2016 Youth Summit Report:
A collaborative meeting for peer supporters, peer supporter supervisors & representatives from national networks of young people living with HIV

JUNE 2016
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Acronyms

ANC  Antenatal care
AFHS  Adolescent-friendly health services
ALHIV  Adolescents living with HIV
ART  Antiretroviral therapy
ARVs  Antiretrovirals
ATC  Adolescent Treatment Coalition
AY+  African Young Positives Network
EPP  Expert Patient Programme
FACES  Family AIDS Care and Education Services
KAP  Knowledge, attitudes and practices
MSM  Men who have sex with men
NYP+  Network of Young People Living with HIV
P2Z  Peers to Zero
PMTCT  Prevention of mother-to-child transmission
REACH  Re-engaging Adolescents and Children with HIV
RIATT-ESA  Regional Inter-Agency Task Team East and Southern Africa
RNJ+  Reseau National des Jeunes Vivant avec le VIH
SRH  Sexual and reproductive health
SRHR  Sexual and reproductive health and rights
UNYPA  Uganda Network of Young People Living with HIV
YAP  Youth Advisory Panel
YPLHIV  Young people living with HIV

Emily Turnacliffe,
One to One
Children’s Fund, UK
Executive summary

The Youth Summit, held in Dar es Salaam, Tanzania from 27 – 30 June 2016, was able to provide a dynamic and productive learning and networking platform for adolescents living with HIV (ALHIV) and young people who are engaged as peer supporters. Designed and led by youth, the Youth Summit created a safe space for youth dialogues, peer-to-peer workshops, interactive sessions, skills and team-building exercises for peer supporters, their clinic supervisors and national network representatives. Twenty-eight health facilities were represented, with 100 participants attending from Burundi, Cameroon, DRC, Ethiopia, Malawi, Tanzania, Uganda, Zambia and Zimbabwe.

New and emerging evidence suggests that peer-to-peer engagement may provide an effective mechanism for psychosocial support and improved levels of treatment adherence and health service engagement for ALHIV. Engaging peer supporters as catalysts for effective linkage to care, with ALHIV delivering child- and adolescent-focused activities and psychosocial support provides much needed capacity to over-stretched health facilities. HIV-infected adolescents and youth serve as positive role models for younger children and adolescents as they have first-hand knowledge and experience of the challenges younger children and adolescents face in accessing and remaining in care. PATA recognises the critical role that YPLHIV may play in advancing the paediatric and adolescent HIV response. In this context, and with a 9-year track record of developing this capacity, PATA is uniquely placed to support, develop, incubate, investigate and share learning from its peer support model as a promising practice in the field of engaging YPLHIV.

Whilst the contribution of ALHIV engaged as facility-based peer supporters is increasingly acknowledged, the voices of peer supporters are seldom heard and their efforts often go unrecognised. There is an urgent need to develop and document operational evidence on peer-led interventions at health facilities, as well as better understand how peer supporters can be assisted and integrated into the development, delivery and monitoring of adolescent-friendly health services (AFHS) that affect them. Moreover, greater attention and investment must be made in building resilience amongst peer supporters, who as YPLHIV seek to further explore and expand their opportunities for personal growth and development, economic and social security, health and wellbeing.
Despite significant progress made in HIV treatment and prevention, with various global targets speaking to the end of AIDS, current evidence suggests that this optimism does not hold for young people. AIDS-related deaths among adolescents in sub-Saharan Africa have tripled since 2000. There were 940,000 new HIV infections in the region last year, accounting for nearly half of the global number of new infections, with HIV remaining the leading cause of mortality in this age group in Africa.

Setting the tone at the Youth Summit, Marie Engel from UNAIDS in her UN Statement on Young People and HIV in East and Southern Africa highlighted that “The treatment, care and support needs of young people living with HIV, who were born with HIV or acquired HIV during youth, change as they grow older and begin to take greater responsibility for their own health.” She explained that “Services generally do not keep pace with, or cater to their needs, more so and particularly true for marginalised young people—males who have sex with males, transgender, young people who inject drugs and those sexually exploited—despite the high prevalence of HIV among them.” Of particular concern are “Young girls and women in the region who are also confronted by the challenging realities of teenage pregnancy and gender based violence... If the region wants to end the AIDS epidemic by 2030, we must end AIDS among young people, in particular young girls.”

“Ending AIDS as a public health threat is a commitment made in the Sustainable Development Goals, with the Political Declaration at the United Nations General Assembly High-Level Meeting on Ending AIDS calling for increased accountability, with regional and country level targets established on the prevention and treatment for young people, and also encourages greater leadership and participation of young people.”

Policies and programmes are needed that are adolescent-orientated, with strategies and services that are equitable, accessible, acceptable, appropriate and responsive to the unique and diverse needs of all ALHIV. The provision of a comprehensive, integrated package of AFHS that includes access to HIV treatment, sexual and reproductive health (SRH) and psychosocial support is becoming an operational imperative and requires the active involvement and engagement of YPLHIV. Engagement of ALHIV as peer supporters can improve the uptake of services, programme quality and accountability, but also requires careful consideration and planning, as well as the requisite capacity and sensitivity from health service management and staff to implement meaningfully and effectively.

PATA’s mission is to mobilise, strengthen and give voice to a network of frontline health providers to improve paediatric and adolescent HIV treatment, care and support in sub-Saharan Africa. The PATA network includes healthcare providers at more than 300 associated health facilities who collectively care for over
200,000 children and adolescents on ART. PATA’s partnerships at the frontline create a powerful platform to deliver capacity-building and technical input while facilitating peer-to-peer exchange, shared learning and dissemination of promising practices. PATA forums and summits are collaborative meetings where multiple cadres of health professionals and lay service providers, such as doctors, nurses, pharmacists, counsellors, and community health workers convene in health facility teams for technical capacity-building, peer-to-peer exchange and the design of promising practice pilot projects.

Historically, peer supporters and YPLHIV have not always been included in the composition of attending health facility teams. The Youth Summit, therefore, deliberately created a dedicated space and opportunity to acknowledge, drive action and build solidarity amongst peer supporters and ALHIV on the frontline of service delivery in the region.

PATA Strategy and Theory of Change

PATA aims for children and adolescents living with HIV to receive optimal treatment, care and support by PATA’s growing network of frontline healthcare providers. Using a network model, PATA develops skills, builds constituency, facilitates synchronised action, enables information sharing and creates a platform for intra-regional collaboration. Through strategic partnerships, alliances and associations with local, national, regional and global stakeholders, policy-makers and policy-influencers, PATA sets out to create awareness, build coalitions, and create a gateway for two-way dialogue between civil society and policy-makers to influence change. The PATA network provides access to valuable information and insights regarding effective service delivery models, such as facility-based peer support as specifically highlighted at the Youth Summit. This information has the power to drive policy and programme change and inform the development of peer-led services.
Summit purpose and objectives

The Youth Summit, presented by PATA and AY+, aimed to: create a safe space for ALHIV peer supporters to engage and learn from one another; share barriers and strategies for improving peer-led services and AFHS; and collectively identify and advance service delivery priorities through advocacy and linkage to county-level networks within the P2Z campaign.

The Youth Summit served as a catalyst to inspire peer supporters and showcase peer-led contributions and strategies as being complementary and critical to the HIV response for children and adolescents. As a youth-led summit, all workshops, sessions and exercises were designed to encourage participants to take the lead, direct discussion and develop clinic-based action plans as well as develop a collective mandate and action plan for the P2Z campaign.

As a platform to drive action and gather advocacy messages from peer supporters, the Youth Summit was titled ‘Initiate – Collaborate – Advocate’, with the following objectives:

- **Initiate**: To promote skills-building and leadership capacity for peer-led AFHS.
- **Collaborate**: To form connections and promote dialogue between peers, clinic staff and network structures.
- **Advocate**: To strengthen peer voices and create a collective call to action under the P2Z campaign.

The programme was designed across three days with three corresponding central themes:

**Day 1: INITIATE – Me, Myself and I** focused on psychosocial elements of HIV disease and the personal and lived experience of peer supporters. Workshop discussions explored personal stories, as well as barriers and strategies to secure personal health and wellbeing. Day 1 aimed to better understand and define enabling environments for YPLHIV in the home, clinic and community.

**Day 2: COLLABORATE – Me, My Peers and AFHS** focused on unpacking the meaning of AFHS. This involved identifying the range of services needed and defining how these should be delivered and/or integrated into facilities, with a particular focus on reaching the most marginalised and inadequately served. Attention was placed on how peer supporters understand meaningful youth participation and how peer support activities can better address barriers, whilst providing creative strategies for effective peer-to-peer support.

**Day 3: ADVOCATE – Me, My Peers and Speaking Up and Linking Up** translated central themes that emerged from the first two days into key advocacy messages for the P2Z campaign and established improved linkage with national YPLHIV networks for service-level issues to be raised. The last day culminated in the development of the Dar Declaration, with the collective voices of young people attending the summit articulated and documented, establishing a clear call to action for the P2Z campaign.
PATA peer supporter programmes

REACH is a peer support model which integrates young people living with HIV (YPLHIV) as peer supporters within health facilities in order to improve HIV treatment and care services for, and treatment outcomes in, their adolescent peers age 10-19 years. Launched in 2015, the programme supports 59 YPLHIV peer supporters across 20 health facilities in Cameroon, DRC, Ethiopia, Malawi and Uganda. Its sister programme, the Expert Patient Programme (EPP), has been supporting a further 62 community health workers in Zambia and Zimbabwe. Together, REACH and EPP facilities care for 21,440 ALHIV in urban (81%) and rural (19%) settings.

One of the key lessons from the programmes is that whilst community models importantly drive demand, sensitise communities and link to care, facility-based models like REACH and the EPP are best situated to improve health services, sensitise health providers and engage adolescents accessing care, assisting them to navigate the health system and providing safe and supportive facility-situated spaces.

Since its inception, REACH has demonstrated the critical role that facility-based peer supporters can play in addressing critical gaps in AFHS and improving outcomes. In particular, peer supporters have empowered adolescents through disclosure support (95%), defaulter tracing (90%), adherence counselling (85%), support groups (75%), dedicated spaces or times (75%), and teen camps or clubs (75%). Over the past 12 months, the paediatric and adolescent patient base at participating facilities has increased by 34%, and retention increased by 1%. All facilities added at least one new adolescent-focused service, with peer supporters instrumentally contributing to such expansion. Ninety-five percent of facilities include peer supporters in staff meetings; of these, 85% reported that peer supporter contribution at these meetings has resulted in programmatic change.

Figure 1. Countries with active PATA peer support programmes
Attending PATA peer supporters

Sixty-six peer supporters, 28 peer supporter supervisors and 6 national YPLHIV network representatives attended. Participants came from nine countries and 28 health facilities across Burundi, Cameroon, DRC, Ethiopia, Malawi, Tanzania, Uganda, Zambia and Zimbabwe.

Youth delegates were 60% female, and most (77%) were between the ages of 20-24 years. During the summit, the young people participated in an anonymous knowledge, attitudes and practices (KAP) survey, in order to share their lived experiences and help programmers to better understand how health delivery can be improved to accommodate their circumstances.

The results point to varying quality of health system response to adolescents, and highlight that some adolescents do not receive equitable, accessible, acceptable, appropriate and effective treatment and care from their health providers.

Through the survey, some adolescents and young people reported positive experiences.

- 76% always or usually get the help I need
- 76% always or usually feel my information will be kept confidential
- 82% always or usually reported that health workers listen to me
- In other cases, health providers may express judgmental attitudes or provide misinformation.
- 43% explained that sometimes, usually or always health workers get upset and scold me
- 36% claimed that sometimes, usually or always health workers are too busy to give me the help I need
- 41% say they never or sometimes feel comfortable talking to health workers about any problems
- 43% report that they never or sometimes feel comfortable asking for information about pregnancy and sex
Methodology

The Youth Summit provided participatory, interactive, creative and action-oriented activities throughout various workshop formats. Panel discussions, dialogues and additional skills-building sessions, with networking, team building and performance art were integrated into the daily programme. Open spaces methodology was utilised at times, providing no pre-planned presentations, but time slots and a space for spontaneous discussion on emerging topics. Open sessions allowed participants to move freely between different discussions and session rooms.

Three days of sessions concluded with a formal closing dinner and dance – marked with celebration and festivity before final goodbyes and sad departures.

This report is based on summit presentations, discussions in panel sessions, closed sessions, open spaces sessions, skills-building workshops and action plans.

**PRESENTATIONS**: The start of each day provided an overview and introduction to the day’s theme and programme. Day 1 started with a formal opening session, with Day 2 and Day 3 focused on panel presentations and dialogues. The opening session on Day 1 provided a rapid overview and situational analysis of the adolescent HIV response in the region, linking key challenges to the Youth Summit’s programme.

**WORKSHOP SESSIONS**: Peer supporters and peer supporter supervisors attended parallel sessions in separate venues to discuss key questions related to each of the days’ themes. Discussions and interactive exercises drew out challenges, solutions and strategies specific to each of the central questions. Workshops included closed and open space sessions, as well as skills-building sessions, and provided creative formats to promote participation and dialogue.

**PANEL SESSIONS**: Daily panel sessions provided feedback from different workshop sessions and provided an open ‘fish bowl’ space to share local knowledge and practice, with a focus on facilitated discussion and consolidation of key messages for each of the days’ themes.

**TEAM ACTION PLANS**: Working in health facility teams, peer supporters, their supervisors and YPLHIV network representatives worked together to prioritize action plans for improving adolescent-friendly and peer-led services in their facility, as well as identify mechanisms to promote participation of YPLHIV.

**COLLECTIVE CALL TO ACTION**: The final day culminated in key issues and messages being themed and documented in the Dar Declaration, establishing a collective call to action and advocacy plan for the P2Z campaign.

**YOUTH ADVISORY PANEL**: A P2Z Youth Advisory Panel (YAP) was elected at the summit to drive the campaign forward and provide leadership for peer-led services on return to their respective countries, health facilities and network structures.
The first day focused on peer supporters themselves and took participants through a highly interactive process of examining their own lived experiences. The day explored questions like: What are some of the challenges young people experience and the strategies they have adopted to secure personal health and wellbeing? What value does peer support hold, and how can we build resilience in young peer supporters? What are peer supporter capacity and support needs? How can we create opportunity and identity for peer supporters beyond the clinic and their HIV status? What does a supportive and enabling environment that promotes health and wellness for peer supporters and their peers look like in the home, clinic and community?

Adolescent wellbeing

The role of the peer supporter is becoming increasingly important in the adolescent HIV response, yet the same peer supporter who is tasked with providing care and support on the frontline is also a YPLHIV and facing similar challenges, fears and concerns. With a focus on personal and lived experiences of peer supporters, the importance of self-care emerged, and highlighted the need for intentional actions to be taken to ensure sufficient attention is provided to the physical, mental and emotional health of peer supporters.

Wellbeing is a complex combination of physical, mental, emotional and social factors. A wellness-focused session at the summit assisted participants to explore and assess their own current state of stress and wellbeing, and provided tips on building resilience against life’s stressors.

**KEY MESSAGE:**

Holistic wellbeing is important. Peer supporters cannot support wellbeing, if they are not well themselves.

The session used a ‘wellness wheel’ to help people to assess their own wellbeing and understand where they might need more support. The wellness wheel model asks of us to assess our satisfaction within eight dimensions of wellness. Each of these dimensions acts and interacts in a way that contributes to our quality of life. Participants then spoke about ways of dealing with stress they may encounter, such as talking and sharing experiences.
time away from responsibilities, physical activity, breathing or meditation, and prayer or other spiritual outlets.

**KEY MESSAGES:**

- **Self-care is really important! We matter.**
- **Sometimes we are not aware of our levels of stress and fatigue. It is important to be aware of our well-being and ask for support as necessary.**

With exceptionally low adherence among adolescents, the focus tends to be on ensuring viral suppression, yet suppression cannot be achieved or understood in isolation to that of social, economic and mental wellness.

During the summit, peer supporters undertook personal reflection and focused on remembering and considering the stories of their own lives and histories. People told stories of the past and present, as well as hopes and plans for the future. The narratives that young people shared exposed the similarities between their experiences and that of their peers, with many having suffered loss and bereavement (often due to the AIDS-related deaths of family members), periods of isolation, and rejection and stigmatisation. A number of peer supporters were able to share their experiences of treatment fatigue and treatment interruption, coupled with their own struggles in finding a sense of purpose, belonging, direction and hope for the future. The obstacles overcome and the journeys travelled, so beautifully depicted in the stories they shared, are testament to the individual and collective resilience and tenacity of the participating peer supporters, as well as their drive and commitment to support their peers and ensure that HIV, whilst an important part of their lives, does not define or limit their abilities and future aspirations.

Throughout the day, barriers to and strategies for wellness in young people emerged and were documented.

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**What can I do to keep my viral load suppressed?**

Get tested for HIV and enroll in care if you are HIV-positive. Start ART as soon as possible. Maintain excellent adherence to ART, get regular viral load tests and discuss the results with your doctor.

- **Dr Shannon Shea, Baylor Tanzania**
### Barriers to wellness

- Stigma leads us to feel fearful and isolated
- When we don’t accept our status, we deny our HIV and don’t adhere to treatment
- Sometimes we lack information and don’t understand the importance of treatment
- We struggle when our caregivers do not disclose our HIV status to us early on
- At times, we lack the support of our families
- Many of us do not have the financial means or support to complete our education, pursue training or advance income generating opportunities
- We do not always have guidance and mentorship to rely on
- If we have a poor self-image, we don’t always take good care of ourselves
- Some of us do not have the information we need to make sure we exercise or eat well
- Often, access to health services is difficult and services are not of good quality
- Sometimes, services are not free and involve long distances and travel costs
- We sometimes experience stock outs, and feel discouraged when we are told to return on numerous dates
- When we don’t have access to viral load or other monitoring, we are unable to manage and be informed about our health

### Strategies for wellness

- Get enough sleep, take up regular exercise, and make sure our nutrition is balanced
- Join support groups and connect with peers
- Utilise the networks to which we do have access – our family, staff at the clinic, or a community worker – to support us
- Accept support from friends and family when they are offered
- Get involved with and connected to networks of YPLHIV
- Get active in the community
- Attend school, and explore bursaries and training opportunities
- Learn how to budget and work with money
- Develop a plan for ourselves that goes beyond being a peer supporter
- Participate in fun and recreational activities
- Do relaxation exercises
- Make time for personal and spiritual growth
- Keep a journal
- Adhere to our treatment and engage with our health provider
- Love ourselves, take time out and apply self-care
- Advocate and stand for viral load testing, treatment access and positive, supportive and enabling environments

### KEY MESSAGES:

- My story and my journey matters. My experiences and the experiences of others make us stronger together. Let’s support and build one another. Let’s be the change we want to see. It starts with ME!
- We must acknowledge our limitations as peer supporters and ask for help when things are difficult or we feel overwhelmed.
- Family and community support are critical for psychosocial wellbeing. There is a need to reinforce good disclosure processes, particularly with families, and provide guidance on onward disclosure for YPLHIV.
- Greater investment is needed in financial aid to support returning to school, additional training and income generation opportunities for young people.
- Regular viral load testing and free, unconditional access to HIV treatment and care are needed to fulfil global targets.
- Positive, supportive and enabling environments are an essential part of care for YPLHIV, and necessary in order to provide effective peer support.
Transitioning to adult care

As young people reach adulthood, they must be transferred to adult care and enabled to begin managing their own health. Many peer supporters shared negative experiences associated with their own transition. Transition enacted poorly was felt to be one of the contributing factors as to why young people stop or interrupt their treatment. Across the summit, young people explained that a balance between support and empowerment is needed when they transition into adult care. Adolescents are often unprepared for the transition, with family and health providers often lacking training to support and guide this process and period. There is often resistance to transition from the patient, health provider and family.

KEY MESSAGES:

- Policies should establish a definition and age for transition, and provide clear milestones and guidance.
- Transition should include a preparatory phase and process that is monitored over a period of time to ensure transition readiness.
- The role of peer supporters is essential in the transition process as they are able to share their own transition experiences and act as an effective and supportive link for peers as the transition occurs.

Stigma and discrimination

Stigma of various types – self, community and clinic – was highlighted as a key driver of AL-HIV not wanting to disclose their status to others. Young people explained that stigma also fuels non-adherence, poor clinic attendance and therefore treatment failure. Discrimination and ignorance surrounding HIV emerged as a major point of concern for many. Young people attending the summit explained that they need to be provided stigma-free services, where HIV, SRH and mental health services are integrated, provided at convenient times and accompanied by correct information and guidance that is free from judgement. Increased investments are needed to reach and serve those who are poor and socially marginalised, with targeted strategies to alleviate stigma towards young key populations, including young men who have sex with men, young women who have sex with women, young sex workers, young people who sell sex, young people who inject drugs and young transgender people. Social protection measures must be considered to address structural drivers of vulnerability, with a special focus on keeping youth in school. Health system reforms and policy changes that can transform HIV care, planning and service delivery must be developmental and responsive to contextual factors that impact access whilst also providing the necessary legal and human rights framework and protection.

“I was just told to go to an adult clinic one day. I was scared. I did not want to go. I missed the first two appointments, before another peer encouraged me and went with me to the new clinic.”

- Peer supporter, Uganda

“Stigma and discrimination

“When I was sick, I was always sent to the infirmary. When I misbehaved and was punished with others, the headmaster, in front of everyone, told me that I should not do the punishment with my condition. I was made special and removed from my other school peers – who then wanted to know what is wrong with me.”

Peer supporter, Uganda

Young people discussed different contexts in which stigma emerges and brainstormed strategies for how they and others can deal with and address stigma.
Peer pressure

The power of peers can be harnessed to build, empower, mentor and support. However, peers can also exert negative influence and create anxiety. Peer pressure is common during adolescence, with its harmful effects driven by a strong desire to fit in and be accepted by peers. Young people spoke about feeling fearful, embarrassed and reluctant to disclose their HIV status to peers at school, with many preferring not to present themselves as being ‘different’ in any way. Attraction to destructive peer groups and behaviours was reportedly more appealing during periods of feeling isolated, conflicted or struggling with low self-esteem and/or depression. Such feelings could lead to engaging in risk-taking, such as unprotected sex with multiple partners, drinking or using recreational drugs – all of which can interfere with treatment adherence and overall physical and mental health.

Peer supporters themselves can be a useful tool for modelling positive self-image and behaviour. Young peer supporters are able to demonstrate to their peers how to live positively, adhering to treatment, while still having fun as a teen and connecting with others. This can help to combat the negative effects of peer pressure.

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**Stigma context**

**Strategies**

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<td>• Put ARVs in a pill box or a different bottle in a locker</td>
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<td>• Keep ARVs in pocket and take when going to toilet or brushing teeth</td>
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<td>• Keep ARVs with the matron if she can be trusted</td>
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<th>In the clinic</th>
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<td>• Support groups for young people help to build confidence, and provide mentorship and motivation</td>
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<td>• Support groups and other ALHIV-focused activities should be held in safe spaces</td>
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<tr>
<td>• Arts, sport and music bring people together, and help to focus on life beyond disease</td>
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<td>• As far as possible, adolescents should be seen separately from adults and children</td>
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<td>• Peer supporters help young people to access and link to facilities</td>
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<td>• Health providers must be trained to be more sensitive to the needs of young people</td>
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<td>• Online communication tools and telephonic support lines may be helpful</td>
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<th>In the community</th>
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<td>• Incorrect and harmful messaging must be challenged</td>
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<td>• Communities and caregivers should be sensitised, educated and supported to care for young people</td>
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<td>• Messaging should be positive, upbeat and helpful, including SRH messaging</td>
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“I ran away from school because of stigma. It is difficult to tell your friends at school. I once asked my friend what he would do if someone told him they were HIV-positive. He said he would tell others in the school because he would not be comfortable. I soon learnt that it is not safe even to tell your closest friends at school.”

Peer supporter, Malawi
Together with peer support, the importance of creating safe spaces and engaging in support groups were highlighted as effective strategies. Safe spaces offer YPLHIV an opportunity to meet and engage with peers who may be facing similar struggles, speak openly about sex and sexuality without fear of judgement, access factual up-to-date information and be alerted to relevant upcoming events or social gatherings. Support groups were described as needing to be motivating and inspiring – offering a dynamic space that is able to be flexible in content and programme, shifting as needs of group members change over time. Support groups and teen clubs were seen as critical in widening the circle of support for ALHIV.

However, participants also highlighted some of the challenges associated with running or participating in support groups. Some shared that it may be difficult to convene support groups physically in the community as the group itself may be labelled as a congregation of those infected with HIV and lead to stigma and discrimination. Young people felt that creating a designated space in the clinic is best. Many young people reported that support groups are frequently poorly planned and managed. It was felt that the groups tend to become stale and tedious over time, often repeating the same activities weekly. This led to high rates of attrition. Participants believed that greater attention needs to be given to developing different types of support groups, with changing content areas and programme material. They advised that support groups should be creative and fun, utilising different methodologies, such as arts, crafts, music, drama, writing, sports, and social events. Importantly, young people explained that each session should not focus exclusively on HIV infection and medication adherence, but rather expand to provide content that is of broader interest and speaks to the many facets of being a young person.

‘Fight stigma – Introduce casual days - even nurses put on casual clothes and play games and sports with adolescents’

‘Be kind and courteous in the community - organise fun awareness raising activities in the community, promote testing’

‘Use talents, singing and dance competitions, drama and beauty pageants – these activities can provide positive peer support rather than negative peer pressure’
COLLABORATE: Me, my peers and AFHS

The second day turned beyond the individual peer supporter to peer support services and AFHS specifically. What is the functionality and ‘feel’ of AFHS? What are quality peer-led services, and what do our peers want? What is meaningful youth participation and how do we ‘walk the talk’? How do we reach marginalised youth and address stigma? What is the range of services needed and how should these be delivered and/or integrated into current health systems? How can we strengthen peer support activities and address barriers, whilst providing creative strategies for effective peer support?

AFHS

AFHS delivery was highlighted as a significant challenge for many health facilities who are not equipped to deliver services for adolescents that are equitable, accessible, acceptable, appropriate and effective. Discussions centred around what being adolescent-friendly means, and how what is required is far more than an operational ‘checklist’ in terms of staff, training, opening times and physical structures. Instead, young people spoke about how the most crucial aspect of a facility being considered adolescent-friendly relies on provider attitudes. They wanted health providers to actively listen to what they have to say, be patient with them and respect their right to privacy and confidentiality. Young people said they expected providers to offer them accurate SRH information – including family planning options – and give them space to make their own decision. They explained that without adolescent-friendly and sensitized health teams, AFHS have no real meaning.

Summit participants spent time defining what AFHS means to them by creating descriptive posters, and executing a series of role plays wherein they were able to act out their ‘dream clinic consultation’.

“Healthcare providers must be friendly, non-judgemental and able to offer services with accuracy, care, acceptance and respect.”

Peer supporter, Uganda
What AFHS means to us:

- Training for caregivers on parent-child communication & parenting skills
- Choose health provider I am comfortable to talk to
- Psychosocial support
- Friendly, welcoming & providing adolescents with freedom of expression
- Convenient – dedicated time or space for adolescents
- Health providers who are trained & knowledgeable
- Peer Support – support groups & teen clubs
- Integrated HIV prevention, treatment & monitoring, SRH and mental health services
- Non-judgemental, approachable & confidential health providers
- Receive multiple services in one appointment

Figure 4. Young people’s descriptions of what AFHS means to them
Above all, young people valued peer-led services, service integration, dedicated times, and positive SRH messaging. They spoke about the many potential roles of young people within health facilities, acting as mentors, lay counsellors and service providers. They felt it important that services are integrated, offering a comprehensive package of care that includes HIV prevention, treatment and support (including access to viral load monitoring) as well as broader SRH and mental health services. Young people wanted to be attended to separately from adults and children. They also felt that providers should offer positive health messaging and framing, which would be more motivating for them and their decision-making. In addition, they wanted facilities to have mechanisms and processes for them to be able to assess and provide feedback on the quality of services they receive. Finally, they valued online forums and social media as age-appropriate platforms for sharing information that is relevant, fun and interesting.

Sessions discussed the service environment in great detail, and young people focused on the importance of inclusiveness. The group reinforced that AFHS should be sensitive and responsive to young key populations. In order to actualise this, discussions focused on health provider sensitization and training.

**Peer supporter identity, challenges and needs**

Various activities provided participants with time to reflect on their role and responsibilities as peer supporters. The sessions intended to help peer supporters to better understand their challenges, vulnerabilities and resilience-building strategies.

One of the key discussion sessions focused on what is they need in their workplace to support their wellbeing. Overall, participants wanted to feel respected, to be heard, able to contribute, to be paid on time, in a friendly environment and amongst colleagues.
Access for all

Various factors outside of our control such as gender, race, class, sexual orientation, age, financial ability and gender affect our ability to access services. Participants spent time in a simulation exercise designed to establish barriers and limitations to treatment access, and provide the space for people to think about who is NOT accessing services and why. The young people spoke about the global dynamics of privilege and marginalisation, and how they determine quality and access to treatment. At the same time, people can demonstrate agency, and have determination. Finally, they discussed how we as health workers can facilitate better access for all.

Overall, the group felt that some of the key barriers to access were:

- Physical isolation (e.g. living in remote area, or attending boarding school)
- Long distances, and high transport and service-related costs
- Lack of family support, and unwell, uninformed or unsupportive caregivers
- Service inefficiency, with delays, long queues and staff shortages
- Negative health provider and peer educator attitudes
- Food insecurity
- Transition from paediatric to adult services or being moved from central, to a district or local facility

Participants spent time discussing strategies to improve access. These included:

- Create safe and inclusive spaces
- Advocate for NO FEE clinics
- Provide treatment in the community, closer to where people live
- Schedule appointments and medication pick-up for every 6 months when patients are well and stable
- Peer supporter to reach young people inside and outside of the health facility
- Ensure support groups are inclusive and fun
- Peer supporters to become active in national network structures and raise issues in the clinic
- Peer supporters to act as role models and ‘be the change we want to see’

The session also debated laws that prohibit certain services and/or criminalise key population groups, limiting access to services.

The most marginalised and inadequately served groups were described as including:

- Adolescents with disabilities
- Orphans
- Sex workers
- Substance users
- Young men who have sex with men
- Transgender adolescents
- Pregnant teens and young mothers
- Discordant partners
- The very poor
- Out of school youth

Nicholas Niwagaba from UNYPA explained that young people who belong to one or more key population groups are vulnerable to HIV due to discrimination, stigma and violence, and may be more likely to experience power imbalances in relationships and alienation from family and friends. Young people from key populations tend to be reluctant to seek services at health facilities as they often fear stigma and discrimination. Nicholas provided an update on the Link Up project, and highlighted the key role that peer supporters can play in health and community settings. He explained that peer-to-peer education by well-trained peer educators, from within the same communities, with condoms, information and referral slips and a budget to accompany young people to health facilities can assist in improving access for the most marginalised. Finally, more attention needs to be placed on training health providers on key population issues...
and communication skills. It is critical that health providers know how to listen, know what questions to ask/ not ask, and how to support young people holistically. Importantly, providers must be trained on confidentiality. Young people need to know that the information we share is safe.

**KEY MESSAGES:**
- Not all adolescents are the same! Services must recognize diversity amongst young people.
- Accept and respect us all, as we are!
- Address our own self-stigma.
- Sensitize health providers to the needs and rights of key populations and marginalized youth.
- Create safe spaces and dialogues between health providers and young key populations to build better understanding and awareness.
- Have peer supporters from key populations represented in facilities and in decision-making bodies.
- Adopt innovative and creative ways to find hard-to-reach populations, and take services to inadequately served and key populations—via mobile clinics and medicine delivery services.
- Eliminate restrictive laws and policies that prevent young people from accessing SRH services.

We need to **think and plan for those who are NOT coming** to the health facility and ask ourselves, “WHO is not coming?” and “WHY are they not coming?” How do we make it easier for them, or how can we reach out?

**Viral load testing**

Viral load testing is an essential part of HIV disease monitoring. Viral load tests are used to monitor response to ART as well as diagnose treatment failure when needed. Viral load monitoring helps us predict disease progression, assess risk for opportunistic infections and gauge likelihood of onward transmission. Although many governments have committed to providing routine viral load testing, not enough people know about the importance of getting the test and most peer supporters reported at the summit that they do not receive regular testing. Advocating to know your viral load and always regularly receiving this result from your health provider is an important part of managing your health. Dr. Shannon Shea from Baylor College of Medicine-Tanzania encouraged and motivated peer supporters to become more active in the management of their health, and to engage with their health providers.

Join the [campaign](#) to know your viral load.

**Peer Supporter Thoughts**

“We, the peer supporters, are the ones who let them come and let them go”.

“Clinics must partner with NGOs that can offer different support in the community. For example, there are NGOs who can provide food, and others, psychosocial support.”

“Even where sex work is illegal in my country, we can use peer models to identify young sex workers and young MSM. We can provide night outreach, offer support and encourage linkage to the clinic, as well as accompany them to make sure they receive the service and are treated well.”

“Despite improvements, stigma and discrimination remain a key barrier that discourages people, especially young key populations, from going to the facility. Young men having sex with men is associated with deviant behaviour, and viewed as being contagious and is seen negatively.”
Linkage and retention in care

Engagement in medical care soon after HIV diagnosis is essential to remaining healthy. New guidance suggests immediate initiation of treatment following an HIV-positive diagnosis irrespective of age, viral load or CD4 count. Being linked into care and then staying in care and adhering to treatment are critical to securing viral suppression and good health outcomes.

KEY MESSAGE:

Peer supporters play a vital role in linking YPLHIV to quality HIV and SHR services, assisting them to navigate services and providing the support they need to stay in care.

SRH as a rights issue

Participants spent time discussing sexual and reproductive health and rights (SRHR). They concluded that young people have the right to full and accurate information, as well as service, support and skills-building to protect themselves and their peers. SRH services must be accessible, acceptable, confidential, and respectful, and support young people’s right to autonomous choice and options.

Young people value SRH services that are comprehensive and include STI prevention, screening and treatment; offer a range of family planning methods and tools; cervical cancer screening; and antenatal care (ANC) and prevention of mother-to-child transmission (PMTCT). Participants spoke of a preference for receiving services from other young people, but specified that peer providers must be well-trained to provide effective SRH counselling. Peer supporters should also act as gateways and links to the clinic and other services.

Young people explained that SRH information should be shared in a creative way, and didactic teaching avoided. They want to be educated, but then respected for whatever decisions they choose to make. Finally, they ask for care and acceptance – without judgement.

‘The most challenging as a peer support is when your peer come to you, and explain his/her issues and you can do nothing to help a part. Part of you is crying with her/him. Sometimes I wonder if I give condoms and information will this save a life of someone who didn’t get something to eat during the last 2 days. And I just keep talking about condoms, and adherence...how so?’

“I can’t take it when someone who is older than my mom is talking to me about sex. I need to go to someone my age, a peer, and talk about sex. Honestly me, I am a patient at [ … ]’s clinic, when the nurse asks me if I use protection, I tell her yes. But when I go to [ … ] I tell her the truth, that I don’t use condoms. We can speak freely as young people.”

“Health care worker attitudes and those from others make us scared of sex. When I asked the nurse about family planning, she just shouted at me. She told me I am HIV-positive and should not have sex. She scared me, like, if I had sex, I would maybe die.”
The final day translated central themes that emerged from Day 1 and Day 2 into key messages. Activities focused on engaging existing national youth networks on how these messages can be taken forward. The day prioritised key messages to underpin P2Z, which would then be taken to the 21st International AIDS Conference (AIDS 2016), which would take place shortly after the summit from 18-22 July 2016. Participants discussed how to build linkages such that facility-level issues can be better raised. Finally, a Youth Advisory Panel for P2Z was elected, with a representative nominated to serve on the PATA Board of Directors.

We are proud to share the Youth Advisory Panel membership as:

<table>
<thead>
<tr>
<th>Country</th>
<th>Clinic/Institution</th>
<th>Representative</th>
</tr>
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<tbody>
<tr>
<td>ZIMBABWE</td>
<td>United Bulawayo Hospital</td>
<td>Phakamani Moyo</td>
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<tr>
<td>MALAWI</td>
<td>Zalewa Clinic</td>
<td>Grace Ngulube</td>
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<td>CAMEROON</td>
<td>Chantal Biya Foundation</td>
<td>Ange Fouakeng Mireille</td>
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<td>DRC</td>
<td>Kalembelembe Clinic</td>
<td>Ariel Nymba</td>
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<tr>
<td>TANZANIA</td>
<td>Baylor College of medicine-Tanzania</td>
<td>Joan John</td>
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<tr>
<td>UGANDA</td>
<td>Mulago COE ISS Clinic</td>
<td>Lubega Kizza</td>
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Please contact PATA offices if you would like to be put in contact with one of the panel members.
The Youth Advisory Panel objectives are to:

1. Promote peer supporters as effective advocates of SRHR and HIV service access
2. Build an audience of proactive young leaders amongst fellow peer supporters and YPLHIV, and link them to technical resources, tools and opportunities for capacity-building and training
3. Raise the visibility of adolescent and youth peer supporters, with a focus on improving access to services and mechanisms to raise facility-level concerns and gaps
4. Promote the meaningful role of facility-based peer supporters and YPLHIV in planning, delivering and monitoring services that affect them
5. Facilitate the development and dissemination of youth-driven advocacy messages, and inform the development of P2Z and PATA programmes, media and materials

Cedric Nininahazwe, RNJ+, Burundi
1. We, the peer supporters and network representatives of young people living with HIV from Cameroon, the Democratic Republic of Congo, Ethiopia, Malawi, Tanzania, Uganda, Zambia and Zimbabwe have assembled at the PATA-AY+ Youth Summit in June 2016.

2. We are inspired by the resilience, creativity and courage of our young African peers who have led the way before us. Many of these young people lost their lives as we waited for treatment access to be realised.

3. The end of AIDS is now much closer, and with enthusiasm and dedication we embrace the vision of the Fast-Track strategy to end AIDS by 2030, including 95-95-95, 200,000 new infections among adults and zero discrimination.

4. We are, however, dismayed and concerned that AIDS-related illness is the leading cause of death among adolescents in Africa, and that adolescents have worse treatment outcomes, higher rates of loss to follow-up and worse adherence than adults.

5. We call for the rapid fulfilment of international commitments to make viral load testing and free treatment available to all, including young people.

6. We ask for easier to-take medication; including fewer, smaller and better tasting tablets, as well access to longer-lasting treatment options.

7. Young people offer a unique voice in the global fight against HIV. We play a crucial role as peer educators and peer supporters, providing and linking youth to quality HIV and SRH services.

8. We must be genuinely involved and at the forefront of developing, implementing, monitoring and evaluating services that affect us and organisations that seek to represent us. Our voices count and must be heard.

9. Peer service provision is work and should be taken seriously. We call for remuneration, guidance, supervision, training, capacity-building, resources, autonomy and belonging. We also require investment in young peer supporters beyond delivering services, and request the creation of study, livelihood and income generating activities for us.

10. We are more than just our HIV status, and our holistic wellbeing is important. We cannot give wellbeing if we are not well ourselves. We ask for positive, supportive and enabling environments to receive and deliver healthcare.

Call to Action - Peers to Zero

The Dar es Salaam Peer Supporter Declaration
11. As young people, we need HIV and SRH services that are comprehensive and integrated. A comprehensive package should include private and confidential HIV prevention, treatment and monitoring; supportive psychosocial and mental health services; and sex-positive messaging and counselling. We demand options for unwanted pregnancy and access to a range of family planning methods, including regular cervical screening.

12. We request friendly and sensitised healthcare workers with positive attitudes and ask that HIV and SRH services be provided to us with care, acceptance, respect and without judgement. We should be provided with comprehensive information and recognised as capable of making our own decisions. Don’t lecture us, empower us!

13. We call for accessible adolescent- and youth-friendly services. Let us move beyond a checklist and ensure that services are appropriate and context-sensitive.

14. We insist on access for all, as we are! As young people, we are not all the same. We acknowledge that access may be more difficult for key and vulnerable populations, including young men who have sex with men, young women who have sex with women, transgender and intersex young people, young people who use substances, young people who sell sex, young people with disabilities, orphaned youth and pregnant/young mothers. We call for innovative and creative efforts to engage difficult-to-reach populations. Services should recognise our diversity and strive to be inclusive. As peer providers, we will endeavour to reach these populations and ensure that all young people – including the most marginalised – receive services free from stigma and discrimination.

15. Transition to adult health care, as well as to tertiary education or boarding school is a time where many of us falter. We call for greater attention, strategies and services to support us in making transition safer.

16. We acknowledge the physical, economic, and social factors that make accessing services and staying in care difficult, and call for creative, positive and youth-sensitive responses that address the socio-economic drivers that render us vulnerable.

17. As young peers living with HIV, we commit to providing services as we wish to receive them. We endeavour to actively listen, understand the needs of young people, be patient and address our own stigma. We will act as positive role models to our peers and dedicate our efforts so that future generations of young people will not live with the burden of HIV and AIDS.
Summit evaluation

The summit received very positive evaluative feedback. Peer supporters reported identifying key concerns, as well as novel and effective strategies to support YPLHIV in care. They stated experiencing the summit as a useful team-building opportunity that promoted dialogue with their supervisors. Most importantly, they felt the summit promoted skills-building and leadership capacity for peer-led AFHS.

“I learned that as peer supporters we should also think about our self. Not only to care about others and forget about ourselves.”
Peer supporter, Zimbabwe

“I learned to always think about those that can’t come to the clinic or those that can’t reach the information.”
Peer supporter, Zimbabwe

“I learned to be visible to the community and to stand tall always.”
Peer supporter, Zimbabwe
Resources and links


• WHO’s *Health for the world’s adolescents: A second chance in the second decade*. Geneva: World Health Organization; 2014


• WHO core competencies in adolescent health and development for primary care providers

• WHO guidelines for testing and counselling and care for adolescents living with HIV

• WHO technical briefs on *HIV and young men who have sex with men, young people who inject drugs, young people who sell sex* and *young transgender people*

• PATA Promising Practices: *One-stop adolescent shop.*

• PATA Promising Practices: *Grab the gap*. Available at PATA Resource Hub
YOUTH SUMMIT REPORT

Initiate - Collaborate - Advocate

#PEERS2GETHER2ZERO

YOUTH SUMMIT REPORT
ANNEX 1: Agenda

INITIATE – Me, Myself and I
DAY 1: Tuesday 28 June 2016

06:00 – 07:45  BREAKFAST  Main Restaurant
07:00 – 07:45  Registration
08:00 – 09:30  PATA (South Africa)
   Nevala Kyando, Network of Young People Living with HIV (NYP+) (Tanzania)
   Welcome and opening - National Anthem of Tanzania
   Youth and HIV - ESA regional update
   Carlo Oliveras Rodriguez, Adolescent Treatment Coalition (Puerto Rico)
   Overview of the Adolescent Treatment Coalition and key messages from the 2016 High Level Meeting on ending AIDS
   Luann Hatane, PATA (South Africa) and Paddy Masembe, AY+ (Uganda)
   PATA-AY+ Youth Summit overview

09:30 – 11:00  Personal reflections: My, myself and I
   Closed Session: Workshop Rooms

11:00 – 11:30  TEA

11:30 – 13:00  Open Space Session: Let’s talk about…!
   Disclosure - stigma and discrimination
   Peer pressure - living and loving safely
   Transitioning to adult care
   My future - opportunities beyond peer support Ruaha Lounge

13:00 – 14:00  LUNCH

14:00 – 15:00  Closed Session: Dialogues for wellbeing

15:00 – 16:00  Panel Session: adolescent well-being
   Chaired by Dr Patrick Oyaro Owiti, FACES (Kenya)
   Bahati Kasimonje, Newlands Clinic (Zimbabwe)
   Tips and tricks for self-care
   Lesley, Gittings, Mzantsi Wakho (South Africa)
   Adolescent ART adherence – findings from the Mzantsi Wakho study
   Dr Shannon Shea, Baylor College of Medicine Children’s Foundation (Tanzania)
   Wellness and viral supression

16:00 – 16:30  Group photo

17:00  Optional evening activities
   Movie OR Beach volley ball

18:30 – 21:00  Casual dinner  Main Restaurant
COLLABORATE – Me, My Peers and Adolescent Friendly Health Service
DAY 2: Wednesday 29 June 2016

06:00 – 07:45 BREAKFAST
08:00 – 08:30 PERFORMANCE –SONG: Phakamani Moyo (Zimbabwe)
   Morning check in
08:30 – 10:00 Open Space Session: Feel! Think! Act! Service delivery and youth engagement
   Quality peer support services and safe spaces
   Adolescent-friendly health services
   Integration of HIV and sexual reproductive health and rights
   Meaningful participation of young people living with HIV at my health facility
10:00 – 10:30 TEA
10:30 – 12:00 Closed Session: Access for all?
12:00 – 13:00 LUNCH
13:00 – 14:30 Panel Session: Exploring access
   Chaired by Dr Patrick Oyaro Owiti, FACES (Kenya)
   Lesley, Gittings, Mzantsi Wakho (South Africa)
   Charity Maruva, Zvandiri (Zimbabwe)
   An ecological model
   Socio-economic barriers
   Nicholas Niwagaba, UNYPA (Uganda)
   Reaching and serving young people from key populations
   Bahati Kasimonje, Newlands Clinic (Zimbabwe)
   Adolescent mental health and wellbeing
   Feedback from open spaces and access workshop
14:30 – 15:00 TEA
15:00 – 16:30 Skills-building
   Lovincah Nakayiza, UNYP (Uganda)
   Working with young people from key populations - Exploring attitudes, values and decisions
   Charity Maruva, Zvandiri (Zimbabwe) and Bahati Kasimonje, Newlands Clinic (Zimbabwe)
   Counselling, mentoring and leadership
17:00 Optional evening activities: Movie OR Beach volley ball
18:30 – 21:00 Casual dinner
ADVOCATE – Me, My Peers - Speaking Up and Linking Up
DAY 3: Thursday 30 June 2016

06:00 – 07:45  BREAKFAST

08:00 – 10:00  Panel Session: Key emerging advocacy messages
Chaired by Carlo Oliveras Rodriguez, Adolescent Treatment Coalition (Puerto Rico)
Country network representative
Meaningful engagement of YPLHIV in policies and programmes that affect them
Heleen Soeters, PATA (South Africa)
Adolescent-friendly service beyond the checklist
Cedric Ninahazwe, RNJ+ (Burundi)
SRHR and HIV service integration from the Link-Up experience
Annah Sangho, AY+ (Zimbabwe)
What women want campaign
Naume Kupe, RIATT-ESA (South Africa)
Consolidated messages from the Summit

10:00 – 10:30  TEA

10:30 – 11:00  Arsene Ngombe, PATA (South Africa) and Paddy Masembe, AY+ (Uganda)
Advocacy – Peer Supporter voices from the frontline Gillmans Hall

11:00 – 12:30  Open Space Session: Advocacy methods
Dream consultation
Say it in a poster!
Social media mobilisation
Participatory action research for change

12:30 – 13:30  LUNCH

13:30 – 14:30  Team action plan
14:30 – 15:30  Introduction and launch of Peers 2 Zero
Election of Youth Advisory Panel

15:30 – 16:00  TEA

16:00 – 17:00  Wrap up, key messages and closing ceremony
Luann Hatane, PATA (South Africa)
PERFORMANCE – PATA SONG: Dr Patrick Oyaro Owiti, FACES (Kenya)

19:00 – 22:00  Closing dinner, celebration and presentation of the Dar es Salaam Peer Supporter
Declaration
For more information:

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Email: info@teampata.org
www.teampata.org

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