

APN+

My Right to Health:  
Strategic Consultation for YPLHIV in Asia – Pacific

Bangkok, February 16 – 18, 2013

## Overview of the Consultation

### Goals

1. Improve the health and well-being of young people living with HIV (under the age of 25) through increased access to comprehensive health services, including sexual and reproductive health services, HIV treatment and care, psycho-social support and other services deemed crucial for their psychological and physical development.
2. Improve YPLHIV leadership within youth movement(s) and within the people living with HIV movement in Asia-Pacific.

### Meeting objectives

1. Identify priority issues affecting YPLHIV health and well-being;
2. Better understand the extent to which current policies, programs or services meet the specific holistic health (including mental and sexual and reproductive health) and psychosocial needs of YPLHIV in the region.
3. Understand the impact of internalized stigma and issues related to self-perception (self-esteem and other personal barriers) of YPLHIV on:
  - a) Health service uptake including HIV and care retention;
  - b) Relationships (with their family, peers and their sexual partners);
  - c) Sexuality (dating, sexual identity, sexual pleasure);
  - d) Disclosure (family, peers, education, employment and other settings).
4. Understand the impact of the transition from PMTCT services to pediatric and adult treatment on psychological and physical development of adolescents living with HIV.
5. Draft a set of programme recommendations to increase health service uptake and minimize treatment cascade.
6. Inform the development of recommendations to improve community-based organisations and networks' responses to YPLHIV issues through strategic involvement of YPLHIV and YPLHIV capacity development.

### Consultation format

This three-day consultation was organised and facilitated by and for young people living with HIV (under the age of 25); both young people with acquired HIV and those born with HIV. While some sessions followed a group discussion format to allow the participants from

both groups (perinatally and acquired) to explore their issues in-depth, important common issues were highlighted at the end of each of the break-out sessions. Non-YPLHIV stakeholders were invited to join on Day 3.

## **Key themes explored through the consultation process**

Based on the findings from the in-country focus group discussions conducted prior to the consultation, the agenda and sessions for the consultation were designed around the following key themes:

1. **Services:** What services are needed? When is the best time to start these services? How to make the services accessible/ more accessible?
2. **HIV Treatment, Care and Support:** exploring specific challenges with diagnostic, treatment, care and support services.
3. **Disclosure and self stigma:** exploring self-stigma; how it affects self-esteem, health, including mental health and, relationships; understanding the context of disclosure – family, friends, peers, sexual partners, healthcare providers etc.
4. **Sex, Sexuality and Relationships:** exploring issues around dating, sexuality, sexual behaviour; relationships with partners, peers, friends, family etc.
5. **Navigating transition periods:** exploring issues with transition from paediatric to adult treatment; harm reduction services; psychosocial support for transitions.
6. **Specific issues for YKAP:** special needs of young MSM; harm reduction needs for young people who use drugs and young sex workers; special needs for young women
7. **YPLHIV leadership in the HIV response:** understanding current level of involvement in the HIV response; exploring barriers to engagement/ involvement; understanding issues around capacity etc.

**Note** – No reference to the name of any participant has been made. Participants have been identified in the notes using only country, gender and in some places age.

## 1. Services

### **Key issues explored:**

- a. What are the various services, including health, psychosocial, legal, education, YPLHIV need?
- b. At what age should these services be given?
- c. What are the barriers to accessing these services?
- d. How can these services be made accessible/ more accessible?

### **Session format**

This session started with discussions in two small groups – parentally infected and acquired. Participants were asked to go to the one they feel they had more to contribute to. In each group participants talked about the services they think they needed or had used. Each service was listed on a separate cue card. After the discussion, participants from both groups placed each service cue card across an age-timeline indicating the appropriate age to begin a particular service. In effect, participants identified what an ideal package of services addressing their health and well being needs would include and at what age would these services be most effective. This was followed by a group discussion on what are some of the challenges young people face while trying to access/ accessing these services.

### **Summary of discussion, key insights and recommendations**

S.No.	Service Needed	Age when needed	Participant experiences	Recommendations
1.	Diagnosis and Disclosure (For perinatally infected)		<p>Need to know status early on; being involved in managing their own health from an early age; easier to accept diagnosis if told truth from an earlier age.</p> <p>A participant from Thailand shared that she had figured out her status though some of the medical reports that were lying around but wished someone had told her. The participant from Nepal shared that she had Herpes four times before she was tested for HIV at age 16 and it was only after her parents' test that she found out she was prenatally infected. She talked about the stigma from healthcare providers who assumed she had engaged in high-risk sexual activity. The participant from India shared experience of a peer who had been abandoned by IDU parents as a baby but was not tested for HIV till late teens.</p>	<p>Support for greater PMCTC coverage</p> <p>Support early diagnosis;</p> <p>Interventions with parents/ guardians to promote earlier disclosure</p>
2.	Counselling / Psycho-social support		<p>Challenges in accepting status; adherence counselling needed</p> <p>Participant from India reported receiving no counselling and also shared experience of peers – no separate space for counselling and often counselling in open spaces – no confidentiality;</p> <p>Participant from Thailand reported receiving good individual and group counselling.</p>	<p>Non-judgemental; confidential;</p> <p>Interactive ways to help understand adherence; make it simpler</p>
3.	Treatment Literacy		<p>Need to better understand how treatment works; need to know about side-effects. They felt knowing more about treatment would make them better prepared for it and also</p>	<p>Comprehensive but through interactive ways</p>

			<p>more adherent.</p> <p>One participant reported she stopped the treatment when side effects happened. Another participant reported that she was only explained the pills by colour and would take a friend's pill if she forgot to bring her own.</p>	
4.	ARV		<p>Lack of regular supply; frequent visits to the clinic to collect small doses; desire for one pill a day</p> <p>Participants from India and Pakistan reported facing stock-outs. Other participants shared that they had to make frequent excuses at school/ family/ job to explain periodic clinic visits for ARV – would prefer if they could get three months medicine at once.</p>	<p>Regular supply; flexibility to provide medicines for longer duration at each visit to reduce number of visits.</p>
5	OI Diagnostic, Treatment and Management		<p>Participants identified support for OI diagnostic, especially testing for Hep C and TB, as well as OI management/ treatment as one of the key services.</p> <p>Participant from India reported absence of even CD4 machines and no option for Liver Function Tests etc. Participant from PNG identified need for adherence counselling on OI meds as well as information on medicine interactions with ARV, if any.</p>	
6	Peer Support Groups		<p>A strong need for peer support groups that start from an early age was reflected in the experiences shared by participants.</p> <p>For instance, several participants said that it would be good to have a peer support group at the age of 5 so children living</p>	

			with HIV who begin primary school and start taking responsibility for their own medicines can help each other with adherence.	
7	Nutrition and Housing		<p>Participants expressed desire for good nutritional support – poor families and can't afford on their own. Orphans – being raised by grandparents – insufficient means etc.</p> <p>Shelter homes, orphanages and other forms of housing support were also identified as a critical need.</p> <p>Participant from Nepal shared that while there are orphanages for children up to the age of 16, there are no shelter homes/ housing options for young people older than 16.</p>	
8.	Sexual and Reproductive Health Services		<p>Participants expressed strong need for 'real' sexuality education that addresses positive sexuality for YPLHIV along with access to contraception (condoms included) and safe abortion services.</p> <p>Participants also reported need for interventions to prevent and address sexual harassment, violence and abuse.</p>	
9.	Harm Reduction Services		<p>The need for youth-specific harm reductions services, particularly for young people using drugs, was reflected in the discussions.</p> <p>Participant from India shared his experience where after leaving the rehab services he switched to harder drugs influenced by some of the older users he met at the rehab.</p>	Youth-only/ youth-friendly

10.	Training for parents /guardians		<p>Participants identified the need to provide parents and guardians support with understanding the special needs and circumstances around raising children/ adolescents living with HIV.</p> <p>Participant shared that her grandparents brought her up and it would be helpful if her grandparent received some training/support so that she can better take care of her.</p>	
11.	Addressing stigma		Anti-stigma programs in schools, universities and workplaces + counselling for YPLHIV on how to deal with stigma	
12.	Legal Support		<p>For young people living with HIV who may be in conflict with law;</p> <p>Participant from India shared an experience where a friend, also positive and living on the street, was picked up by the police and had no legal representation, no one to fight for him with the Police for wrongful arrest etc.</p>	
13.	Educational support		Support with school fees, books etc.	
14.	Vocational training		<p>Industry or job market specific skills training</p> <p>Participant reported being kicked out of home at an early age and was thus forced to provide for himself. In such situations, vocational skills would be helpful.</p>	
15.	Recreational activities		Recreational activities, particularly around festivals and other such occasions, in treatment centres etc particularly for YPLHIV who are not living with family.	

The participants felt that all of these services needed to start early on. It was astonishing that no service cue card was placed beyond age 17 implying that participants felt they needed these services to start, in some form or the other, before the age of 18.



**Participants shared that they would want the services to be:**

- a. Confidential
- b. Flexible (with school/ university timings)
- c. Involve some component of peer support
- d. Involve some component of psychosocial support. For example, OI management could include counselling on adherence to OI meds.

**Some of the barriers identified to accessing these services were:**

- a. Long queues
- b. No flexibility for picking up ARV (interferes with school/ university/job)
- c. Judgemental healthcare provider
- d. No treatment literacy – e.g. No information about how to manage ARV side effects; fear of starting treatment
- e. Lack of transport
- f. Lack of money to pay for OI medicines
- g. Religious and cultural beliefs (condoms)
- h. Lack of linkages between ARV and other needed services
- i. Lack of confidential services (service centres are publically known as HIV clinic; fear of disclosure if seen at centre)

## 2. HIV Treatment, Care and Support

### **Key issues explored:**

1. Adherence
2. Treatment literacy
3. Diagnostic and Management of Co-infection
4. Linkages with primary health care and treatment cascade
5. HTC and linkages to care

### **Session Format**

This session was conducted World Café style. Five discussion stations were set up – with a set of key questions and facilitator assigned for each issue. Participants were randomly assigned one station to begin the café session and were asked to move to the next station after 10 minutes. This ensured that all participants got an opportunity to participate in discussions on all the issues, but in small groups.

### **I. Adherence**

#### *Summary of discussion and insights*

Guiding questions to spark discussion.

- For those who are not yet on ARV treatment, do you feel ready to start taking it if your doctor recommends that you start?
- Do you always take HIV medications regularly? What and who helps you take them at the same time at home and in school?
- When have you missed your doses? Have you thought of 'taking a break' from your HIV medications? What did you do?

Key insights from the discussion

- Challenges to starting treatment: participants shared that lack of complete information about treatment and about its side effects create hesitation to starting treatment. One participant shared that he was not confident about sticking to regimen and after hearing how even missing one dose can create problems, he decided not to start treatment.
- Disclosure and adherence: participants shared that often they often faced a challenge when they had to take medicines in front of people they hadn't disclosed to (parents, teachers, friends or colleagues) as this would require explaining to these people why they were taking medicines. In these cases, they would take the dose later than the prescribed time.
- State of mind and adherence: One participant reported missing a dose when there was an emotional fight with the family. Another mentioned that some

- friends forget to take medicines when they are having fun. A participant shared that he was in denial about his HIV status but taking medicines reminded him that he has HIV, so he would try to avoid taking medicines but eventually did take them. He felt that he did not receive 'real' counselling - neither on ARV and adherence nor on coming to terms with one's status.
- Adherence for perinatally infected: Participants reported that as kids, parents reminded them to take medicines. However, as they grew older responsibility shifted onto them. Participants expressed feeling 'tired' of taking medicines for so long. "Young people want to have fun...they don't want to think about taking medicines". Few have thought of not taking medicines to rebel against 'having' to always take medicines.
  - Ownership of health and treatment: Several participants expressed a strong sense of responsibility towards taking care of their health. This reflected in their attitude towards ARV and they reported good adherence. The participant from PNG said "Its my life, so I take it!" Reported adherence seemed better in those who had acquired HIV in comparison to those who were perinatally infected.
  - Support systems for adherence: Almost all participants found mobile phone alarms really helpful. Participants also mentioned forming a small group who take medicine at the same time to support each other with adherence.

## II. Treatment Literacy

### *Summary of discussion and insights*

Guiding questions to spark discussion.

- If you currently take medication for HIV, do you feel you adequately understand why you are taking it?
- Who provides information on treatment?
- What type of information do they provide?
- What you'd like to know more from them?

Key insights from the discussion

- Sources of information: Participants shared that they received treatment information from a lot of different sources. Primary sources of treatment information, in most cases, were the healthcare providers i.e. doctors, counselors and nurses at the ART centre/ clinic. Most of the YPLHIV were connected to some local NGO or community centre and the staff at these organizations/ centers also commonly provided information on HIV treatment. Participants also mentioned looking up information on the Internet or finding it through e-chats. Some participants mentioned getting information through peers, mobile phones and books.
- Information provided as treatment literacy: Several participants shared that the information provided to them on HIV treatment was inadequate. They felt that the information they received was very basic. For example while several participants claimed to have received

information on what possible opportunistic infections they might face, they received no information on what the symptoms would be or how to manage these OI. Almost all participants felt they needed more information on how to manage side effects. Few participants reported receiving only information about ARV and adherence and nothing else. Participants shared that would like to better understand drug regimens and drug interactions particularly between OI drugs and ARV as well as between STI drugs and ARV. The young girls from Thailand also expressed the desire for information on generics and development of new regimens.

- Challenges with treatment literacy: Young people shared several challenges they faced with the treatment literacy given by the healthcare providers. Most of them reported that the doctors and nurses were often hard pressed for time so they weren't able to share a lot of information, answer questions or explain things in detail. Several participants also felt that language was too medical. Young people expressed the need for comprehensive information that was given in simplified language and using interactive methods.

### **III. Diagnostics and Management of co-infections**

#### Summary of discussion and insights

Guiding questions to spark discussion.

- Do you have any co-infections or have you ever experienced treatment interactions among ARVs with other drugs you took?

Key insights from the discussion

- Diagnostic Management: The participants shared different experiences with regards to diagnostic management in their countries. Participants from Nepal and Philippines reported going for CD 4 tests on a need basis whereas participants from Cambodia and Vietnam shared they took CD4 tests every year. Young people from Indian and Pakistan reported facing challenges with CD4 test. One participant from Manipur, India reported that the machines for viral load testing were often broken or malfunctioning. The PNG participant reported not having access to CD 4 testing at all. Participants shared that doctors who sometimes explained the results often keep test results.
- Co-infections: Young people living with HIV face particular challenges with co-infections. The participants reported different experiences with OI management. Most of them seemed to have access to diagnostics and treatment for TB co-infection however the same for Hep C seemed to be a challenge. Participants expressed that they weren't given enough information on how to manage OI and ARV drug interactions. The participant from PNG shared that it would be helpful to have adherence support for co-

infection treatment. Some young people shared that they prefer going to NGOs for STI treatment, as often the govt. healthcare providers are judgmental and stigmatizing.

#### **IV. HCT and Linkages**

##### Summary of discussion and insights

Guiding questions to spark discussion.

- How was your pre- or post- HIV test counselling? Did you still receive counseling long after diagnosis?
- How often do you go back to the hospital after you have received your HIV test result?
- Was it easy for you to receive further health-check, care and support?

Key insights from the discussions

Participants from different countries shared different experiences. Participants from few countries reported having good linkages between HCT and HIV treatment, care and support services. Others reported several challenges faced by them or their peers.

- Inadequate counselling support: Participants reported that they didn't receive counselling on emotional or psychosocial aspects of HIV. The counselling session was often limited to medical aspects and adherence. Often counsellors didn't follow the specific guidelines etc. A participant from India reported that he didn't receive any pre-ART counselling.
- Challenges with healthcare providers: Participants shared that their doctors changed frequently and were often not sensitized enough to address the issues of YPLHIV. A few participants mentioned that there were often long queues at hospitals to receive further check-up and support.
- Need for scaling up youth-friendly services to rural areas: Participants also shared that often services and linkages were good in the capital city and few urban areas but the availability, accessibility and quality of services was different in rural areas.
- Financial support: Several young people shared that while there was financial support available for testing they faced a challenge in accessing care and support due to financial reasons.

#### **V. Linkages to primary healthcare and treatment cascade**

##### Summary of discussion and insights

Guiding questions to spark discussion.

- Where do you receive your health care for HIV? (WHO)
- What type of primary health care provider do you see and how often do you see them?
- Have you ever missed an appointment with a health-care provider? (WHO) and why?

#### Key insights

- Healthcare for HIV: Most participants reported receiving healthcare for HIV (ARVs only!) through government hospitals/clinics/treatment centres. One participant in India reported receiving healthcare from private doctor because the service is non-judgemental and the doctor has flexible timings.
- Primary healthcare and OI management: Two distinct models of health care service delivery were reflected. In Thailand, Malaysia, Philippines, Indonesia, Nepal and PNG, the ART doctor/ clinic is the first point of contact for primary health care and/or OI related issues. The ARV doctor further refers to specialists based on his/her own assessment. However, in Cambodia, Vietnam, India and Pakistan, the first point of contact is the general hospital or closest clinic – Out Patient Department Specialist or GPs. Only if the symptoms are very severe do YPLHIV in these countries go to ARV doctor first. Participants from these countries shared that the reason for this was limited time that ARV doctors are able to give to the patients.
- Appointments: Once again countries where ARV doctor was reported as first contact point, also reported having flexibility of visits. Most of these mentioned not needing an appointment at all while others mentioned that it was easy to reschedule appointments if missed. However, in countries where ARV doctors were reported to have limited time, prior appointments were reported to be necessary. Rescheduling is difficult and the doctor is unable to give 100% of time and energy.
- Concern areas: One-stop healthcare service models where first contact point is the ARV clinic are able to provide better quality of service as the doctors are able to give time, are non-judgemental and build strong relationships with YPLHIV thus improving quality of healthcare given. However, in countries where there are no strong linkages between ARV clinics and primary health centres, YPLHIV find judgemental, poor quality services for both primary healthcare and OI management. Further, they often have to disclose status to healthcare professionals who are neither trained nor sensitized on HIV issues. Thus while most participants seem to be receiving good quality ART, other healthcare needs including OI management seem to be a challenge.

### 3. Disclosure and self-stigma

#### **Key issues explored:**

Self-stigma; perception of self; how it affects self-esteem, adherence, general behaviour and/or relationships; how to overcome self-stigma?

The contexts of informed disclosure; to whom do YPLHIV feel comfortable in disclosing their status; under what circumstances do they feel comfortable disclosing their status?

#### **Session Format**

Sharing and discussion in a big group: To spark the discussion and sharing on self-stigma, participants were given the following two situations and asked to draw how they felt on the front of individual cue card as well as write how they dealt with the situation on the back of the cue card.

Situation1: How did you feel when you first learned about your HIV diagnosis? How did you deal with your feelings?

Situation2: How did you feel when you liked someone and you thought about having a relationship with them? Talking to them about your HIV status? Boyfriend? Girlfriend? Partner? Relationships?

Similarly, to begin the discussion around disclosure, participants were asked to write who they would disclose their status to on one cue card and who they wouldn't disclose to on another cue card.

#### **I. Self-stigma and perception**

##### **Summary of discussion and insights**

“When I know (of my status) I thought it was the end of the life...dream destroyed.”

“I just stay alone and wait time make me forget it (my status)”

Most participants shared that they felt sad, upset and desolate upon learning their status. They felt anxious about the future, about receiving support from family, peers etc. Some of them even stopped doing things they love, tried to be alone. Later on, to cope, several of them participants shared that they listened to music, cry, spend time with family etc. One participant reported feeling normal because she was perinatally infected and had been living with the virus all her life. However she added that sometimes she felt afraid, as she didn't know everything about her condition.

“...that I am going to lose the most important thing of my life.”

“ I chose to leave him, find someone who is (in the) same condition to start a relationship”

Most participants shared that while they wanted to disclose to their partners but they felt anxious, as they were uncertain about what it would mean for the relationship. Two participants shared disclosing status to their negative partners and finding support with them. One participant shared that he chose leave the relationship he was in to find a positive partner instead.

Insights: One, participants probably didn't receive good pre and post-test counselling as most of them reported feeling like this was the end of life and didn't seem to have the psychosocial tools/ support to deal with such feelings and come to accept their status.

Two, several participants reported that they chose to stay alone, avoid people, listen to music as opposed to acting out or engaging in high-risk behaviour.

Three, when it came to relationships, participants didn't share any reflections on how they felt about themselves (not good enough to date etc.) but instead showed great concern for the well-being of their partners.

## **II. Disclosure**

### *Summary of discussion and insights*

Young people talked about disclosure of their HIV status in different contexts. Some of the participants who had been perinatally affected shared how they accidentally learnt of their HIV positive status. One girl from Thailand shared how she learnt about her status at her pre-school after one of her friend was told not to play with her (by her grandmother) who assumed that since the participant's parents died of AIDS, she had AIDS too. A participant from India spoke of how after losing his parents at the age of six, his grandmother was told of his HIV status after he fell sick. That is when he was introduced to the local PLHIV network and learnt of his status. Participants discussed disclosing to family and friends. Some found it easier to disclose to friends than family. Some participants felt it was not necessary to disclose to family or friends if one didn't want to. One of the participants mentioned that he chose to disclose to friends because there were asking questions about his medicine routine and were curious why he needed to take a dose everyday at the same time. Another participant mentioned he didn't want to disclose his status because he didn't want people to give him any kind of special treatment. When asked who would the feel comfortable disclosing to, one of the girls form Thailand shared:

“...Before I disclose to someone, I would assess that person's knowledge and attitude about HIV. I would also think about how that person would react – would they be



violent, would there be rejection or something else. If it is about a potential date or a boyfriend – would he still love me or still take care of me?”

Several of the participants shared that disclosing their status gave them a certain relief mentally and also allowed them to receive emotional support from the person they disclosed to.

## 4. Sex, Sexuality and Relationships

### **Key issues explored:**

1. How do you feel about dating, whether now or in the future?
2. What does safe sex mean to you?
3. What does pleasurable sex mean to you?
4. What information or support do you need in this area to feel confident going on dates or being intimate with someone?

### **Session Format**

For this session, the participants were divided into three groups – Women, Men who identified as gay and Men who identified as heterosexual.

### **Summary of discussion, key insights and recommendations**

#### ***Women's Group***

- *Dating:* The participants shared that like any other girl they would also like date and be in a relationship. However, often the people they like are sero-negative so they don't approach them fearing their reaction. Almost all the participants felt the stigma was very high in their societies and it would be difficult to expect acceptance from the person they want to date.
- *Disclosure:* The participant from Thailand shared that she discloses her status upfront because it helps have more important discussions later on about the relationship, sex and other things. However the participant from PNG and Nepal felt the stigma was too high in their communities for them to disclose their status to a potential partner that early on.
- *Sex and sexuality:* Some of the participants shared that after they learnt about their diagnosis they didn't feel like having sex anymore.
- *Sero-discordant couples:* Almost all the participants agreed that they lacked information and knowledge about sero-discordant couple. They agreed that this influenced how they viewed their possibilities with regards to dating, sex

and relationships. One suggestion was to bring more awareness about sero-discordant couples in the public domain to minimize the stigma attached to positive sexuality and relationships.

- Pregnancy and children: Some of the girls shared that there was counselling available if they wanted to consider having babies. However the participant from PNG said that there was no such counselling available in her community.
- Peer support groups and workshops for YPLHIV: A strong suggestion that came out of the discussions was the need for more peer support groups and workshops for YPLHIV on dating, sex and relationships related issues. Few participants felt that while it was more comfortable to talk to peers about these issues often these peers were equally inexperienced or uninformed.

### ***Men's Group***

- Dating: Most participants shared that after their diagnosis they didn't feel like dating much. They expressed feeling low self-esteem and low self worth. A lot of the participants mentioned that now they prefer dating other YPLHIV as they feel a burden to prevent transmission with sero-negative partners.

Disclosure: Participants shared that they would disclose to a partner only if he or she wanted to have sex without a condom. Few of the participants shared that they weren't ready to disclose. They discussed that safe sex means taking care of your partner and yourself and shared that they always used protection. All the young men agreed they would really benefit from more support on understanding best ways to disclose their status to potential sexual partners.

Sex and sexuality: Some of the participants shared that they felt like they should pull back after diagnosis. Few participants said that it was harder to feel 'in the mood' with Efav especially since they were expecting to be more in the mood after the drugs. One of the interesting points of the discussion was how to make safer sex more pleasurable, including oral sex, and how to safely experiment with more options such as group sex, using additional elements. etc

Children: Participants of both sexual orientations shared that they would prefer adopting children if they decided they wanted to have children.

Support groups: The discussion was a bit interesting as some young men shared that they were comfortable talking about sexual issues with their friends while others felt they would not feel comfortable talking to anyone and especially not in a support group setting.

## 5. Navigating transition periods

### **Key issues explored:**

1. Different ARV issues for continuation from PMTCT to paediatric and adult treatment
2. How does a changing environment (school, employment, health care providers, residence) affect you?
3. How often does your mother/caregiver bring you back for further diagnostics, treatment and enrollment in care system?

### **Session Format**

This session was conducted along with the sessions on 'Special needs of Young key affected populations' in World Café format.

### **Summary of discussion, key insights and recommendations**

Participants expressed a need for greater support to better manage transitions from paediatric to adult treatment. They discussed several challenges that they faced in their communities and also shared best practices and recommendations.

### ***Challenges***

- One of the common challenges shared by the participants was frequent changing of doctors. Participants from Nepal reported that sometimes doctors change as often as every three months. Young people find having new doctors cumbersome as they have to answer the same questions again and have to repeat their stories to a new person very time. The new doctors also sometimes changed regimens and YPLHIV found it difficult to keep switching between drugs.
- Another challenge was conflicting information about transition and drug regimens. Many mentioned that they lacked support and guidance during transitions and were often confused by the differing information given by different doctors.
- Young girls living with HIV had particular difficulty in discussing sexual and reproductive health issues with their doctors who were mostly male. They felt that part of the overall transition support should include information on sexual and reproductive transitions as well.

### ***Best practices and recommendations***

The participants from Thailand and Cambodia shared several best practices from their communities including the following:

- Hospital provides travel allowance to groups of YPLHIV to help with transition
- ART centre has specific days to provide transitioning YPLHIV SRH information and also organizes dialogues are organized with parents and guardians on SRH issues
- Cambodia is in the process of developing clinical paediatric transition guidelines

The participants also made the following recommendations:

- Provide peer-based services to meet non-medical needs
- Increase access to services beyond capital cities
- Develop a one-stop model that provides services for all phases of PLHIV's lives from EMCTC to paediatric to adult and beyond.

## 6. Special needs of young key affected populations

### Key issues explored:

1. Harm reduction needs of young people living with HIV who use drugs and young people living with HIV who sell sex
2. Special needs of young HIV positive MSM
3. Special needs of young women

### Session Format

This session was conducted along with the sessions on 'Navigating transition periods' in World Café format.

### Summary of discussion, key insights and recommendations

#### **1) Harm reduction services for YPLHIV who use drugs / sell sex.**

- Participants shared that they lacked **access to youth-friendly harm reduction and SRH services**. When they accessed some of these services with the older PWUD/ people who sell sex, the providers were not sensitized to work with young people and were judgemental or had stigmatizing attitude. Further, YPWUD/ YSW felt that they often engaged in riskier behaviour or switched to harder drugs under the influence of older community members.
- Young people who use drugs particularly lack access to information and services for prevention, management and treatment of **overdose**.
- Young people living with HIV lack access to **legal support** and are **often imprisoned with no access to ARVs**, counselling, harm reduction services or even nutrition support. Furthermore, there is a lack of legal environment that protects young people who use drugs or sell sex from abuse by peers, community members, law enforcement or in prison settings.

#### **2) Young MSM & psycho-social support needs.**

**Need for psychosocial support:** Participants shared that families are often unable to provide psychosocial support to YMSM living with HIV and in this context, peer support groups and drop-in-centers need to provide the necessary support. One of the participants also suggested having separate support groups for parents whose children are YMSM and living with HIV.

**Access to counseling:** Several participants mentioned that there needs to be better counseling services, including peer counseling services, available in

govt hospitals for YMSM living with HIV in addition to sensitized healthcare providers.

**Trans MSM issues:** One of the key points of discussions was the lack of information geared towards young trans MSM. Participants shared that more information on Sexual reassignment surgeries and drug interactions, including for ARV, STI and OI drugs would be very helpful in addition to psycho-social support.

### **Recommendations**

- Counseling in sexuality at an earlier age
- Access to information on sexuality and HIV services for people below the age of consent (India)
- Reach YMSM through online forums (India)
- Need for trained counselors in schools to address YMSM issues
- YMSM often live with HIV – shelter, drop in centres needed
- Information dissemination through peer groups

### **3) Young women's issues.**

- Several participants shared that the side effects of taking ARV for so long had begun to change their appearance and this had a detrimental effect on their self-esteem. Some of them shared that they had already battled issues of their self-worth since the diagnosis and were now in a good place, mentally and emotionally, but with these changes they had started to feel less beautiful again.
- One of the participants from PNG shared the situation of young women living with HIV in her community. 'PNG has mandatory testing for women at ANC so while a lot of young women are getting tested for HIV, young men who are often their partners, can chose to go for test or not. As a result, the women get diagnosed early and often their male partner/spouse refuse to get tested, blame the woman and leave her/ threaten to remarry etc. Young girls suffer a lot of violence in the community and they can't speak up. The participant shared the story of one woman in the in-country FGD who was infected by HIV when sister's husband raped her. The man is now living with both the sisters; the young woman got pregnant from rape but had no option to leave the man because of economical reasons.
- Participant from Cambodia shared that women in their community are generally more subdued and shy due to culture so they are more vulnerable to HIV/STDs as they can't negotiate condom use. She also stated that they don't generally pay attention to own health until very bad; can't negotiate condoms etc.

## 7. Leadership in the HIV response

### **Key issues explored:**

1. Understanding the level of involvement of YPLHIV in existing youth and positive networks
2. Capacity building process for organisations to better work with YPLHIV

### **Session Format**

Participants were divided into two groups. One group discussed issues in the context of positive networks and the other group discussed issues in the context of other youth networks.

### **Summary of discussion, key insights and recommendations**

#### ***Is being involved in a youth and positive networks beneficial?***

Almost all the young people felt that being a part of a youth network or a positive network was beneficial in many ways. They shared that a network is a helpful platform to exchange thoughts and reach out to other young people with key information for example the condom distribution related issues in the Philippines Reproductive Health Bill. Another benefit of being in the network is having access to psychosocial and emotional support with other network members. A participant shared that networks help take care of members who are hospitalized or bedridden at home by making services more accessible to such YPLHIV.

The participants strongly felt that as a network they could respond better to social or govt. action that affected their health and lives. They shared that since the positive networks do not normally consult YPLHIV, it is important to push for youth chapters within the PLHIV networks and community networks to ensure young people have a voice. Youth chapters can provide specific peer support that can change the lives of other YPLHIV and YKAP in their communities and fill the gaps missed by the main networks.

#### ***What are some of the barriers to being involved in these networks?***

Young people shared several barriers they face in being more involved with local positive and community networks.

- There is widespread stigma attached to association with positive networks;
- Often families and parents isolate YPLHIV due to stigma in the society which prevents them from associating with these networks;

- Parents also sometimes feel uncomfortable allowing their children to be involved if IDUs, MSMs or sex worker groups are running the positive networks.
- Participant from Pakistan shared that often other members from the network would come to his home asking for help and would end up disclosing his status to his neighbours/community and that was reason why he was hesitant in getting more involved with the local positive networks.
- Several young people shared that there were no clear activities within the network for them to engage in and mostly networks facilitated only information sharing. They also felt that networks looked at YPLHIV as leaders of tomorrow and not as agents of change today.

### ***How can networks encourage more YPLHIV leaders?***

The participants had a very productive discussion in this regard and made the following recommendations.

- It is important to overcome challenges with disclosure in order to be fully involved with the positive network so it would be helpful if the networks could help with providing support to YPLHIV on disclosure related issues before involving them further.
- The network could have a specific platform to engage YPLHIV and could also have a support group for YPLHIV to articulate key advocacy priorities for this group.
- Some participants suggested having a youth role model who is open about his/her status and is actively engaged with the network activities would be helpful in making young people and their parents more comfortable and it will also motivate them to join the network.
- Using ICT to reach out and engage with YPLHIV would help reduce some of the stigma related issues that young people face in joining the networks. Using SMS, social media and other such platforms were suggested.
- Another suggestion was to remove 'HIV' from the name of the networks to address HIV related stigma.