

IMPACTS OF COVID-19 ON WOMEN LIVING WITH HIV WHO USE DRUGS IN NEPAL

Results from a community-based,
participatory rapid assessment

October 2020



ABOUT ITPC

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through the focus of three strategic pillars:

- Treatment education and demand creation (#TreatPeopleRight)
- Intellectual property and access to medicines (#MakeMedicinesAffordable)
- Community monitoring and accountability (#WatchWhatMatters)

To learn more about ITPC and our work, visit itpcglobal.org.

ABOUT WATCH WHAT MATTERS

Watch What Matters is one of three core strategic pillars of ITPC that seeks to ensure that duty-bearers remain accountable to the communities they serve, both through identifying matters of importance and concern to these groups, and then in gathering data to inform, analyse, and co-construct healthcare solutions to improve the lived reality of these populations.

Community-led monitoring, research and advocacy fall under community-led projects where initiatives are fully community owned – from determining the research question, to generating and managing community data, to targeted action and related wins. Over the past decade, ITPC has implemented a number of community-led monitoring and research interventions to improve access to and quality of treatment and services for HIV, hepatitis C virus and tuberculosis. Such interventions include the Missing the Target research report series, stock-out monitoring in Eastern Europe and Central Asia, and community treatment observatories (CTOs) in West and Southern Africa.

CTOs aim to streamline and standardize treatment access data collected by communities, ensuring that data is not collected in a fragmented way or in hierarchical manner. ITPC uses its hallmark CTO model for community monitoring: synergising local data collection methods and findings with advocacy commitments that aim to empower communities to systematically and routinely collect and analyse qualitative and quantitative data on barriers to treatment access.

ABOUT THIS REPORT

ITPC, in partnership with Dristi Nepal and the Director of the AIDS and Society Research Unit at the University of Cape Town, Dr. Rebecca Hodes, presents in this report the key results from a Covid-19 Rapid Assessment conducted in Nepal from June to July 2020. In identifying the focus of research and advocacy, Dristi Nepal (Dristi) played the leading role in advising which methods, research topics, participants and locations were best positioned to provide insights into the healthcare realities confronted by women living with HIV and using drugs during the Covid-19 pandemic. Dristi was also the lead implementer for the assessment on the ground. Dristi is a women's rights, gender justice and harms reduction organisation established in 2006 to advocate for access to health and human rights in the HIV epidemic. In the first quarter of 2020, Dristi began to adapt to meet the fundamental survival needs of women with HIV and their families during Covid-19. They delivered food and other essential supplies to women who contacted them asking for urgent support, while capturing and relaying their experiences within local advocacy networks and to government partners. To protect anonymity, pseudonyms are used for all participants in the community-led monitoring tool.

FOR MORE INFORMATION

To learn more about Watch What Matters and our community-led monitoring work, visit www.WatchWhatMatters.org or send us an email at admin@itpcglobal.org.

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ABBREVIATIONS AND ACRONYMS

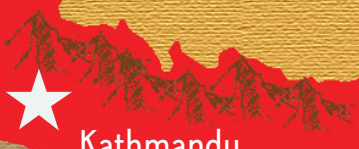
AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral treatment
ARV	Antiretroviral
Covid-19	Coronavirus disease caused by SARS-CoV-2 (2019)
CTO	Community treatment observatory
DTG	Dolutegravir
GDP	Gross domestic product
HIV	Human immunodeficiency virus
ITPC	Global International Treatment Preparedness Coalition
MSM	Men who have sex with men
NGO	Non-governmental organization
PCR	Polymerase chain reaction
RVLT	Routine viral load testing
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
VL	Viral load

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CHINA

NEPAL



Kathmandu

INDIA



Based in Kathmandu,
Dristi Nepal is a community
of women living with HIV
who use drugs.

EXECUTIVE SUMMARY

The global evidence-base on Covid-19 has been rapidly populated by clinical studies and epidemiological models. But there is a critical lack of data about the impact of the pandemic on the health and human rights of people living with HIV globally. Informed by advancements in HIV treatment and prevention, UNAIDS and its partners (including national governments, bilateral agencies, advocacy coalitions and community-based organisations) had committed to the ambitious 90-90-90 targets, to be met by the year 2020 (UNAIDS 2014). The Covid-19 pandemic threatened to defer or even reverse the gains made in meeting these targets, undermining critical progress in the global HIV response.

In June 2020, the International Treatment Preparedness Coalition (ITPC Global) embarked on an ambitious project to map the impact of Covid-19 on people living with HIV, and to support and strengthen community-led monitoring of essential health services and human rights in specific locations around the globe. From June to July 2020, ITPC worked together with Dristi Nepal (an advocacy organisation of women living with HIV and who use drugs), to gather first-hand accounts of the effects of the Covid-19 pandemic on women living with HIV and using drugs in Nepal, particularly in Kathmandu and surrounding valleys.

A participatory research tool was developed collaboratively by Dristi Nepal (hereafter 'Dristi'), and ITPC to capture and assess the impact of Covid-19. The qualitative survey tool used images and emoticons to encourage participants, regardless of literacy, to relate their experiences of healthcare services as people living with HIV, and to rank their government's actions on health provisions and human rights both prior to and during the Covid-19 pandemic. Every component of the tool's

COMMUNITY INDICATORS	RATING	COMMENTS
HIV testing	0.0	Handwritten Nepali text
Antiretroviral treatment (ART)	0.0	Handwritten Nepali text
Integrated Care (sexual and reproductive health, chronic care, harm reduction)	0.0	Handwritten Nepali text
Employment and income (economic vulnerabilities and impacts)	0.0	Handwritten Nepali text
Food security	0.0	Handwritten Nepali text

Figure 1: A page from a rapid community assessment of the impact of Covid-19 on health and human rights in Nepal, piloted by the ITPC and Dristi Nepal (June 2020)

development and implementation was collaborative, from the formulation of indicators, to its inclusive design and analysis of findings.

The tool included eight indicators:

- * HIV testing
- * ART
- * Integrated care (sexual and reproductive health and harm reduction)
- * Employment and income (economic vulnerabilities and impacts)
- * Food security
- * Safe place to live
- * Violence and stigma
- * Government accountability

While structured according to these indicators, narrative response fields were blank, encouraging women to relate whatever they determined to be relevant and meaningful. Two response fields for each indicator elicited information about users' experiences either prior to, or during the Covid-19 pandemic. The last section of the tool encouraged users to reflect on strengths and weaknesses in the public health and social support systems, and to articulate their most urgent needs for health and social services now and in the near future.

The tool focused primarily on the HIV treatment cascade, providing community-based organisations—in this case Dristi Nepal—with detailed, context-specific information about HIV testing, ART access, and viral load suppression. Data analysis demonstrated the negative effects of the Covid-19 pandemic on each step in the HIV treatment cascade.

Nepal's lockdown, instituted on 24 March 2020, closed all public and private facilities, except those providing 'essential services'.

Some public health services that were essential to sexual and reproductive health, such as family planning clinics and HIV treatment centres, were also closed or furloughed (Cousins, 2020). Yet, government ministries, bilateral agencies and community-based organisations also worked closely to plan the emergency response, including through arranging clinic referrals. Particular healthcare facilities – perhaps with greater experience of the treatment and management of people living with HIV – increased 'take-home' doses of medicines, and conducted visits at people's homes during the lockdown. Collaboration between government, international agencies and local advocacy groups was therefore critical in shaping and implementing Nepal's Covid-19-response.

Nepal's lockdown severely restricted people's movements. Despite the efforts of a government and civil society networks to provide support to people living with HIV, the lockdown had profound consequences for

women living with HIV and on ART. Leaving home during lockdown aroused the suspicion of families, neighbours and landlords, who questioned women's reasons for going out or seeking healthcare. Without public transport (which was prohibited or severely restricted during the lockdown), women had to walk lengthy distances to healthcare facilities, taking along their children who were also on ART. Due to changes in location and restrictions on movement, many women could not continue to access ART from the facilities in which they had initiated treatment or were previously retained in care.

Within some healthcare facilities, staff were fearful of COVID-19 transmission, and treated women with HIV with rudeness and disdain.

Numerous respondents reported that healthcare workers were annoyed by their presence and served them abruptly and unwillingly. Anticipating that their facilities would be overrun by Covid-19 patients, and perhaps hoping to delay or to avoid this, healthcare workers seemed to be discouraging patients requiring chronic care from continuing to burden the health service in the midst of a more urgent threat to public health: Covid-19. The continued provision of medicines for chronic care patients was deprioritised, as attention shifted, and fears were directed, to Covid-19.

Women themselves were afraid to seek ART and other healthcare services.

They worried that their transferral to ART facilities that were closer to where they were living during lockdown, might lead to breaches in patient confidentiality as new healthcare staff learnt their HIV-status. They also worried that their families and neighbours would discover that they were HIV-positive, and that they would face stigma or even expulsion from their homes (as some women had in the past).

Women described the stigma and discrimination endured after disclosing their HIV-positive status to their spouses, families or communities, prior to Covid-19. This was

evidence of the ongoing stigma and violence that women living with HIV confront in Nepal, with findings from the rapid assessment suggesting that living with HIV may deepen economic and social vulnerabilities in the Covid-19 era, as access to public services are restricted and as chronic care patients were deprioritised.

Findings from the rapid Covid-19 assessment foregrounded the difficulties that women faced in monitoring the efficacy of their own ART regimens, including in accessing biomarker tests (such as viral load and CD4 count tests). Both are critical to monitoring patients' quality of care, as described by Swann et al. in a critical article on 'Overcoming access barriers to affordable, lifesaving diagnostics and treatments for HIV and opportunistic infections' (July 2018).

These collaborative and participatory methods of the rapid assessment demonstrated starkly that the difficulties faced by women living with HIV and using drugs in Nepal had been exacerbated by the Covid-19 pandemic. Prohibitive difficulties in procuring a viral load test had a direct and negative impact on many people living with HIV in Nepal, as the switch to dolutegravir as the first-line ART regimen coincided for many with the outbreak of Covid-19. The requirement for VL testing prior to the switch delayed or complexified the ART regimen change for many, and exacted a direct cost for users. Women reported that they were required to pay for VL tests in the public sector, and struggled to access these tests due to the limited number of VL machines. Women worried that, with the growing burden of Covid-19 on the health sector, ART would no longer be free to access publicly.

In addition to findings about the HIV treatment cascade, data from **the rapid assessment tool revealed the real-world economic toll of the Covid-19-pandemic on an already marginalised and precarious population.**

Nepal's lockdown suspended economic activity, with casual workers (known as 'daily wages')

who only receive payment on the basis of piecemeal work, among the hardest hit. Most of the women in Dristi's community of care had lost their jobs during the lockdown. As a result, they were unable to pay their rent or provide enough nutritious food for their families. One woman explained that she ate only enough to fill 'half of her stomach' with each meal, to ensure that her children did not go hungry.

During lockdown, as their incomes evaporated, women went on daily searches for menial work such as 'household chores' (domestic work) to bring in an income, however small. They were often unsuccessful. As a result, these women and their families faced greater hunger and insecurity – with the threat of losing housing due to rent shortages looming larger with each passing week. The cash payouts promised by the government to support and sustain families were insufficient (RS 1000 per child), and were difficult or impossible to procure to the extent that they had been formally promised. When women succeeded in accessing cash grants, the amounts they received were significantly smaller than the stated commitments of local government officials.

The rapid assessment highlighted the strengths of civil society in collaborating with government partners to face a novel public health crisis. Through long-established relationships and coalitions, activists worked to secure the necessary permits to visit extremely vulnerable women, to provide emergency health services and food aid, and to prevent people from getting ill or, indeed, starving. In many contexts, the community-based response to the Covid-19 pandemic has been led by organisations that have coalesced around HIV treatment access, women's rights, and 'grassroots', civil society monitoring of state policies and expenditure. The work of Dristi Nepal – and the aspirations of the women it supports – convey the strengths of civil society in providing vital support to their communities of care and, moreover, in helping citizens to articulate their needs, priorities or indeed

demands for improved service delivery, particularly in the realms of health and social support.

This project has demonstrated the vast potential for grassroots advocacy organisations to gather and analyse detailed, context-specific data about the impacts of the Covid-19 pandemic on their communities of care. Using visual, participatory tools, these organisations can gather and disseminate data highlighting citizen's priorities for urgent improvements in health and human rights, while monitoring the performance of their governments. In this case, the design and implementation of the tool was used by community-based activists to provide

direct support to women living with HIV and using drugs – including ART literacy and awareness about Covid-19 prevention and management, psychosocial support, and food aid. Through rolling out the tool and collating its findings, Dristi forged stronger links with civil society organisations, bilaterals and government partners. From July 2020, when Nepal's lockdown was temporarily lifted, Dristi members played a leading role in new advocacy coalitions – in which members of civil society took stock of the impacts of the Covid-19 epidemic, assessed the government's performance, and formulated their future demands.



**NEPAL
POLICE**

24 HOURS

NEPAL ON THE CUSP OF THE COVID-19 PANDEMIC

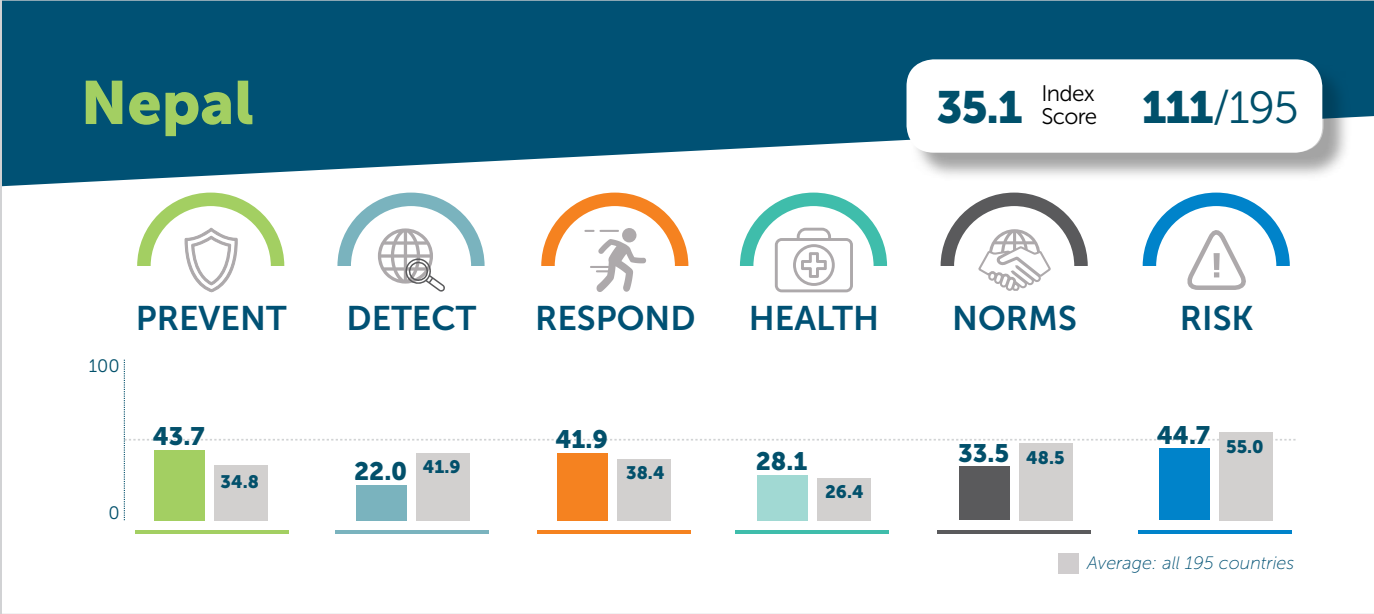


Figure 2: Key indicators in Nepal’s country profile in the Global Health Security Index (October 2019)

In recent years, Nepal has benefited greatly from global partnerships such as the Sustainable Development Goals, which have committed countries to ambitious improvements in health and human development. Between 2010 and 2019, the percentage of Nepal’s population living in extreme poverty (on less than US\$1.90 per day) decreased from 15% to 8% (World Bank, 2020). But, in 2019, a third of Nepali people subsisted on US\$1.90 - US\$3.20 a day, making them extremely vulnerable to economic shocks. Persistent high rates of unemployment (exceeding 50% of the working-age adults in 2019) had, for many years, driven Nepali

people to seek work abroad, with remittances constituting almost a third of annual GDP in 2019. The conditions of Nepali migrants have gained notoriety in recent years, with forced labour, servitude and debt bondage locking many into modern forms of slavery (McQue 2020; Labour Exploitation Accountability Hub).

Domestically, Nepal confronts its own challenges of inequality and exploitation, and these are strikingly gendered. According to the Gender Development Index, Nepal ranks 110th out of 144 nations for gender equality. Data remains sparse, but existing evidence shows that women have fewer years of schooling than



Figures 3 - 4: Screengrabs from the many reports and journalistic accounts about the exploitation of Nepali migrant labourers, Open Society Foundations (2014), and the Kathmandu Post (2020)

men (less than a third of women have reached secondary school), and higher rates of illiteracy and unemployment (Human Development Index 2019). Violence against women is common, and land ownership is rare: both powerful indicators of women's power and security in a society (United Nations Women 2017; United Nations Migration 2016).

UNAIDS estimated that approximately 30,000 people in Nepal were living with HIV in 2019. Notably, this figure was substantially higher by USAID estimates, at approximately 52,000 (2020). Nepal's HIV epidemic is concentrated among particular key populations: including women who sell sex, people who inject drugs, men who have sex with men, and seasonal

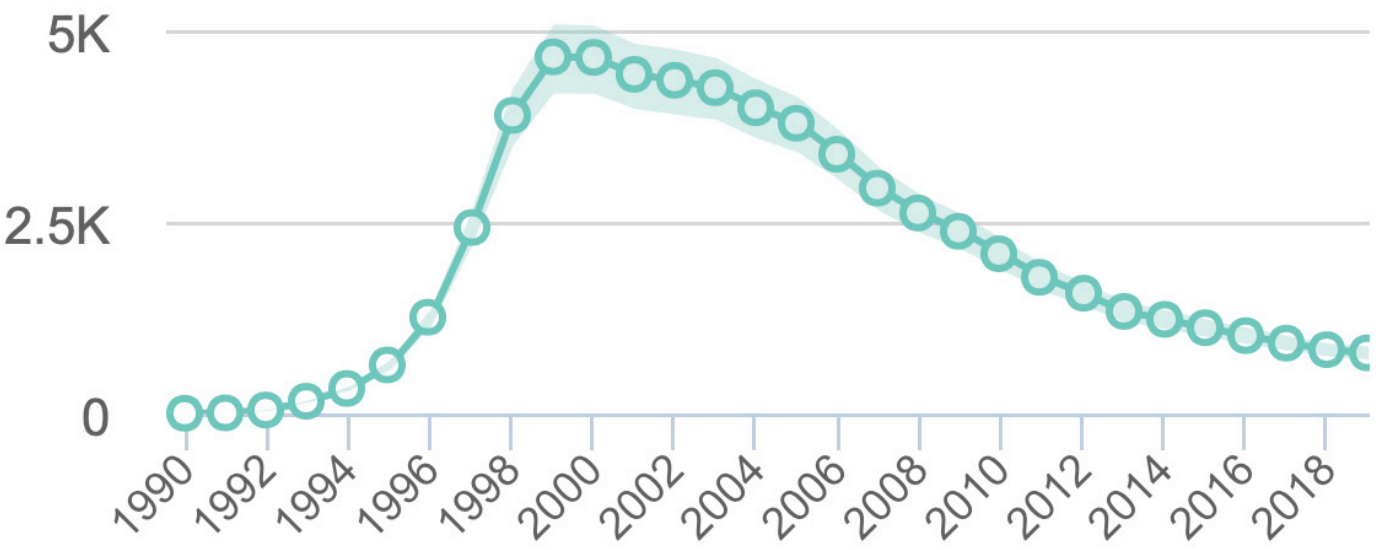
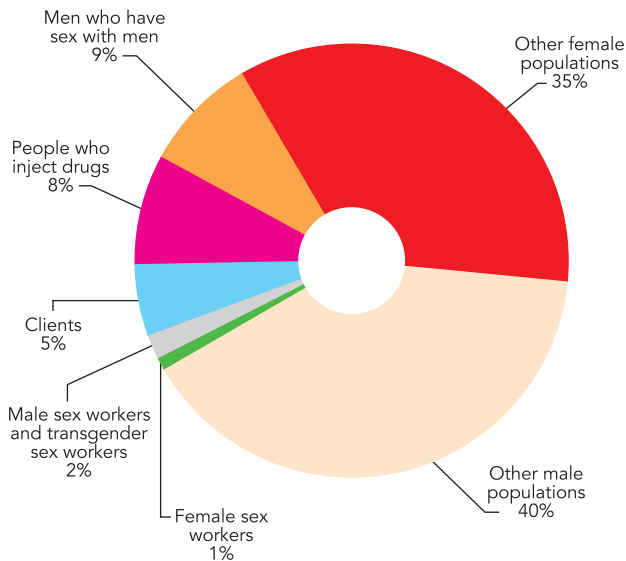


Figure 5: UNAIDS epidemiological statistics, "New HIV infections (all ages)." UNAIDS 2020



Source: National HIV infection estimation, 2015 (N = 37 807).

Figure 6: A diagram from Nepal’s National HIV Strategic Plan 2016-2021 estimates the proportion of adults living with HIV by key population, demonstrating high percentages of HIV infection among ‘other’ populations of males (40%) and females (35%) i.e. within the ‘general’ population rather than within specific, identified risk groups

migrant labourers (USAID 2020; UNAIDS 2020). While these groups bear a disproportionate burden of HIV infection, the epidemic is not confined to them alone. The strong associations between HIV and stigmatised behaviours, such as injecting drugs or selling sex, may obstruct access to HIV-testing, ART initiation and retention in care, particularly during the Covid-19 pandemic. As this research has shown, HIV remains highly stigmatised in Nepal.

In the last decade in particular, Nepal has made progress in providing public access to HIV testing and treatment (XHIVision 2020). But, in 2017, Nepal’s National HIV Strategic Plan described HIV treatment coverage as ‘unacceptably low’ (p. 9). Based on 2019 data, UNAIDS estimated that about a third of Nepali people who are HIV-positive do not know their status, and that fewer than half had suppressed viral loads (UNAIDS 2020). Prior to the

Covid-19 outbreak, ART coverage for adults and children in Nepal was estimated at about 63% (UNAIDS 2020).

Based on the strength of its health system, including its potential to prevent, detect and respond to diseases, and to protect public health, the Global Health Security Index Based ranked Nepal 111th out of 195 countries. When the Global Health Security Index was first completed, in October 2019, Nepal’s ‘infection control and availability of equipment’ within the health system was scored as ‘0’.

In January 2020, when the General Secretary of the World Health Organisation (2020a) declared the novel coronavirus outbreak ‘a public health emergency of international concern’, Nepal was poorly equipped to respond. Its first case of Covid-19 was confirmed in the same month, among a 31-year-old man studying in Wuhan (China) who had returned home to Nepal for a winter vacation (Shrestha et al. 2020). Because public laboratories lacked the reagents necessary to conduct PCR testing for SARS-CoV-2, the sample was collected in Kathmandu, but tested in Hong Kong. The Director of Nepal’s National Public Health Laboratory, Runa Hja, was quoted in The Himalayan Times, explaining the limits to Nepal’s testing capacity at this time: ‘Reagents come in bulk and are expensive. Though we have a proper laboratory to test the sample and skilled manpower as well, we can’t perform the test here as we don’t have reagents’ (Dhakal, 2020).

Confronting a public health crisis, Nepal’s Health Emergency and Disaster Management Unit counted the number of emergency hospital beds available for Covid-19 patients: total 55 (Ministry of Health and Population, Government of Nepal, January 2020). In January, Nepal closed parts of its borders with China and India, and restricted international arrivals (Piryani, Piryani & Shah, 2020). When the World Health Organisation declared Covid-19 a global pandemic in March 2020, Nepal faced critical shortages of medical

supplies to identify, prevent and manage the new disease. On 22 March, Nepal suspended all international travel, and closed its borders with India and China. Two days later, the government enacted a country-wide lockdown, closing all public and private workplaces and facilities (including schools, colleges and universities), and instructing citizens to remain at home except to buy food or seek medical attention. Faced with an indefinite lockdown, and fearful of Covid-19, approximately a third of a million people left Kathmandu in March 2020, seeking shelter outside the capital (The Himalayan Times 2020; The Rising Nepal 2020).

The evidence base on the impacts of Covid-19 on health and human rights is rapidly emerging. However, accounts from community-based organisations, at the frontline of healthcare advocacy and social support, remain scarce. If the response to the Covid-19 pandemic is to be effective, locally, nationally and globally – the needs and experience of citizens must be at the forefront of programme design and implementation.

In April 2020, the ITPC convened the first-known, community-driven virtual discussion about the potential impacts of the Covid-19 pandemic on people living with HIV. Hundreds of public health practitioners, including activists, researchers and clinicians, joined the discussion transcontinentally. This demonstrated powerful interlinkages within a global community of organisations that work to strengthen public health and human rights for marginalised populations, to confront and counter stigma, and to ensure that their nations' health programmes are empirically based and reflect advances in HIV prevention and treatment. Over the course of three hours, presenters outlined their hopes that the strength and resilience built through the global HIV response might empower health and human rights activists to react – quickly, collectively and consequentially – to Covid-19.

From June 2020 onwards, the ITPC began a new collaboration with advocacy organisations in five

countries to document, map and monitor the health and human rights impacts of the Covid-19 pandemic, particularly among people living with HIV. For the project's pilot, ITPC partnered with Dristi Nepal, a community-based organisation that aims to provide treatment and support for women who use drugs and live with HIV, as well as to provide education and psychosocial support services for these women.

When the Nepali government announced the partial closing of borders in March 2020 to curb the spread of the novel coronavirus, Dristi activists set to work immediately. As casual workers themselves, and with direct experience of the precipitous difficulties of accessing HIV treatment and other essential healthcare – even within the best-resourced of Nepal's health districts – Dristi activists knew that the pandemic would have seismic effects on the health system, playing havoc with the objectives of meeting UNAIDS '90-90-90' targets for 2020 (UNAIDS 2014). From the first notified cases of Covid-19 in Nepal, Dristi mobilised quickly and collaboratively to promote public health (through prevention and management of Covid-19), to strengthen access to essential health services, and to hold its government accountable for its commitments to an effective Covid-19 response that would also include women living with HIV.

With a growing need for data on the impacts of Covid-19 among people living with HIV in the global south, with little time, and with no potential for direct, in-person engagements, ITPC and Dristi designed and implemented a rapid assessment of the impacts of Covid-19 on the women within Dristi's community of care. To amplify the voices of these women, a participatory research tool was developed to assess their experiences of health and human rights, both before and during the Covid-19 pandemic. The methods, findings and recommendations from this collaboration are described below.



PROCESS UNDERTAKEN

Designing a community-led assessment of the impacts of Covid-19

Three primary methods were combined in conducting this rapid assessment:

- * A review of emerging evidence about Covid-19 and a critical assessment of the government of Nepal's pandemic response
- * The use of this evidence to design and implement a community-based participatory tool to capture and convey the impacts of Covid-19 on women who live with HIV, who sell sex and who use drugs; and
- * The analysis of findings to expand the evidence-base on Covid-19 in Nepal among community-led health advocacy organisations globally, and the sharing of these findings to inform civil society's future monitoring of essential health and human rights.

During the first half of 2020, while epidemiological forecasts about the mortality and morbidity of Covid-19 abounded, there were glaring gaps in information about the responses and needs of community-based organisations, within resource-constrained contexts. From the beginning of the pandemic in January 2020, Dristi and ITPC partners followed the emerging evidence base on Covid-19 epidemiology, and quickly realised that the pandemic was going to have a profound effect on access to public health services, in particular for the marginalised women whom Dristi supports. Nepal's lockdown measures from March 2020 closed or restricted public healthcare services, including sexual and reproductive health services (Cousins 2020).

In April 2020, the United Nations Nepal published *Covid-19 Nepal: Preparedness and Response Plan*. The Plan provided extensive and ambitious commitments to confronting and managing the Covid-19 pandemic, apportioned according to pillars. It provided a blueprint for the government's response as well as for advocacy organisations support government partners in providing access to healthcare and in protecting health and human rights, while also holding government accountable to its commitments.

From June 2020, the ITPC and Dristi built an evidence-base on emerging findings about the Covid-19 pandemic globally, focusing on its effects among marginalised women in Nepal. A Dropbox folder was established as a resource portal for project partners, populated with scientific articles, policy and programming documents, and news sources. ITPC and Dristi began to capture divergences between the official commitments of Nepal's government to managing Covid-19, and the lived realities of Nepali citizens. Through online conversations, three principal challenges to the continued health and survival of the women within Dristi's community of care:

- * Access to essential health services for people living with HIV and who use drugs (including antiretroviral treatment and sterile syringes);
- * Sexual and reproductive healthcare and antenatal care; and
- * Protection from violence and stigma, particularly among women, migrants, and people living with HIV.

Through these digital conversations, activists shared their priorities for healthcare and social support, and described how they were holding the government accountable. Online

conversations were typically held from 19:00 Kathmandu-time, and often in the midst of childcare, food shopping, and preparation for the following day's work. The ability to capture and share this information was premised on certain material resources, such as access to a computer or smartphone with a steady internet connection. Partners worked through the radical contingencies of the Covid-19-pandemic, powered by determination and by the urgent needs for healthcare and social support among women whose HIV status, whose use of drugs or whose income through sex work exacerbated their social marginalisation and vulnerability.

The impacts of Nepal's lockdown on the economy had drastic consequences for many of the women who were part of Dristi's network. Some had left Kathmandu or moved to other parts of the city to wait out the lockdown, facing disruptions in income and healthcare access, and facing greater poverty and hunger.

For most of Nepal's lockdown, Dristi worked in 'crisis mode', providing emergency food supplies and toiletries to the women in its networks. As news of Dristi's efforts spread, activists began to receive urgent requests for support from women facing violence, hunger and the disruption of chronic medical care (particularly ART). Having identified the need for community-led data about the local impacts of Covid-19, to drive greater government accountability, and to amplify the voices of marginalised women, Dristi and ITPC designed a participatory research tool.

The tool took the form of a 'citizen's report card', adapted from a participatory research tool developed in the Mzantsi Wakho study about ART adherence and sexual health among adolescents living with HIV in South Africa (Hodes et al. 2018; South Africa's National Department of Health et al. 2017). The tool aimed to challenge traditional power hierarchies. Rather than being 'reported on' – as was typical within health services such HIV treatment – women were the key authorities:



Figure 7: Clockwise from top left: Rebecca Hodes, Nilam Rai, Parina Subba Limbu and Helen Etya'ale during an online evening briefing (June 2020)

assessing the performance of their government in ensuring essential healthcare and social support services, and protecting human rights (Baptiste et al. 2020.). The tool was structured according to eight indicators, developed iteratively by ITPC and Dristi. These were based on a rapid review of the emerging evidence base on Covid-19 and HIV, in which gaps in information were identified by Dristi colleagues, in resonance with their experiences of the challenges in service delivery for women living with HIV and using drugs as the Covid-19 pandemic-hit Nepal. Working in partnership with ITPC, and using a new, customised research tool, Dristi moved to gathering and analysing participatory data on the critical health needs of the women in its 'communities of care'. Through an interactive process in which a series of indicators were established, these indicators could be used as the backbone for interviews and engagements with women living with HIV to encourage and empower them to assess the government's response to Covid-19 in relation to key facets of the HIV response, and of continued access to essential health and social services in the midst of the Covid-19 pandemic. Indicators were:

- * HIV testing
- * ART
- * Integrated services (sexual and reproductive health, chronic care and harm reduction)
- * Employment and income (economic vulnerabilities and impacts)
- * Food security
- * Safe place to live
- * Violence and stigma
- * Government accountability – i.e. are policies implemented?

Two response fields were provided for each indicator, to capture women’s experiences both before and during the Covid-19 pandemic. Images for each indicator were selected to be relevant specifically to current HIV treatment and testing guidelines in Nepal, and to strengthen visual recognition and conceptual understanding of the field of enquiry. A definition of each indicator was developed, and was shared by the tool’s facilitators as prompts for participants should they ask for more information on what was meant by each indicator.

Due to the limited time that would be available to conduct the tool with each participant, it was designed to be completed within an hour, and by participants themselves. For women who could not write, the tool could be completed by a facilitator who wrote out women’s responses verbatim.

The ITPC has developed an advanced community-monitoring tool that empowers civil society to monitor the HIV cascade along a continuum, following the ‘Five A’s framework’. This is a person-centred conceptual approach to monitoring the HIV treatment cascade that recognises interlocking determinants of access and adherence to essential medicines, incorporating availability, acceptability, affordability and appropriateness. This approach had been critical in the design and adaptation of research tools used in this rapid assessment. While extremely valuable in

Figure 8: Covid-19 Impact Assessment Tool

capturing the challenges and hidden costs of each step along the cascade of HIV testing, treatment and viral suppression, due to the limited time available for this rapid assessment, the framework was simplified into three questions used to prompt participants in completing the rapid assessment tool. With a focus on the eight indicators, participants were asked to describe their responses in relation to three questions:

- * Do these services exist?
- * Can we access them now?
- * Do they work for us?

Data collection and analysis

To generate greater familiarity and confidence among the community-based activists working with Dristi, ITPC and Dristi held an online training in late June 2020. The training aimed to introduce participants to quantitative and qualitative methods used in public health research, and to demystify quantitative and community monitoring research methods in particular. Dristi subsequently hosted trainings on community-led data gathering – both online and in-person – with its wider team of project managers and outreach support staff. In-person trainings were held outside, with all participants wearing masks and practicing social distancing to prevent the transmission of SARS-CoV-2. From the first week of July, Dristi began to implement the tool while visiting women who had requested the organisation’s support.

The tool followed a purposive, convenience sampling strategy, with Dristi aiming to engage participants of different ages, living within different domestic arrangements and locations, and working in different livelihoods. Prospective participants were provided with a package containing rice, lentils, cooking oil, sanitary pads and soap, but these packages were provided whether or not women agreed, or indeed had the time or privacy, to speak with Dristi activists and to find out about and use the tool. Acutely aware of the ways in which just their presence might arouse the suspicion of families or neighbours, Dristi workers facilitated the tool with caution. Participants were invited to use a made-up name if they chose, and each of the completed tools was anonymised. Dristi workers explained that use of the tool was entirely voluntary and there would be no negative implications for women if they chose not to participate. The first page of the tool






Availability	Accessibility	Acceptability	Affordability	Appropriateness
 <ul style="list-style-type: none"> ■ Do the required health services, medicines, commodities and supplies exist? ■ If so, do they exist when they are needed and in adequate supply? 	 <ul style="list-style-type: none"> ■ Are there long travel distances or wait times? ■ Are hours of operation convenient? ■ Are referral processes along the care cascade smooth? 	 <ul style="list-style-type: none"> ■ Is there a high quality of care? ■ Are services provided free of stigma and discrimination? ■ Are the human rights of patients promoted and protected? 	 <ul style="list-style-type: none"> ■ Do services require out-of-pocket spending on behalf of the client? ■ Is the service delivery model(s) efficient? ■ What is the sustainability of the response? 	 <ul style="list-style-type: none"> ■ Are services tailored to the specific needs of key and vulnerable populations? ■ Are age and gender considered in service packages?

Figure 9: The Five A's framework: A Person-Centred Conceptual Framework for Monitoring the HIV Treatment Cascade

included a consent box, which women ticked and signed if they agreed to participate.

Fifteen women within Dristi's 'community of care', who were living with HIV, using drugs or selling sex, completed the tool. They ranged in age from their early twenties to their mid-forties, and all were living with HIV.

Restrictions on movement curtailed the mobility of Dristi care workers, even though they had received official permission to visit vulnerable women as 'essential services' workers. On one afternoon, Kathmandu police clamped the wheel on the car that they were using to conduct visits, requiring hours of negotiation at a police station before they could resume their work. Limited airtime, for both Dristi workers and for the women they supported, also derailed appointments and delayed data collection. Despite these challenges, fifteen rapid assessments using this primary, participatory research tool were completed by the third week of July.

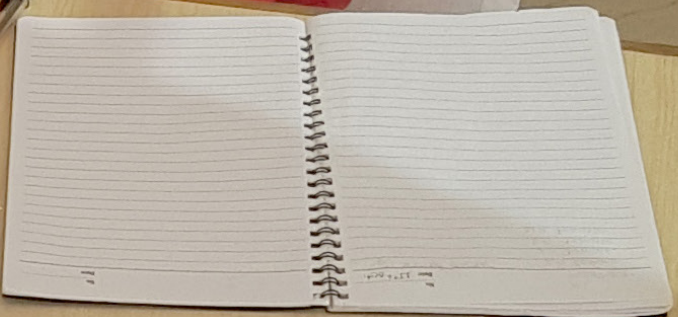
As with the tool's design, the processes of data analysis were layered and iterative. Each of these assessments was translated from Nepali

into English through a two-step process: with text translated by one researcher, and then checked and co-translated by a second researcher. Both Nepali and English versions of the completed tools were uploaded onto a password protected digital data-sharing platform.

Data was interpreted by Dristi and ITPC colleagues using two forms of qualitative analysis. First, common themes were identified according to the eight indicators that structured the tool. Second, open coding was used to reveal findings that were prioritised by participants across different indicators. Findings were shared, checked and summarised through digital discussions among Dristi and ITPC workers, in which each of the assessments was analysed, and a consensus of its key messages developed. Findings are similarly presented below: with results on each indicator, followed by a cross-cutting description of participants' most fundamental concerns for the health care and human rights of women living with HIV in the era of Covid-19 in Nepal.



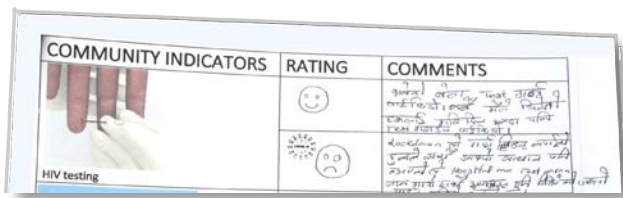
Handwritten notes on a piece of paper, including a logo and some text. The text is partially obscured and difficult to read, but appears to be related to a health or medical report.



FINDINGS

HIV testing and treatment during Covid-19

All of the women who completed the rapid assessment tool had tested HIV-positive before Nepal's lockdown began on 24 March, and all had been initiated onto ART. This was evidence of Nepal's successes in scaling-up HIV testing and treatment as a part of global commitments



COMMUNITY INDICATORS	RATING	COMMENTS
	😊	पहिले कोरोना लागेको थियो, तबसँगै मलाई एचआईभी परीक्षण गर्न सकिने थियो। तबसँगै मलाई एचआईभी परीक्षण गर्न सकिने थियो। तबसँगै मलाई एचआईभी परीक्षण गर्न सकिने थियो।
	😞	कोरोना लागेपछि एचआईभी परीक्षण गर्न सकिने थियो। तबसँगै मलाई एचआईभी परीक्षण गर्न सकिने थियो। तबसँगै मलाई एचआईभी परीक्षण गर्न सकिने थियो।

Figure 10: HIV testing: '[Before Covid-19] I got support from the ART centre and it was easy. But due to Covid-19 now it's not possible to go out. I don't have a vehicle so it's hard to do any kind of testing'

to reaching UNAIDS targets of 90-90-90 (UNAIDS 2014). It was also evidence of women's trust in Dristi as an advocacy and support group for women living with HIV. During Nepal's Covid-19 lockdown, restrictions on personal movements, bans on public transport, and the ad-hoc tapering of healthcare services obstructed HIV treatment access and retention in care.

"Due to Covid-19 we are unable to move or visit the lab [for HIV-testing]." –Anita, 32 years old

Because they had already tested HIV-positive, women interpreted the indicator about 'HIV-testing' in relation to the access and affordability of biomarker tests. Viral suppression is a key component of Nepal's HIV response in meeting the third of the '90's targets. But all participants reported problems accessing viral load testing prior to the Covid-19 pandemic, including through the direct costs allocated to viral load testing at public healthcare facilities. Charging for viral load tests was understood as a kind of tax on continued to access HIV treatment, similar to the charges levied for kidney- and liver-function tests required for women who used drugs (Dristi/ITPC coding and analysis session, 30 July 2020).

"Covid-19 has affected us very badly. It is difficult to get testing done and viral load done on time." –Sima



ADVOCACY ALERT 1

Free access to viral load testing

As Nepal changed public ART provision to a dolutegravir-based regimen, a viral load test seemed to become requisite for public access to the new ART regimen. While UNAIDS had waived Nepal's payment of royalties for the

DTG-based regimen (2017), this did not mean that access to the regimen was free-of-charge, as switching to the DTG-based regimen required viral load testing. Participants therefore felt that they had no choice but to pay for viral load testing to access the new regimen – one example of the importance of considering ‘affordability’ alongside ‘access’ as key determinants in the HIV treatment cascade.

Difficulties in accessing viral load testing and in continuing to access ART became acute during the Covid-19 pandemic. Transport was suspended or restricted and, in order to continue to access HIV medicines, most women had to walk. As Nisha (24 years old) explained: ‘During the lockdown, there was restriction in transportation mobility, so I went by walking to have my ART medicines. It took about a total six hours of walk to get to the ART clinic and return to home’. Another walked for an hour and a half to reach an ART facility, where she collected ART for herself and her husband. Next she walked to the prison where her husband was jailed to drop off his treatment, and finally, she walked home.

Women with HIV feared attending public health facilities, where they thought they may be exposed to the novel coronavirus.

"It's difficult to get ART due to Covid-19. There are a lot of contaminated people in hospitals, and everyday there are new case findings, so it's scary to go to the hospital and get ART." –Rakshya, 40 years old



ADVOCACY ALERT 2

Multi-month dispensing of ART

Some healthcare workers seemed, in turn, to fear their patients. One participant explained that she had been satisfied with the care she had received in a public health facility before the pandemic, but that she felt badly treated by doctors in recent visits. Her frustration was worsened because of the sacrifices made to access health services, including walking to the hospital and risking potential exposure to the virus, only to be met with a hostile doctor.

Women also felt that having to leave their homes to walk to health facilities for ART refills raised the suspicion of their neighbours. As Nisha (24 years old) explained:

"During the mobility restriction, I was compelled to bring my ART by walking. The people around used to suspect me of where I was going from time to time and that made me very uncomfortable."

–Nisha, 24 years old

Many worried that the necessity of going to clinics to fill their medical prescriptions would ‘out’ their HIV-status, and that they would face violence and discrimination from their families and neighbours.

The necessity of integrated care

Nepal's Constitution guarantees free access to basic health services for citizens, including HIV testing and 'first-line' HIV treatment. Nepal's National Strategic Plan 2016-2020 reported that, as of June 2016, ART was available at 65 sites within 56 districts. It stated: 'Most antiretroviral therapy centres in public health facilities have adopted a one-stop shop approach by providing antiretroviral therapy, including paediatric antiretroviral therapy, elimination of vertical transmission, services for sexually transmitted infections and HIV testing services together'.

However, the same National Strategic Plan included the findings from a review of Nepal's HIV response, which described 'fragmentation' and 'insufficient integration' as among the greatest 'systemic' challenges in Nepal's HIV response (p. 13). The plan recommended that a comprehensive package of healthcare services be made available in combination with HIV prevention and treatment, including TB, sexual and reproductive health, and maternal and child health (p. 13).

While completing the rapid community assessment tool, women living with HIV were asked to assess and describe their experiences of 'integrated care' at ART facilities. No participants were accessing integrated services, including TB testing and treating, sexual and reproductive health, and maternal and child health, as stipulated by the Plan. The need for integrated services was captured within the assessment's focus on 'priorities'. After continued access to free, public ART, and improved access to free biomarker laboratory tests (specifically viral load), integrated care was the greatest priority.



ADVOCACY ALERT 3

Re-linkage to care for people living with HIV who have fallen out of treatment services

"We don't have inclusive health services. In the ART clinics we receive treatment [for HIV]. When there are other health issues we need to visit other hospitals, but I feel we are not treated properly there. So the government should think about 'one-door' services. Inclusive and comprehensive health services should be provided within the ART clinics."

–Alisha, 35 years old

"I wish to get HIV treatment, viral load, CD4 count and lab tests done in a convenient environment and quickly. I wish to get all facilities in one place and in a convenient environment."

–Sima, 35 years old

When asked if integrated care had been available in the time before the Covid-19 pandemic, Saru (age unknown), stated: 'It was never available at one place. We have to visit different, respective health centers for treatment [including sexual and reproductive healthcare and maternal and antenatal care].'

"The centre where I am taking ART doesn't give other health services. If any other conditions or disease occur I need to visit other hospitals." –Bina

This data showed clearly that ART clinics lacked integration with other essential healthcare services. Because women could not receive treatment for opportunistic infections, chronic conditions, sexual and reproductive health, or maternal and antenatal care at ART facilities, they had to travel to other healthcare facilities – often a number of different hospitals - to seek treatment.

Growing poverty and hunger

The Covid-19 pandemic, and the economic shutdowns enacted by many countries to slow and to stop it, has sunk the globe into an economic recession (World Bank Group, June 2020). Decades of developmental gains, in health, education and employment, are in

jeopardy. The pandemic and its economic shocks are being felt most acutely in poorer countries like Nepal, where the disease weighs heavily on an already overburdened healthcare system. Economic impacts include job and income losses, disruptions to the food supply, school closures and lower remittances flows. Tourism accounts for approximately a third of Nepal's GDP and, as a spout for economic growth and employment in the tourist sector for 2020, Nepal's government had launched the campaign, 'Visit Nepal 2020'. The pandemic laid to waste its plans. The World Bank projects a substantial deacceleration for Nepal's economy for FY2019/20, with a projected 1.8% decline.

Before Covid-19, the majority of women interviewed had worked in the informal labour sector as 'daily wages' or 'casual' labourers. The economic shocks of the pandemic hit Nepal's informal labour market with full force, and most of the women surveyed had lost their jobs during the lockdown.



Figure 11: Official branding for Nepal government's 'Visit Nepal 2020: Lifetime Experiences' tourism promotion campaign



"[Before Covid-19] I was doing my small job so it was pretty convenient to make the ends meet. [During Covid], since I had no work, I had no earnings, and it was difficult to make the ends meet. I have my daughter with me and it is hard to sustain being a single woman. There were no circumstances to do work." –Jeetu, 32 years old

Food aid and social support for people who have lost income and face hunger and illness due to COVID-19



Figure 12: Jeetu’s responses capture the negative impacts of Covid-19 on employment and income

Together with many other women, Sima (35 years old), struggled to pay her rent, but was unable to search for work as she was forced by her landlord to stay indoors. She explained: ‘Due to Coronavirus, it’s been difficult for me because my workplace cut off my wages. So I am having problems... I don’t have money to pay rent and live in with my landlords. They don’t allow me to go out and work because they think I’ll be the carrier of Covid, that I may be contaminated. Since lockdown, I don’t have work so I am not able to eat good and nutritious food... They [landlords] treat me badly.’

To ensure they could continue to buy food and pay rent, women searched for any source of income, offering to do domestic labour or ‘household chores’ for their families or neighbours.

Emergency government grants provided some economic relief, but women had to negotiate an unwieldy bureaucracy to access these grants, and their amounts were relatively small (around US\$8 per person in June 2020). Dristi and other community-based organisations began providing emergency food aid in June 2020, to stop hunger and malnutrition. Some women were able to access food via their children’s schools. But the majority of women reported difficulties in feeding themselves and their families during the Covid-19 pandemic. To ensure adequate nutrition for their children, some women, like Bina , went hungry:

"I keep searching for work. Some days I find work, some days I don't. I hardly manage for food. There are days when I don't eat and feed my child due to lack of food... There is always a lack of food in my house. I need to feed my children even while I eat [only enough to fill] half of my stomach. We eat when I get work. Otherwise, we don't eat." –Bina

A number of women described the positive impacts of previous food initiatives (such as Nepal's Nutrition Programme, which had gathered momentum in the push to reach the Sustainable Development Goals). But the implementation of these development programmes – even for goals as fundamental as childhood nutrition – was uneven prior to Covid-19. Once the pandemic hit, as money and food ran out, women sought support from whichever networks of aid were still active. Rupa (36 years old), for instance, was able to get food for her family from her daughter's school. But this was only a 'once-off', after which her daughter had gone 'door to door' to ask for food.

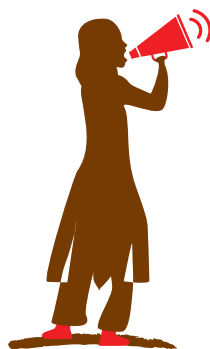


CONCLUSION

Lessons for using community-led approaches to evaluate health programming for people living with HIV and TB in the age of Covid-19

The Covid-19 pandemic has exposed critical inequities in global health provision. It has also emphasised the power and effectiveness of community-based, activist organisations in confronting and managing public health crises, drawing deeply on their inlaid experience of responding to and treating diseases, and of promoting health and human rights. To be effective at local levels, civil society and activists organisations must play a key role in developing operational research studies, implementing their methods, analysing their data, and disseminating their findings, among local, provincial and international audiences. It is critical that primary research about the effects of Covid-19 on local communities be led, and their findings shared, by advocacy groups with many years of experience of working within local contexts.

The ITPC and partner organisations have shown that community-led monitoring can improve healthcare services, locally and systemically, while empowering communities to hold governments accountable (Baptiste et al. 2020; Oberth et al. 2019). With experience of using community-led tools to monitor and improve health services, and with evidence that these tools work, the ITPC began to collaborate with Dristi Nepal from June 2020 to monitor the impacts of Covid-19 on health and human rights among women living with HIV, who use drugs, and who sell sex, in Nepal.



ADVOCACY ALERT 5

Support for survivors of gender-based violence, and advocacy for gender equality in Nepal

Dristi's work confronts many socio-economic and cultural barriers: focusing on the highly-stigmatised and marginalised populations of women who use drugs, sell sex and live with HIV, and as a small-scale, community-based group. For the ITPC and for other multinational health advocacy groups, who have – over the last decades - focused on improving access and quality of human rights and healthcare for people living with HIV, the lessons of the HIV epidemic are paramount. To instil and propagate change within local societies, based on a model of 'bottom-up', rather than 'top-down' advocacy, it is essential to partner with advocacy organisations that will champion the needs and the rights of 'key populations' within their own neighbourhoods, cities,

districts and nations. These groups are crucial to an effective and just response to the Covid-19 pandemic, and their work – by Dristi Nepal for instance – will ensure that local and national healthcare commitments, plans and programmes are informed by the evidence that these organisations have gathered about their own needs, in relation to the global pandemics of HIV, TB and Covid. The first advocacy lesson from this collaboration is the necessity of partnering with local, community-based organisations to understand and then to plan to improve the healthcare and human rights responses of governments and healthcare facilities for people living with HIV.

From June 2020, Dristi adapted its advocacy work to meet the survival needs of these women – providing food aid and toiletries to women who had lost their income and whose mobility was severely restricted under Nepal’s lockdown. While visiting women who had contacted Dristi directly in need of urgent support, Dristi shared a participatory tool that captured and relayed their experiences and priorities for healthcare and human rights. Their responses provide a new evidence-base on the impacts of the Covid-19 pandemic on marginalised populations in South Asia, and the global south more broadly. They show that the Covid-19 pandemic threatens to halt or even reverse hard-won developmental gains sought through UNAIDS’ targets of 90-90-90. The impacts of Covid-19 on public health systems has been so severe that the pursuit of these ambitious development targets may not only be weakened or delayed, but abandoned altogether. The emergency response precipitated by Covid-19 has subsumed other health programmes, to the detriment of continued access to HIV treatment together with care for other infectious and chronic conditions. As described above, Dristi’s advocacy, and insistent collaboration with national health and human rights agencies such as Nepal’s Ministry of Health and Government, has demonstrated the flexibility and adaptability of community-based organisational

responses managing the emerging health effects and socio-economic fallout of the pandemic (including in the loss of employment, the threat of hunger, and the difficulties of women living with HIV in accessing medicines for themselves and their families (including their children). The second advocacy lesson here is that community-based organisations must define and disseminate their needs and priorities for improving access to health and human rights for people living with HIV and TB during the Covid-19 pandemic. ITPC will partner with these groups to ensure that they establish, implement and analyse data that tracks the performance of their governments and healthcare services, to inform future advocacy interventions.

Civil society organisations must now support their communities of care, while engaging critically with government to ensure accountability and transparency in the Covid-19 pandemic response. A new evidence base on the impacts of the pandemic on the health and livelihoods of people living with HIV provides a powerful source for locally-informed and -directed advocacy, and greater government accountability, as Covid-19 collides with the health and human rights challenges that community-led HIV advocacy organisations have devoted decades to solve.

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