined	Covid-19 was stabilized, got the viral load testing, but it took one month to get the report Accessibility (administrative), Acceptability, Quality: -NGO staff accompanied to get HCV viral
	-Was not given proper counselling during HCV screening by a local NGO and told could start on HCV treatment or not (after receiving result of HCV antibody reactive); did not start on treatment because staff	and advised to come back with the report as it was found missing; an Out-patient ticket is mandatory to undergo test so went through a long process standing in a queue taking nearly 2 hours to get OPD ticket; after getting it, he went for registration and was referred from one lab to another without	load test at Model Treatment Center JNIMS; took about 30 minutes to get OPD ticket; noted that the attitude of service provider was not decent enough maybe because of being a drug user; waited one week for the HCV viral load test report
	at drug rehab center said to stay until completed HCV treatment -When tested HCV antibody reactive was worried and anxious but counselled well and told HCV treatment is free and is curable so felt better	proper guidance; felt uncomfortable, made to feel ignorant and discriminated (being a drug users) during the whole process; residence is about 30 KM from the hospital; limited transport service due to COVID-19; in the end, went back home without the doing the test for fear of missing public transportation service	Accessibility (physical), Quality: Underwent HCV viral load test at Model Treatment Center JNIMS but due to breakdown of PCR machine was told to collect the report after 15 days – still not picked up his report due to negligence (drug habits) and far distance from home to Model Treatment Center JNIMS which is not
	Acceptability: -Visited Model Treatment Center JNIMS for HCV antibody test alone but did not get test done as couldn't find the testing location; also self-stigmatized being an injecting drug user - felt reluctant to ask the location of the testing area	back home -NGO team visited Model Treatment Center to request for prescription of baseline investigation; treatment was denied because of not having Aadhar Card (Government ID) Quality: -Not properly counselled about treatment; only told that medicine is taken for 3 months - Immediately after confirmed by the HCV viral load test to have chronic infection	convenient Quality: -Blood sample taken for HCV confirmatory test was drawn on the same day as the HCV antibody test however it took 1.5 months to receive the viral load report - Visited an NGO to get a viral load test, but was not shown the test report - verbally told the result
		was guided by an NGO to get baseline investigation done for initiation of HCV treatment	

# Table 9. Summary findings from FGDs with PWID on the barriers to accessing HCV services

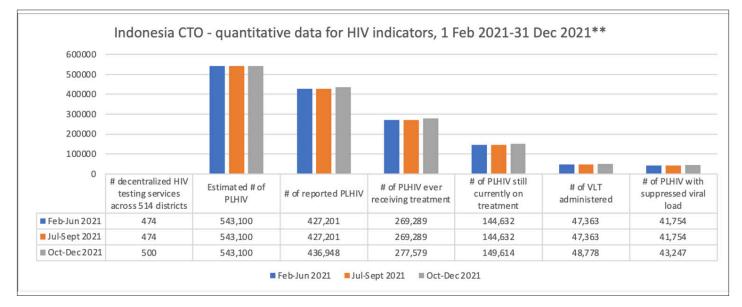
Type of Interviewee / Site	SUMMARY FINDINGS
FGD 1 with people who inject drugs who were undergoing drug treatment at a rehabilitation center, The Overcomers De-addiction Center, Lamphelpat, Imphal West	<ul> <li>Fear of disclosure of their HIV/HCV status in the workplace</li> <li>50% of the PWID attending the meeting have poor access to information, knowledge on HCV</li> <li>Myths and misconception about the route of transmission on HCV</li> <li>Denial of HCV treatment due to relapse into the drug habit was also common</li> <li>Lack of information about the importance of early diagnosis and early treatment</li> <li>Fear of being stigmatized and discriminated by the health care service provider</li> <li>Character of HCV being asymptomatic is one common factor for the delay in accessing HCV screening, diagnosis and treatment</li> <li>Providing treatment literacy on HCV helps us motivate participants for early treatment</li> </ul>
FGD 2 with people who inject drugs who were on opioid substitution therapy from the OST center attached to the Community Health Center (CHC) located at Saikul Sites mentioned: MTC JNIMS, MTC RIMS	<ul> <li>No facilities available for HCV screening, diagnosis and treatment in Saikul</li> <li>Facilities for conducting clinical investigation test are not available for HCV and other tests at the Community Health Center Saikul</li> <li>Access to HCV-related service information among PWID community is very poor</li> <li>Travel inconveniences to reach the nearest Model Treatment Center JNIMS are a huge financial barrier for most people in Saikul, as the MTC is 38 km away from Imphal</li> <li>Issue of OPD ticket being mandatory while accessing HCV services a barrier, keeps people from testing and treatment</li> <li>Too much time to get HCV viral load test result; another barrier to treatment</li> </ul>
FGD 3 with people who inject drugs who were undergoing drug treatment at a rehabilitation center, Anouba Mayol Rehabilitation Center, Sekmai Imphal West	<ul> <li>Drug use habits are a key factor preventing people who inject drugs from accessing HIV/HCV testing and treatment services</li> <li>HCV treatment completion is one of the big challenges for people who inject drugs in the community due to frequent relapses due to drug habits</li> <li>Access to information and education on HIV- and HCV-related services, level of understanding about HCV screening, diagnosis and treatment among the people who inject drugs is still very low / limited</li> <li>Lack of support mechanism for strong linkages to HIV and HCV care in the existing drug rehabilitation centers of the state</li> <li>Some of the doctors still do not encourage patients to access HCV treatment service from the national program, rather they encourage them to buy the medicine from the open market</li> <li>Myths and misconceptions among the PWID community on the concept of needle syringe exchange program in the state</li> </ul>
FGD 4 with people who inject drugs who were undergoing drug treatment at the Alliance Substance Abuse De-Addiction Center, Mongsangei, Imphal West	<ul> <li>Most of the participants have very poor knowledge of HCV</li> <li>Lack of information on the availability HCV services under National Viral Hepatitis Control Program</li> <li>Myths and misconception about HCV are very common among the participants</li> <li>The process of accessing HCV services under National Viral hepatitis Control Program is very lengthy and time consuming which becomes a barrier (e.g. long queue to get Out Patient ticket, working hours for blood collection too short, test result report received after more than a month)</li> <li>Due to asymptomatic of HCV infection people keep on delaying getting an HCV antibody test</li> <li>Introduction of an innovative model of HCV treatment for current drug users is needed as drug use behaviour is one of the major treatment access barriers for people who inject drugs who are actively using drugs</li> <li>There is a need for an HCV literacy program to help people who inject drugs understand the importance of early diagnosis and treatment</li> </ul>
FGD 5 with people who inject drugs at the Wide Angle, OST Drop-in-center (DIC), Patsoi, Imphal West	<ul> <li>Lack of information on the availability of HCV free services under National Viral hepatitis Control program</li> <li>Poor knowledge of HCV overall (e.g. need to do Sustained virological test after completing treatment)</li> <li>Inability to abstain from drug use is another treatment access barriers</li> </ul>

## **INDONESIA**

## **HIV QUANTITATIVE RESULTS**

Data were collected from February through June 2021, July through September 2021 and October through December 2021.

#### Figure 3. Indonesia CTO – quantitative data for HIV indicators for the period of February through December 2021



\*\* Quantitative data on the following indicators was not available for all three reporting periods:

- Number of PLHIV that have received a viral load test result 1.
- Number of PLHIV switched to dolutegravir-containing first-line antiretroviral medicines 2.
- 3. Number of PLHIV initiated with dolutegravir-containing first-line antiretroviral medicines
- 4. Number of rapid molecular machines procured and used for viral load monitoring Number of HIV PCR cartridges procured and used for viral load monitoring
- 5.



#### **HIV QUALITATIVE RESULTS**

#### Table 10. FGD responses with PLHIV and PWID on select quantitative indicators on access to HIV services

Guide	lines / regulations on HIV testing	
Questions	Responses from FGD with PLHIV and PWID	
What is the status of the HIV testing guideline/regulation: (drafted/ finalized/published/disseminated/ enforced)?	There are no new guidelines developed at the moment.	
Are they getting the result fast enough?	Most of the HIV services have offered test and treat although not all basic health centers have provided ARVs, but almost all basic health centers have provided HIV testing.	
Whether or not the patient feels that the procedures is simplified enough?	The procedure for HIV testing is simple enough.	
Are the results being delivered as quickly?	Yes, mostly the same day	
	Access to HIV treatment	
Questions	Responses from FGD with PLHIV and PWID	
Are you receiving Tenofovir, Lamivudine and Dolutegravir (TLD) or Tenofovir, emtricitabine and Dolutegravir as the preferred first line ARV from the national HIV program?	Yes, but not for all patients.	
If yes, is it the people who are newly initiated on ARV the ones prescribed TLD? Or are people who have been on ARV being switched to TLD?	TLD is recommended for people who are newly initiated or switched to TLD because of side effects of the other ARVs, or with indication of resistance.	
How many days/months of ARVs are dispensed to you at a time?	Once a month. Twice a month for West Kalimantan or three months for people who are working in palm oil areas. For people who are newly initiated on ARVs, the ARVs are given every two weeks to monitor side effects.	
Acce	ess to routine Viral Load Testing	
Questions	Responses from FGD with PLHIV and PWID	
Do you get a viral load test from the government every 6 months or yearly?	6 months after treatment and then every 12 months. Cost for viral load testing is not covered by the government. Community members who are not a National Health Insurance member or do not have any ID find it difficult to do routine VLT.	
Do you have to pay for the viral load from your pocket?	Different areas have different policies for HIV viral load coverage. For National Health Insurance members, some areas are covered for viral load, and some do not cover it.	
What is the quality of services?	Most of health facilities and staff are now overburdened with assisting with Covid vaccination or Covid testing so when FGD participants approach them, they always mentioned that they are still focusing on Covid.	

# Province-specific FGD responses on access to HIV testing, treatment and routine viral load testing (VLT)

All provinces:

- On average, HIV tests are available at all Community Health Centers for free. However, not all Community Health Centers that provided HIV testing services already have ARV treatment services.
- Not all services related to HIV and HCV are open daily. Meaning, patients need to make an advance appointment to confirm the doctor's schedule.

West Nusa Tenggara:

- The GeneXpert machine is currently under repair.
- West Nusa Tenggara Health Office has started to initiate a onestop service test for HIV, Hepatitis B, and HCV but is still having problems with the current lockdown.

Bogor, West Java:

 Bogor Regional Hospital: free service charge for HIV and HCV but now it is a COVID-19 referral center

North Sumatra:

- HIV outreach recommends HCV testing, but there are problems if community members do not have an ID card (required for all services, paid or using National Health Insurance. Most the PWID and transgender people have difficulty paying for the monthly premium.
- Provide HIV mentoring and outreach both in North Sumatra and Aceh region under the Global Fund implementation scheme. Hepatitis programs had recently been introduced in Aceh and all key populations are recommended to be tested for viral hepatitis and HIV.

#### HIV services for children

As reported in the HIV Quarterly Report<sup>2</sup> published by the Ministry of Health in May 2021, the Indonesian Government had no estimation for pediatric patients. Without the information about the number of patients enrolled, the treatment regimen used, and the percentage of utilization per ARV, it is difficult to quantify the pediatric ARV requirement. As a result of this lack of information, there is a risk of stock-outs, overstocks, or expiration of ARVs. To gain a perspective on the particular situation regarding HIV services for children, the CTO interviewed Lentera Anak Pelangi, an NGO representing children living with HIV.

## Table 11. Responses from interviews with Lentera Anak Pelangi on HIV services for children

Issue	Response
Guidelines for children living with HIV	No updated guidelines for children living with HIV; latest guidelines are from 2014 based on 2010 World Health Organization recommendations. The only updated document available is the 2019 National Guidelines for HIV Clinical Services. Unlike the previous document (which is more comprehensive), the 2019 document provides guidance only about clinical management and treatment options, mostly for adults but there is a section for children with HIV.
HIV testing guidelines for children	Only children exposed to HIV (mostly through the risk of mother to child transmission) are recommended to be tested for HIV. For children, especially asymptomatic, HIV screening should be based on doctor's presumption and parental consent. HIV test results are usually available on the same day.
HIV treatment guidelines for children living with HIV	- The limitation of the 2019 Guidelines compared to 2014 is that there is no information on drug formulations for children and dosages, formulations as well as administrative procedures (which drugs may be crushed/split). Information is only available through webinars.
	- Pediatric fixed-dose combination of zidovudine (AZT), lamivudine (3TC), and nevirapine (NVP) was still available until April 2021.
	- The 2020 Expert Panel recommended that the preferred first-line regimen for children less than 3 years old is ABC+3TC+LPV/r (abacavir, lamivudine, lopinavir, ritonavir) and for children 3-10 years old, AZT+3TC+EFV (zidovudine, lamivudine, efavirenz). Due to the unavailability of the pediatric formulation, children were given crushed/split adult formulation of ZDV/3TC/NVP (zidovudine, lamivudine, nevirapine). The pediatric formulation ABC+LPV+LPV/r is only given to children who have previously used the crushed adult version of ABC+3TC+LPV/r.
	- Dolutegravir (DTG) can only be given to children over six years old and weighing 20 kg or more.
	- Application in the field varies; some doctors say that granule + dispersible can be used together, while other doctors say they cannot be co-administered.
ART for children living with HIV	ARVs are dispensed once a month, on special cases (for example children with disability and higher adherence level can receive four months prescription of ARVs).
Trained health staff to manage cases of children living with HIV	Human resources are poorly trained and uninformed (both doctors and pharmacists). Sometimes in the hospital itself, doctors do not know what preparations and dosage are available in the pharmacy.
j i	Screening for children who are born to HIV positive mothers are now being done at the smallest level of health facility (Puskesmas/Community Health Center)
HIV viral load testing for children living with HIV	<ul> <li>No government program so patients have to pay; not covered by National Health Insurance. Price for a viral load test (VLT) differs from place to place – range from Rp. 660,000 (\$46) to Rp. 1 million (\$70). Lentera Anak Pelangi supports a total of 87 children; covers the costs for children who do not receive the free viral load test from health facility. In 2021, Koja, Sulianti Saroso Infectious Diseases Hospital, Tarakan, Cipto Mangunkusumo Hospital, and Cengkareng Community Health Center provided the tests for free.</li> <li>Results are usually available within 1-2 weeks but can be faster if you have a contact number. One hospital in Jakarta had to wait for pediatric patients to come to give results. E-results are also not available.</li> <li>The result of an HIV antibody test is immediate but result of viral load takes longer (1-2 weeks).</li> </ul>
	Other issues: - Some caregivers are also working so it is difficult to accompany their child - Some children are reluctant to get a VLT. - Several viral load machines were malfunctioning and some machines were used for Covid-19 PCR. - For those attending hospitals with free viral load test, the transportation fee has been offered by Lentera Anak Pelangi. However, some children with special conditions have difficulty to travel using public transportation (e.g. cases of children and caretakers having to carry oxygen cylinders; teenager with mental disability and paralysis (when younger, the caretaker can carry but as the child gets older and heavier, very difficult to carry).

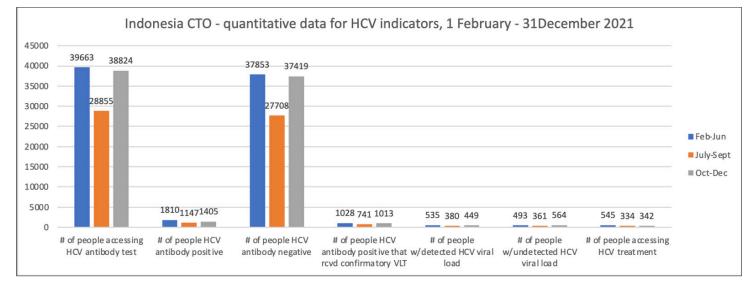
 $^{2}\ https://hivaids-pimsindonesia.or.id/download/file/Laporan_TW_L_2021\_FINAL1.pdf.\ Indonesian\ Ministry\ of\ Health.\ Published\ on\ 25th\ of\ May\ 2021.$ 

#### **HCV QUANTITATIVE RESULTS**

Table 12. Qualitative results on national viral hepatitis plan and HCV diagno	osis and treatment quidelines

Hepatitis National Plan (Rencana Aksi Nasional Hepatitis 2020-2024)				
Questions	Responses from FGD with PLHIV and PWID	Responses from Health service provider		
What is the status of the Hepatitis National Plan: (drafted/finalized/ published/disseminated/ enforced)?		The 2020-2024 national plan was signed by the health officials on the 28th of December 2020 and disseminated to 34 provincial health offices in 2021.		
Has the National Plan been read and understood by health facility staff?		Since currently there are only 18 priority provinces. The Ministry of Health expects that at least the National Hepatitis Plan is read and understood by these 18 priority provincial health office and hospitals.		
Are there Human Resources trained?		There are plans to train health service providers on the national plan using the national budget.		
Have the activities in the National Plan been costed?		Yes, it is costed. Hepatitis B and C is under the Hepatitis program and Hepatitis A is under the Gastroenterology program. For HBV, the program is prioritized for positive mothers, babies born from positive mothers and healthcare workers. For testing and treatment of HCV, all key populations are included in the national program.		
Are there any revisions or plan to revise the guideline?		Not any time soon since the national plan was recently developed and shared.		
Are cost of Hepatitis C services covered by the National Health Insurance?	Not all services are covered by the NHI. For community members with no NHI, the cost of registration ranges from \$0.57 (Jakarta) to \$12.8 (North Sulawesi). The cost for other lab work also ranges from \$0.57 (Jakarta) to \$39.2 (West Nusa Tenggara).	Only limited to HCV Rapid Diagnostic Test, viral load cartridges (both for confirmatory test and SVR12), DAA (Sofosbuvir and Daclatasvir), and Elbasvir/ grazoprevir (for HCV patients with chronic kidney disease)		

## Figure 4. Indonesia CTO – quantitative data for HCV indicators for the period of 1 February through 31 December 2021



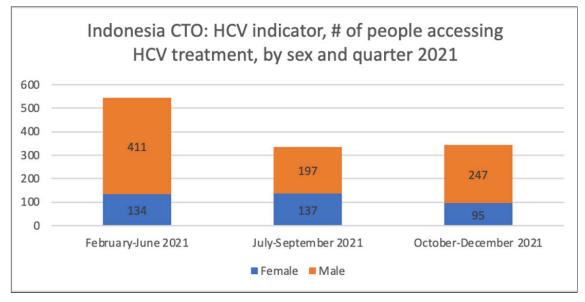


Figure 5. Indonesia CTO – quantitative data for HCV indicator, number of people accessing HCV treatment, for the period of 1 February through 31 December 2021



# Table 13. Responses from FGDs with PLHIV and PWID, and interviews with HSPs on access to HCV antibody testing and confirmatory HCV viral load testing

	Access to H	ICV antil	body testing, confirmatory HCV viral load test
Indicator / HCV service	Questions	FGD or HSP	Responses
Number of people accessing HCV antibody test	Is it easy to get an HCV antibody test done?	FGD	Yes, but not all HCV services are open daily. Mostly only twice a week or by doctor appointment only.
	Would you suggest to any of your peers to get an antibody test done?	FGD	Yes, most of them are still reluctant to come since the stock-out in 2019. There is a fear of being cut in the middle of treatment and then they have to pay the viral load test for re-treatment out-of-pocket.
	How quickly do you get the result?	FGD	Result of HCV antibody ranges from next day (Jakarta) to the same week (other provinces).
	Can you describe the process for getting HCV antibody test?	HSP	Antibody test can be acquired from the referral hospitals or Community Health Centers (CHC). However, confirmatory test as part of national program is only available in 18 priority provinces.
	Is HCV antibody test accessible for all who needs it?	HSP	The ones covered by the government is only available in 18 priority provinces.
	How many people have availed the HCV antibody test?	HSP	Around 38,000 people during Oct-December 2021
	How many have had a positive result?	HSP	Around 1,400
	Why are people not accessing the test?	HSP	Analysis of the impact of COVID-19 on hepatitis services in health facilities showed a significant decrease compared to the same period in 2019. In response to this situation, the Indonesian Ministry of Health issued a Circular Letter of the Director General of Disease Prevention and Control Number HK.02.03/III/9204 /2020 concerning the Implementation of Prevention and Control of Hepatitis B and Hepatitis C during the pandemic to ensure all Hepatitis efforts can continue to run optimally in the midst of a pandemic situation.
Number of people with positive HCV antibody test result that receive the confirmatory HCV viral load test	Did you have to come back to the hospital for giving blood sample for the viral load test?	FGD	Yes, most of the patients from the provincial level have to go to another hospital to get their lab test. In Medan for example, out of three hospitals, only one has a machine to do viral load test. People in Bekasi have to travel to Jakarta. In West Kalimantan, PCR machines are being used for COVID-19. West Nusa Tenggara: GeneXpert machine is currently under repair.
	Do you find it easy to access the viral load test?	FGD	No. it is not easy in terms of access and price especially for non-National Health Insurance Members.
	How long did you have to get the test result?	FGD	Same week. However, in some provinces, the machines are being used for Covid 19.
	Can you describe the process for getting confirmatory HCV viral load test?	HSP	Antibody test can be acquired from the referral hospitals or CHC. However, confirmatory test as part of national program is only available in 18 priority provinces.
	Why are people not accessing the test?	HSP	The COVID-19 pandemic that broke out in the first quarter of 2020 had a significant impact on people living with hepatitis. Several studies suggest that, in addition to longer hospitalization days, the risk of mortality from COVID-19 is higher in patients with a history of chronic liver disease. In might be because patients are afraid to come to the health center. However, there are also period of stock-outs during the pandemic. To prevent future stock-outs, the MOH established a WhatsApp group to remind provincial health offices to request if they have reached a minimal stock of 3 months.
	Is HCV viral load test accessible for all who needs it?	HSP	Viral load tests as part of the national program are only available in 18 priority provinces. Other than those priority provinces, patients have to pay around Rp. 1,000,000 (USD 71) or more.
	How many people have availed the viral load test?	HSP	Around 1,000 people during October-December 2021
	How many have had a chronic infection result?	HSP	Around half of them

#### Table 14. Responses from FGDs with PLHIV and PWID, and HSP interviews on access to HCV treatment

	Access to HCV treatment				
Questions from FGD FGD or HSP		Responses from PLHIV and PWID participants			
Can you describe the process for getting the treatment?	FGD	National Health Insurance Member: referral from basic health facility to referral hospital> registration> doctor appointment> lab			
	HSP	Treatment using directing-acting antivirals (DAA) (i.e. Sofosbuvir and Daclatasvir) as part of the National Program is only available in 18 priority provinces. Once people are diagnosed and confirmed (whether or not they avail the anti HCV and viral load test as part of the program), they can avail the treatment in the HCV referral hospitals in those 18 provinces.			
What are the enabling and inhibiting factor to access treatment?	FGD	Limited number of referral and Community Health Centers (CHC) that provide HCV testing. In North Sulawesi for example only 5 CHC can do HCV testing. DAA is provided elsewhere and not in the same health service site.			
	HSP	COVID-19 is playing a major part in reducing the access to treatment.			
Is information affecting access to HCV treatment?	FGD	The information is given by the community to the community. Most of the stock problems are because the national govt did not communicate or the provincial level did not receive the information from the national govt.			
		In West Kalimantan, after one year of stock availability, the stock of Sofosbuvir is still not available to patients because local health officials were not aware that they could procure the medicine already available from the national warehouse.			
	HSP	Ministry of Health developed a user-friendly pocket book but the distribution is still limited. MoH had not evaluated the impact or assessed the impact of the information upon the number of people accessing test and treatment of HCV.			
Were people in need of the treatment unable to receive it due to drug stock out?	FGD	Yes. And re-treatment is difficult because people who had previously treated and experienced stock-out had to pay for their own viral load test, which is expensive.			
	HSP	Some of them had not received since there are stock-outs especially in 2020. In early 2021 the stocks are better and the Clinton Health Access Initiative is helping the MoH to develop a mobile app for patients to be notified about the stocks.			
How many people have accessed treatment so far?	HSP	Around 340 people during October-December 2021.			
Why do you think people are not coming for treatment even after having a chronic infection?	HSP	Some people are working and some people are outside the area of priority provinces.			
How do you suggest we can improve treatment linkages?	HSP	The MoH are planning to include 4 more priority provinces in 2022 (West Nusa Tenggara, Riau Islands, South East Sulawesi, and Maluku). So in total there will be 22 provinces in 2022. All 34 provinces are planned to be provided with HCV related services (as part of the national program).			
Number of procured DAA in 2021		15,000 (same for all reporting periods)			

## Province-specific FGD responses on access to HCV testing and treatment

West Nusa Tenggara:

- The GeneXpert machine is currently under repair
- To be able to use National Health Insurance to cover the hospital registration fee, doctor's fee and laboratory work fee, first-tier health facilities need to make referrals to the second or third tier health facility that provides hepatitis-related services. However, the referral code from Indonesia Case Base Groups (INA-CBGs) cannot display "Hepatitis C treatment" so patients from the firsttier health facility cannot be referred to the next level facility.
- West Nusa Tenggara Health Office has started to initiate a onestop service test for HIV, Hepatitis B and HCV but is still having problems with the current lockdown.

• Hepatitis-related services are only available twice a week.

North Sulawesi:

- Most of PWID do not have National Health Insurance.
- Methadone is not available in North Sulawesi area. For those who need opioid substitution therapy, they are advised to use buprenorphine. As the need varies among people, for some people, the cost is burdensome since some people use up to 8mg per week. buprenorphine price for 8mg is Rp. 800,000 (\$57). In addition, some also need alprazolam for drug treatment and depending on the user, there are people who use 4 strips per week at a price of Rp. 400,000 (\$28.5). With a doctor's fee of Rp. 150,000 (\$10.7) per week (Bhayangkara Hospital), the total



expenditure per week is around Rp. 1,350,000 (\$96) per week or Rp. 5,400,000 (385.7) per month, making it difficult for care recipients to access other services (including HCV services).

#### West Java:

• Bogor Regional Hospital: free service charge for HIV and HCV but now it is a COVID-19 referral center.

#### West Kalimantan:

• The HCV PCR machine is being used for COVID PCR.

North Sumatra:

- HIV outreach recommends HCV testing, but there are problems if community members do not have an ID card (required for all services, paid or using National Health Insurance. Most the people who use drugs and transgender people have difficulty paying for the monthly premium.
- 30 community members were tested and treated, there were 2 people who did not finish the treatment due to stock out of direct-acting antivirals (DAAs) (i.e., sofosbuvir and daclatasvir). Community members are afraid to start over because of fear of stock-out and there is an added out-of-pocket cost to do a viral load HCV test again before re-treatment.

# DATA FROM STOCK-OUT MONITORING

Both India and Indonesia CTOs monitored for stock-outs of medicines, diagnostics and related supplies. For India, no stock-outs were reported. For Indonesia, stock-outs were reported and detailed below.

In Indonesia, although enough stocks of sofosbuvir 400mg, daclatasvir 60mg, daclatasvir 30mg, rapid diagnostic tests, and viral load (VL) cartridges are available at the National Level, 14 out of 17 priority provinces had reported stock-outs on the Hepatitis Information System portal (Sistem Informasi Hepatitis/SIHEPI). Health facilities need to submit a request for the health commodity requirements to the Provincial Health Office, which then submits the request to the national program. When health facilities failed to send the request, commodities could not be delivered in a timely manner.

Νο	Name of facility	City/Province	Stock-out as reported in SIHEPI (Sistem Informasi Hepatitis/Hepatitis Information System)	Resolution Status
1	RSU Dr Pirngadi Rumkit Bhayangkara Medan RSU H Adam Malik	Medan, North Sumatra	Daclatasvir 30mg, rapid HCV antibody tests, Viral Load cartridge	No official response from the MoH about the stock-outs. However, By July 7th, patients confirmed that Daclatasvir 30mg, RDT, HCV Viral Load cartridges were accessible.
2	RSU Raden Mattaher Jambi	Jambi	HCV Viral Load cartridge	By July 15th, HCV Viral Load cartridges were available at a limited number of 9 cartridges.
3	RSU Dr. Mohammad Hoesin	Palembang, South Sumatra	Daclatasvir 30mg, rapid HCV antibody tests, HCV Viral Load cartridge	21st of July 2021: Daclatasvir 30mg was available at a limited number of 9 bottles. 559 rapid HCV antibody tests were available 104 HCV Viral Load cartridges were available
4	RSU Dr H Abdul Moeloek	Lampung	Daclatasvir 60mg, rapid HCV antibody tests, HCV Viral Load cartridge	25th of July 2021: 61 bottles of Daclatasvir 60mg were available 615 rapid HCV antibody tests were available 14 HCV VL cartridges were available
5	RSU Prof Dr Margono Soekarjo RSU Dr. Moewardi Surakarta RSU Dr. Kariadi	Central Java	Rapid HCV antibody tests	21st of July 2021: 3924 rapid HCV antibody tests were available
6	Sardjito Hospital	Jogjakarta	Rapid HCV antibody tests, HCV Viral Load cartridge	Unsolved by the 31st of December 2021 <sup>3</sup>
7	RSUD Dr. Soetomo (Surabaya) RSUD Dr. Saiful Anwar (Malang) RSUD Dr. Soedono (Madiun)	East Java	Rapid HCV antibody tests, HCV Viral Load cartridge	15th of July 2021: 907 Rapid HCV antibody tests were available 36 HCV Viral Load cartridge were available
8	RS Sanglah	Bali	RDT, VL cartridge	15th of July 2021: 2398 Rapid HCV antibody tests were available 36 HCV Viral Load cartridge were available
9	RSUD Provinsi NTB	West Nusa Tenggara	Daclatasvir 60mg, Daclatasvir 30mg, RDT, Viral Load cartridge	<ul> <li>15th of July 2021:</li> <li>36 bottles of Daclatasvir 60mg were available</li> <li>18 bottles of Daclatasvir 30mg were available</li> <li>Rapid HCV antibody tests and HCV Viral Load cartridges were</li> <li>not available until December 31st, 2021<sup>4</sup></li> </ul>
10	Soedarso Hospital	Pontianak City-West Kalimantan	Daclatasvir 60mg, Daclatasvir 30mg, RDT, Viral Load cartridge	15th of July 2021: 15 bottles of Daclatasvir 60mg were available 5 bottles of Daclatasvir 30mg were available 1723 Rapid HCV antibody tests were available HCV Viral Load cartridges were not available until December 31st, 2021 <sup>5</sup>
11	RSUD Ulin Banjarmasin	South Kalimantan	Sofosbuvir, Daclatasvir 60mg, Daclatasvir 30mg, RDT, Viral Load cartridge	15th of July 2021: 6 bottles of Daclatasvir 60mg were available Daclatasvir 30mg was not available until December 31st, 2021 784 Rapid HCV antibody tests were available 11 HCV Viral Load cartridges were available
12	RSU H A Wahab Sjahranie	East Kalimantan	Daclatasvir 30mg, Viral Load cartridge	15th of July 2021: Daclatasvir 30mg was not available until December 31st, 2021 255 HCV Viral Load cartridges were available
13	RSU Prof.Dr. R.D Kandou Manado	North Sulawesi	RDT, Viral Load cartridge	Unsolved by the 31st of December 2021 <sup>6</sup>
14	RSU Dr Wahidin Sudirohusodo UP RSGM FKG Univ. Hasanudin	South Sulawesi:	RDT, Viral Load cartridge	21st July 2021 52 Rapid HCV antibody tests were available 7 HCV Viral Load cartridges were available

## Table 15. Reported stock-outs of viral hepatitis products in 14 priority provinces, and status of resolution

<sup>3</sup> Until the end of reporting period in December 2021, both Rapid HCV antibody tests and HCV VL cartridges are not available.
 Ministry of Health had informed that messages were broadcasted through WhatsApp group on a monthly basis to remind hospitals to make official request to the Provincial Health Office.
 <sup>4</sup> GeneXpert machine in West Nusa Tenggara is currently under repair

 $^{\rm 5}\,$  HCV PCR machine is being used for COVID PCR

Ministry of Health had informed that messages were broadcasted through WhatsApp group on a monthly basis to remind hospitals to make official request to the Provincial Health Office.

<sup>&</sup>lt;sup>6</sup> Until the end of reporting period in December 2021, both Rapid HCV antibody tests and HCV VL cartridges are not available.

July to September 2021: Although there was enough stock of DAAs at the national level, there were 4 community reports of stock-outs at the provincial level. Three were related to DAAs and one to GeneXpert cartridges.

No	Name of facility	City/Province	Case reported	Resolution status
1	Sardjito Hospital	Jogjakarta	Soon to be expired Sofosbuvir (August 2021)	64 bottles of Sofosbuvir were available at Sardjito Hospital by August 2021
2	Soedarso Hospital	Pontianak City-West Kalimantan	Soon to be expired Sofosbuvir (August 2021)	Waiting for West Kalimantan Provincial Office to request to MoH
3	Soetomo Hospital	Surabaya City-East Java	Stock-out of Sofosbuvir	206 bottles of Sofosbuvir were available at Soetomo Hospital by September 2021
4	Cengkareng Regional Hospital	Jakarta	Stock-out of viral load cartridge (unable to do SVR12)	964 cartridges were available at Jakarta Provincial Health Office by September 2021

Table 16. Stock-outs of DAAs at provincial level and status of resolution

# **NEXT STEPS**

The first year of project implementation fell during the COVID-19 pandemic and related restrictions on clinical care and transportation. Given the local contexts, the CTOs did a substantial amount of work to ensure that data collection continued and advocacy initiatives were conducted to identify and mitigate problems in the services. The providers, care recipients and service centers also found it difficult to maintain high levels of engagements with one another. Overall, the restrictions limited the ability of the CTOs to engage with stakeholders, collect data and conduct advocacy activities.

In the coming year, it will be important for the two CTOs to reflect internally on the issues to be monitored, indicators and data collection processes. This reflection will require discussions with data collection team members and documenting what has been learned for future reference, in order to improve processes and systems for the next data collection effort. A set of guiding questions can be used for these reflection discussions.

Issues to be monitored and indicators:

- Are there other/additional issues related to HIV and HCV services that should be monitored?
- Are all the indicators appropriate/relevant to continue monitoring? [Note that in Indonesia, data could not be collected for five indicators.]
- Are there any quantitative indicators that should be removed or added for the next data collection effort?
- Did the qualitative questions elicit useful responses? Should there be any changes to the wording of questions?

Data collection processes:

- Was it easy or difficult to access data? (quantitative and qualitative data)
- What data were not available or accessible? (quantitative and qualitative data)
- What relationships were established in order to collect data?
- Were the data collection tools easy or difficult to use? How can the tools be improved?
- Was the online database easy or difficult to upload data to? How can the database be improved?
- Did the data collection teams function effectively? How can the data collection teams be strengthened?

Equally, if not more important, will be the use of this data analysis report by the two CTOs to identify advocacy priorities and then develop an advocacy plan. A basic process includes:

- 1 Identifying issues common to more than one health service site
- 2 Identifying the level of decision-making at which the advocacy needs to be directed (i.e., health service site, district health officials, provincial or state health officials, national level)
- 3 Ranking issues in terms of: a) importance for PLHIV and PWID; b) potential ease of achieving a resolution; c) short- vs medium- vs long- term advocacy

Following this basic process, advocacy planning can first include sharing the data with decision makers at the appropriate levels and discussing potential solutions. The responses from these decision makers can then inform the advocacy planning for and execution of follow-up activities.





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