

+ The Newsletter of the Asia Pacific Network of PLHIV

APN NEWS



**APN
PLUS**
POSITIVE CHANGE

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About US

APN+ was established in 1994 to create a collective voice for PLHIV in the Asia Pacific region. Our mission is working together to improve quality of life for PLHIV in our region. All country representatives to our Board are positive leaders. We work alongside 30 country members represented by national networks of PLHIV or smaller organisations of PLHIV.

Steering Committee

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Ms Sina Soo - Cambodia (Co Chair)
Mr. Khurshedul Alam - Bangladesh (Treasurer)
Mr. Vu Tran Dung - Vietnam (Member)
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2014 marked our 20th year in operation. It was a year of reflecting on what we have achieved to date, and on how we can continue our fight for PLHIV in the Asia Pacific.

With the HIV funding crisis deepening and impacts being felt across the region, our work is increasingly more challenging and demanding. PLHIV funding is under real threat at a time when it is critically needed. We continue, however, to complete our work, execute our advocacy campaigns and work towards securing some victories.

Treatment access continues to be a key focus of our Peer Led Advocacy campaigns. In 2014 new medicines were developed that cure Hep C but nobody could afford them! Our advocacy efforts, along with our supporters, has achieved good results. Prices have started dropping in countries where these medicines are available. Access to 2nd and 3rd line HIV medicines remain a big challenge for many people. Free Trade Agreements with TRIPS-Plus Intellectual Property Rights (pricing and patents) will further keep these medicines out of reach for the majority of PLHIV and people living with Hep C.

This is why we continue our efforts, to give the power of knowledge to our networks and community on intellectual property literacy. Our work on building knowledge and mobilising community in this way helps us to be advocates and to take the lead in responding to

the crisis of medicines that are unaffordable.

APN+ continues to advocate for gender equality and to maintain focus on sexual reproductive health rights. Positive women's working groups have been able to access pap smears and continue to break down barriers that prevent full participation in political, economic, social and cultural aspects of their lives.

APN+ Leadership, under the direction of network members and in collaboration with strategic partners, builds a community force with knowledge and advocacy capacity for a positive change. However results of our Leadership and Peer Led Advocacy is sometimes dependent on governments and key stakeholders being willing to engage with us. This barrier has always existed, but we continue building our force and keep them engaged.

On the next pages you will read highlights of our current and upcoming work. Our efforts always represent the voice and needs of people on the ground when we influence national, regional and global policy, so that people living with HIV can have a better quality of life. We continue our work in solidarity.

Mr. Edmund Chak (Co-chair)

Ms Sina Soo (Co-chair)

Mr. Khursedul Alam (Treasurer)

Ms. Jahnabi Goswami (Member)

Mr. Vu Tran Dung (Member)

CAT-S PHASE II ROLL OUT



APN+ and partners in Bangladesh, Indonesia, Laos, Nepal, Pakistan, the Philippines and Vietnam have collaborated on the Community Access to HIV treatment, care and support services study (CAT-S) since early 2011. Phase I generated baseline evidence in HIV treatment, care and support access experience for community peers. What are the barriers on the ground? What is really happening? Phase II builds on this evidence to conclude the study at the end of 2016.

Phase II roll out began in March 2016 with a workshop to prepare national sub recipient teams for field data collection between June and August 2016. The 5-day training program supported participants to strengthen technical skills in data collection and to facilitate a country level training program for data collectors. The workshop also supported each country team to schedule a detailed country plan for study implementation.

CAT-S Phase II study will further develop baseline data to measure longitudinal changes in key issues identified through phase I. This information provides us with the community generated evidence we need to advocate to regional and national level policy makers

and program planners. This study is really important to our advocacy work around improving treatment and support access. It is especially important that community have been involved in leading and driving the entire process. Representing PLHIV, implemented by PLHIV for the benefit of PLHIV. We look forward to seeing the changes between Phase I and Phase II of the study and to building on this work further with our regional KAP program.



REGIONAL KAP PROGRAM (NEW APPLICATION TO GLOBAL FUND)



The regional concept note is the first of its kind to support a consortium of regional KAP networks (APTN, APNSW, ANPUD, APN+) in partnership with networks in 11 countries: Bangladesh, Cambodia, Nepal, Sri Lanka, Thailand, Philippines, Pakistan, Indonesia, Myanmar, Lao PDR and Vietnam.

In January 2015 we received notice that the grant approvals committee had endorsed the technical review panel's recommendations. It was commended for being strategically focused, demonstrating regional value added and the potential to increase uptake and retention of high quality HIV care and treatment services for PLHIV and KAPs across the 11 countries.

The program seeks to address critical programmatic gaps by increasing access to, uptake and retention of HIV care and treatment services amongst female sex workers, people who inject drugs, and transgender women. Interventions include community level approaches to increase rates of HIV counselling, testing and entry into care, community-led studies to assess barriers to accessing care and retention, advocacy activities to support an enabling environment for HIV prevention and treatment through changes in the existing legal and regulatory frameworks, and the establishment of community-led HIV counselling and testing demonstration sites.

It capitalises on the strength of regional networks who

have more influence than country-level networks of the targeted key populations, which may not be well positioned to advocate on key legal and regulatory issues. There is a clear focus on key populations with strategic consultations and involvement of community based organisations /national networks in program delivery and implementation.

The regional concept note builds on the existing work of APN+ in the region, and uses the existing and effective network of the regional organisations to reach out and build the capacity of new network organisations brought in as sub-recipients, thereby bringing together and bridging the key populations of PWID, transgender women and sex workers. MSM are included in one activity only as they are involved in on-going activities from two existing Global Fund grants. The grant total is USD3.2million over 30 months with 30% allocated regionally and 70% allocated for country networks.



CCM CAPACITY BUILDING INITIATIVE

With funding support from Robert Carr Network Fund APN+ implements a program to build community capacity to engage meaningfully in the GF New Funding Model process of the Global Fund Country Coordinating Mechanism (CCM).

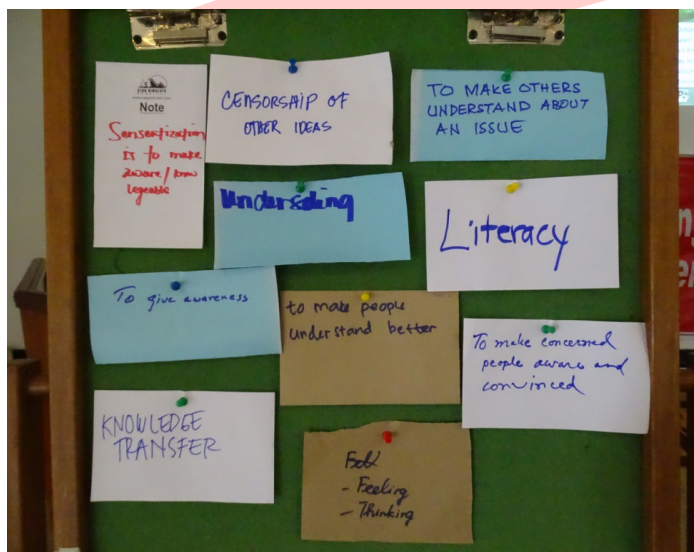
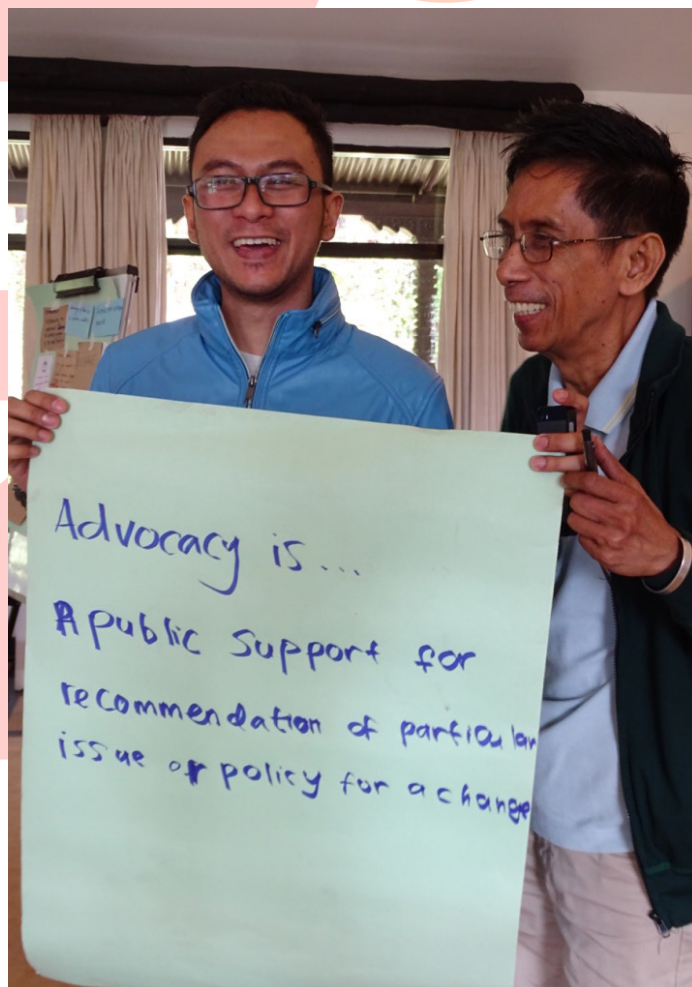
The CCM has underpinned the Global Fund since its beginnings in 2001. It is a mechanism structured to reflect national ownership and participatory decision-making via multi-stakeholder collaboration. Government, private sector, civil society actors represented by NGOs, faith-based organisations, bilateral, multilateral and international partners and NGOs, as well as, people living with one or more of the three diseases are at the table, all bringing different values and work ethics. The aim is to work together to submit proposals that reflect an analysis of existing gaps in national plans and responses, and to collectively oversee grant implementation to ensure successful outcomes.

With so many stakeholders at the table it is difficult to truly collaborate. Some are more powerful than others. In Sept 2014 the Technical review panel reported dissatisfaction with the way that the community and KAP involvement was not reflected in the interventions or budgets. There was agreement that the effective and meaningful involvement of community and KAPS was a political necessity rather than a benefit to the overall outcome of the process.

To address these shortcomings it was concluded that the CCM must make more effort to ensure representatives were involved in country dialogue,

grant making processes, grant management and implementation.

APN+ partnered with 7 PLHIV networks in Cambodia, India, Indonesia, Myanmar, Nepal, Pakistan and Vietnam to roll out initiatives that increase knowledge, understanding and skills to engage in the CCM. The design of activities in each country varied according to local contexts and to meet local needs. However, during the project preparation stages it was recognised there was a need for a regional platform of community representatives to the GF CCM. The platform serves as a space for country level community networks to learn from each other and for regional networks to build stronger coordination mechanisms to ensure robust and united participation in the NFM mechanism.



COMMUNITY BASED TESTING: REGIONAL STUDY

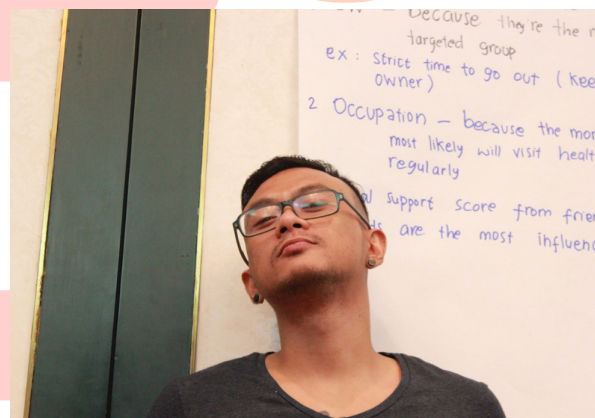


The study considered methods, local definitions and differences across countries, types of VCT implemented and why they were chosen and most importantly to what extent such methods had led to uptake among MSM and transgender communities.

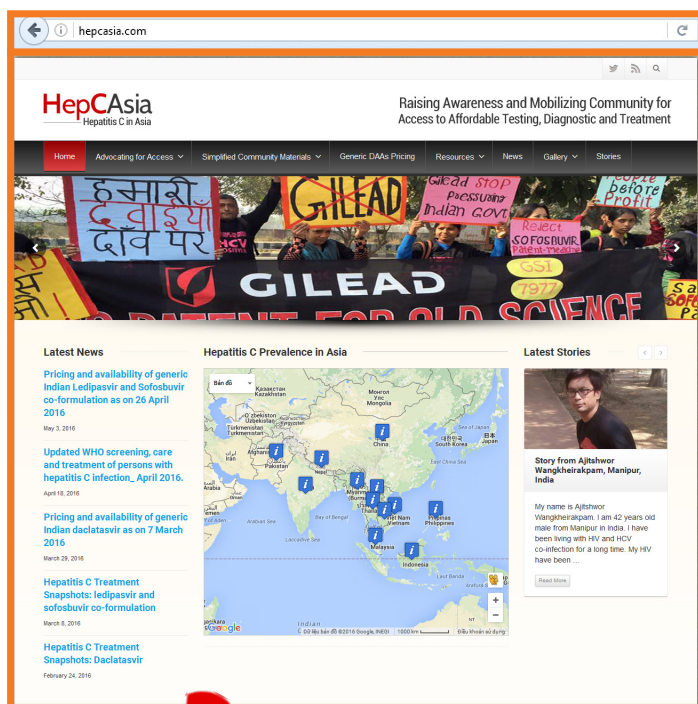
In its recommendations the study considered interventions that could have lasting impact beyond MSM and transgender women to all key populations at risk of HIV. Recommended interventions are multifaceted and seek to address structural factors that influence the social, economic, political environments determining HIV risk and vulnerability. APN+ will use this evidence to support national networks with future planning in community led VCT testing initiatives.

APN+ is involved in a regional study to support evidence around community based testing as a viable way forward in the response for PLHIV communities and KAPs. Community based testing is critically important because community peers know their community and can address barriers to HIV testing and treatment. The CBT regional study was undertaken as part of the GF DIVA program, content has been finalised and is currently being reviewed by UNDP regional office, the PR of the MSA-DIVA grant. Dissemination is expected in early June 2016.

The study assesses innovative models of community initiated voluntary counselling and testing (VCT) services, what makes them effective and how they can be improved. Reporting on these innovations will support the development of effective, evidence-based approaches to be applied in communities across the Asia Pacific region.



ONLINE COMMUNICATIONS



KEEP
CALM
AND VISIT
OUR NEW
WEBSITE

GENERIC PHARMA MEETING BANGKOK

In late May 2015, APN+ organised a meeting with key generic pharmaceutical companies from the region, with financial support from UNAIDS. The meeting aimed to discuss the accessibility of new hepatitis C drugs, as well as second and third line HIV drugs. Eight generic companies from India, Thailand, Indonesia, Bangladesh and Pakistan attended the meeting with PLHIV and other key community leaders from the region.

Key discussion points included the production of new hep C drugs, patents on these new drugs and to share plans on how to tackle patent and other IP related issues in order to be able to produce the drugs locally. The role and advocacy efforts of community groups was also discussed.

Not many of the companies were producing the new hep C drugs yet so the meeting provided an important opportunity to explore how

these medicines can be accessed affordably by people in other countries. Additionally, the meeting brought community and generic company representatives together and created the space to discuss the many issues faced by people trying to access hep C and second and third line HIV drugs in the region. This is the first time in history such a meeting has ever happened between the community and generic companies at the regional level.



PATENT OPPOSITION TO NEW DRUGS

APN+ continue addressing issues on patent and intellectual property rights related to access to medicines. Recently APN+ issued a statement calling on country governments that are part of Regional Partnership Economic Partnership (RCEP) trade agreement to reject all TRIPS-Plus provisions being proposed by some developed countries. The statement issued by APN+ is available on APN+ website. Additionally, our networks in ASEAN countries have also sent out a press note expressing concerns about the negative impact of such IP provisions in RCEP.

As part of building capacity of our networks and addressing issues of IP and access to medicines, APN+ has been implementing a program in Indonesia, Vietnam and Myanmar with funding support from Aidsfonds. Key activities of this program include trainings on IP and its impact on access to medicines, national level meetings with government and other key stakeholders, reviewing country IP law to incorporate all TRIPS flexibilities etc. This program will end in 2018.

Additionally, APN+ and country networks have been actively advocating for affordable new hep C drugs. Despite these new drugs being available in a few countries, access to these medicines remains a big challenge in the majority of countries in the region. In order to allow generic competition APN+ in collaboration with two local groups filed oppositions against the granting of patents on Sofosbuvir and Daclatasvir (new hep C drugs) in India. The Indian authority initially rejected the patent claim by Gilead (pharmaceutical company) but in May this year the decision was overturned and granted the patent on Sofosbuvir.

Currently APN+ and local partners in India are in discussions to file an appeal. The case on Daclatasvir is pending and we hope the decision from the Indian authorities is in our favour. APN+ will continue working closely with our country networks and other partners to address issues related to IP and access to medicines in future.

UN HIGH LEVEL MEETING ON AIDS

The next HLM (UN General Assembly High Level Meeting) on HIV will take place in New York June 8th to 10th 2016.

This one will be different from earlier ones, and in many ways more important. In previous ones (the last was 2011) countries have had to report on their progress towards targets, the end point being 2015 when the MDGs (Millennium Development Goals) finished. HIV had its own specific goal, MDG6. Governments had to provide progress reports against a whole series of indicators, and declarations were made at the HLMs. The most recent was in 2011 and this was a strong commitment of nations to fighting HIV.

Now the MDGs are over and the SDGs (Sustainable Development Goals) have replaced them. There is no specific goal any longer for HIV, just one global health goal. There might never have been another HLM again were it not for activists pushing to get a meeting to ensure commitments are made to continue and strengthen the fight against HIV, even as it slips from the world's agenda. We are now at a cross roads. Unless the global response is intensified now and over the years to come we may start slipping back and losing the progress we have made.

There will be no individual country reports this time. There will however be a declaration and commitments. It is the strength of the declaration and the commitments that will have a great influence on whether we manage to continue to fight and possibly end AIDS by 2030, or not! It will influence whether there

will be money to fund the response, including our treatment!

Will there be sufficient funding for the response? Will the language of the declaration be strong enough? Will community be involved as equal partners in the response? Will countries step up and fund their own HIV responses as donors pull back? Will a strong human rights approach to addressing HIV be sustained? We all need to lobby our own governments to make sure that the answers to all these questions will be 'YES!'

So please, through your own PLHIV networks in each of your countries, get in touch with your own governments and start pushing them to make sure that the outcomes of the 2016 HLM are strong.



COMMUNITY BUYERS CLUB

APN+ and **PLHIV networks** in India, Malaysia, Indonesia and Vietnam have been assisting people to obtain new hep C drugs. Community managed buyers clubs have been established in these countries and have supported several people who urgently needed generic version of sofosbuvir, daclatasvir and ledipasvir (hep C drugs) for their hep C treatment. These drugs are currently not available in the majority of countries and where original versions are available the cost is extremely high. As a result APN+ and PLHIV groups in the above mentioned countries started helping people through community run buyers club to obtain generic version of these medicines produced in India and Bangladesh. Please contact us for more information.



Ayu Oktariani, 29, from Bandung, Indonesia shares her story ...I've known about my HIV-HCV co-infection since 2009.

I started ARVs when I

tested positive so my HIV is managed. When I was diagnosed my Dr suggested interferon injection, but treatment and diagnostics was too expensive. In 2015 I did the test to confirm my hepC viral load was high and impacting on my health and CD4 count.

In 2015 I heard about getting newer, cheaper HCV treatment from India. I first had to find a Dr to prescribe 6 months of treatment, so I travelled to Jakarta for a treatment consultation. By July 2015 I started a combination of ribaririn and sofosbuvir. The first month I felt no problems or side effects. But my family said I was very emotional. By week 5 I felt two faced and fragile. I talked to peers who had been through treatment and I decided to live through the anxiety, without taking anti-depressants, until the end of treatment. At 8 weeks I checked my HCV RNA and the decreased results amazed me. At 24 weeks the results were undetectable. This month I will test my SVR 12 and I can't wait to see the result.

I joined friends at Indonesia AIDS coalition to build community awareness. I want people to know that they can get treatment. For me this is not only about healing hepC but personal learning with my family and society. The Indonesian Government must do more to help people access treatment.



Ajitshwor Wangkheirakpam, 42, from Manipur, India, shares his story. I've been living with HIV-HCV co-infection for a long time. My HIV

was well controlled, thanks to government HIV program. However, having HCV has weakened my liver and without HCV treatment I was advised my risk of fatality was high. I was also told that my liver disease would progress faster because of co-infection.

There was no way I could pay for 1 year treatment using Pegylated interferon and ribavirin. I waited for newer, cheaper medications with improved cure rates and less side effects. Thanks to Indian generic production I started treatment in May 2015. Unfortunately, I had to use sofosbuvir combined with Pegylated interferon and ribavirin since a second DAA was not available. I completed treatment in August 2015 and have undetectable viral load. I am waiting for my SVR 12 results. My chances of a cure have improved. The cost is still very expensive and I only managed it with the support of family and friends. Diagnostics add to the expense, and don't come cheap either.

It's time for government make these newer, more effective medicines available to everyone. They must negotiate to reduce costs of treatment diagnostics. If this is not supported in time, we will see a generation of PLHIV who lived with an incurable infection and died of a curable infection. I thank friends, peers and family who helped me cope during my tough times. It would have been very difficult to do this alone.

REGIONAL COMPREHENSIVE ECONOMIC PARTNERSHIP (RCEP) TRADE AGREEMENT

Kee your eyes on this trade agreement and oppose all IP provisions that are beyond WTO's TRIPS agreement. RCEP is a trade agreement between ten ASIAN countries (Thailand, Lao, Cambodia, Indonesia, Brunei, Malaysia, Singapore, Myanmar, Phillipines and Vietnam) and six other countries. Six other countries are India, China, Australia, New Zealand, South Korea and Japan.

It was officially launched in 2012 during the ASEAN summit in Cambodia, and so far 12 rounds of negotiations have taken place. The last round of negotiation was in Australia and the next negotiation is scheduled to take place in June 2016 in New Zealand. The final round of negotiation is expected to happen in September 2016 in Lao.

According to the leaked IP and investment chapters, several TRIPS-plus provisions appear to be on the table that without doubt will adversely impact public health and access to medicines including:

DATA EXCLUSIVITY

That prevents governments from relying on clinical trial data to register generic versions of medicines even if they are off-patent, their patents have expired or are revoked & complicates the issuance of compulsory licences

PATENT TERM EXTENTIONS

That extend patent life beyond 20 years and further delay generic entry

WEAKENED PATENT EXCEPTIONS

That may impose restrictions on how developing countries in the Asia-Pacific region employ and define research and experimental exceptions to patent rights

INJUNCTIONS AND DAMAGES

That undermine the independence of the judiciary in issuing orders relating to the enforcement of patents in a manner that prioritises the right to health of patients

WEAKENED PATENTABILITY CRITERIA

That could put restrictions in terms of the time period and content of material that the patent office can take into consideration in determining whether a medicine is actually new or inventive (see provisions on grace periods and worldwide novelty)

ACCELERATED PATENT EXAMINATION

That may create undue pressure on already burdened patent offices in developing countries with limited human and financial resources to take hurried decisions on pharmaceutical patent applications that require close, detailed scrutiny

OTHER IP ENFORCEMENT MEASURES

That put third parties like treatment providers at risk of court cases and draw the whole manufacturing, distribution & supply chain for generic medicines into litigation

BORDER MEASURES

That may deny medicines to patients in other developing countries with custom officials seizing generic medicines that are being imported or exported

INVESTOR PROTECTION RULES

that allow foreign companies to sue governments in private international arbitration over domestic health policies like compulsory licences, patent revocations or refusals, health safeguards in patent laws, price reduction, negotiation and reimbursement measures & may prevent governments from promoting local production

TECHNICAL ASSISTANCE

Measures that may result in the indirect introduction of the lower patentability standards of developed countries into developing country patent offices through patent examiner trainings and increasing reliance on patent examination reports and conclusions of developed countries

WTO-PLUS DISPUTE SETTLEMENT ON TRIPS

By including TRIPS compliance in the RCEP negotiations, RCEP countries could sue each other for alleged TRIPS violations outside of the WTO Dispute Settlement Body

We need to ensure all IP provisions that will further delay access to medicines are removed. Contact APN+ Secretariat if you would like to know more about this trade agreement.

REGIONAL EXPERT CONSULTATION ON ACCESS TO AFFORDABLE MEDICINES, DIAGNOSTICS, AND VACCINES

In March 2016, APN+, UNAIDS, UNDP, UNESCAP and APCASO organised a regional consultation on access to medicines, diagnostics and vaccines. Over 70 participants attended from Cambodia, China, India, Indonesia, Myanmar, Malaysia, Thailand, Philippines and Vietnam. They included government sectors on health, trade and foreign affairs, particularly those responsible for patents and pricing of medicines, community representatives especially PLHIV and hep C advocating for access to affordable treatment, and development partners concerned with intellectual property rights and the right to health. The consultation also included international experts knowledgeable on IP and TRIPS.

The consultation aimed to create a better understanding of how to use strategic information, tools, framework guidance and other knowledge products to improve health and meeting sustainable development goal 3, universal health coverage including access to safe, effective, quality and affordable medicines and vaccines for all as well as mitigating impacts of HIV, TB, Malaria and hepatitis C. The consultation enabled south to south information exchange and greater engagement and dialogue between key government officials and community representatives. During the consultation participants also identified priority actions and technical support needs in taking those actions forward. A full report of the consultation is available at APN+.



INDIA

Local positive groups from northeast Indian states together with APN+ organised three workshops on hep C. The workshop objectives were to increase advocacy capacity of local PLHIV and drug users groups, and improve their knowledge on hep C treatment and prevention. All three workshops were held in Guwahati.

Participants of the workshops were selected through local PLHIV and drug users' networks from seven north-eastern Indian states. Work plans were developed for each state during workshops and progress was reviewed at the next workshop. Key activities in the work plans included integrating hep C work into HIV programs that are being implemented by their groups, and to advocate for the same to other NGOs and government agencies, to lobby



government health agencies to include hep C testing and treatment in government health programs, to expand treatment literacy among PLHIV and drug user community. Coalition and alliances of local community groups for each state were also established to lead local level campaigns. Representatives from Indian generic companies were also invited to the workshops to discuss availability and pricing of new hep C drugs.



Delhi Network of Positive People (DNP+) organised a demonstration in front of the ministry of health demanding free treatment for hepatitis C in India. DNP+ was also part of a patent opposition filed at the Delhi patent office against granting patents on sofosbuvir (new hep C drug).

INDONESIA

Indonesia AIDS Coalition (IAC) has been selected to be a Sub Recipient (SR) organisation to implement GF NFM grants in Indonesia. IAC will be working with the principal recipient, the National AIDS Commission, to implement a Community Systems Strengthening component of the NFM grant. The USD1.15 million grant will run for 20 months from April 2016 to December 2017.

IAC will focus on two key program areas to strengthen community systems and remove legal barriers with the following objectives:

1. Establishing patient feed-back mechanism to improve HIV services
2. Increase domestic financing towards country owned transition plan
3. Create enabling environment through annual legal review

The program will be implemented in 75 districts within 21 provinces.

PAKISTAN

APLHIV implements two GF grants, one working at country level to monitor services being provided and to ensure interventions do not discriminate. We also work on regional GF grant with APN+, results of which we use for advocacy. In addition APLHIV were supported to help the PWUD community to establish a national network, DUNE, and also the 1st network of positive females, POFEN. We are engaged in Toll Free Helpline Services round the clock. So far, we provided services to 17,500 callers and processed 250 complaints.

Our advocacy has resulted in the establishment of 3 new treatment centers, PLHIV inclusion in the Prime Minister's National health (insurance) program, provision of three CD-4 machines in

far flung areas, phasing out of Stavoudin and provision of sustainable nutritional support to PLHIV. These achievements were made using evidence we generated from the regional MATA study. In future we hope to be the catalyst between PLHIV community and HIV service delivery in Pakistan.



VIETNAM

VNP+ organised a HCV treatment advocacy workshop in December 2015. Participants attended from CHAI, WHO, CDC, ESTHER, VAAC, VNP+, VNPUD, National Hospital of Tropical Disease (NHTD), Bach Mai Hospital, INGOs and Local NGOs. The meeting focused on the current status of DAAs importation, HCV treatment in Vietnam; sharing information as well as exploring strategies to support DAAs advocacy.

VNP+ raised current issues affecting the availability of generic SOF including import, price, quantity and accessibility. We discussed solutions to speed up the HCV drug registration process (to waive local clinical trial, fast track registration and revise Drugs Regulatory Law). We discussed current barriers - the need for drug registration, importing mechanisms, cost, national HCV treatment guidelines, health Insurance for HCV treatment using DAAs and stakeholders responsibility. Most importantly we planned activities for the next steps of advocacy.

The workshop resulted in a final draft of HCV

treatment guidelines in Vietnam. CHAI, Bach Mai Hospital and NHTD raised the issue of drug interaction among patients with co-infection. This importantly highlighted the need for a robust diagnostics system to manage treatment. The priority of a DAAs regimen in HCV treatment was another point included in this version of the draft guideline.

In the lead up to this workshop we conducted a series of training workshops in 6 regions with 125 participants trained on HCV testing, diagnosis and DAAs treatment for PLHIV. We will continue our advocacy to ensure treatment access options improve in our country



APN+ NETWORKS PHOTO WALL

NAGALAND



NAP+N



NAP+N



VNP+



TNP+



APLHV



DNP+



APN+

