11th PATA Continental Summit Report:
Recommendations, promising practices and key messages

6-9 December 2015
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Acronyms

AFHS  Adolescent-friendly health services
ALHIV  Adolescents living with HIV
ANC  Antenatal care
ART  Antiretroviral therapy
AY+  African Young Positives Network
CBO  Community-based organisation
CHAI  Clinton Health Access Initiative
CHAU  Community Health Alliance Uganda
CIPHER  Collaborative Initiative for Paediatric HIV Education and Research
DFID  Department for International Development
FACES  Family AIDS Care and Education Services
FBO  Faith-based organisation
HBCT  Home-based HIV counselling and testing
IAS  International AIDS Society
IATT  Inter-Agency Task Team
ICW  International Community of Women living with HIV
IEC  Information, education and communication
KYCS  Know your Child’s Status
LTFU  Loss to follow-up
MMC  Medical male circumcision
NASCOP  Kenya’s National AIDS and STI Control Programme
NGO  Non-governmental organisation
OVC  Orphans and vulnerable children
PITC  Provider initiated testing and counselling
PMTCT  Prevention of mother-to-child transmission of HIV
REPSI  Regional Psychosocial Support Initiative
SRH  Sexual and reproductive health
SRHR  Sexual and reproductive health and rights
TAT  Turnaround time
TB  Tuberculosis
TOP  Termination of pregnancy
UNYPA  Uganda Network of Young People Living with HIV
WHO  World Health Organisation
Y+  Network of Young People Living with HIV
Executive summary

Children and adolescents have been left behind in the global HIV response, and the treatment gap persists. At this juncture, it is critical to adapt global targets to local realities, translating discourse into action. The PATA 2015 Continental Summit, titled *Promising practices in paediatric and adolescent HIV services: Adapting global targets to local realities* was held 6-9 December 2015 in Nairobi, Kenya. The meeting brought together 125 participants, including 85 frontline health providers from 29 health facilities across 12 sub-Saharan Africa countries. Also in attendance were representatives from ministry of health, youth networks and organisations who are leading the response to paediatric and adolescent HIV in sub-Saharan Africa. The summit focused on three overarching themes: case identification of HIV-infected children; addressing sexual and reproductive health and rights (SRHR) in health facilities; and caregiver support and family-centred HIV services.

The 3-day meeting used plenary sessions, workshops, panels and world cafés to provide technical input, discuss bottlenecks and strategies and highlight real-world response examples. The summit culminated in health facilities prioritising an intervention, activity or service as a promising practice pilot project for 2016. This report is based on meeting discussions and outcomes.

Several key messages emerged from the summit. Most prominently, technical recommendations focused on involving young people in service delivery, harnessing peer supporters, partnering with communities, service integration and innovation, bold targets and accelerated action, and focusing on data and impact.

Facilities from Kenya, Nigeria, South Africa, Tanzania, Uganda and Zimbabwe presented promising practices, and providers from across the participating countries shared implementation strategies within thematic areas. It is clear that those at the frontline of the HIV response are undertaking bold action to overcome challenges and end the paediatric HIV epidemic. Only through sharing these innovations in service delivery may we close the gap to achieve the 90% targets.
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Introduction

In 2014, there were 2.6 million children living with HIV worldwide. Children have been left behind in the global response, and the paediatric treatment gap persists. Children are a third less likely to receive treatment than adults, with less than one in three (32%) accessing ART in 2014. We are facing staggering rates of HIV-related mortality in adolescents and youth, with AIDS-related illness the leading cause of death among adolescents in Africa. Young people in care are experiencing novel challenges as they move into adolescence, and require specialised and multifaceted support from health providers to remain in care, adhere to treatment, and cope with the developmental issues of adolescence in addition to HIV.

At the same time, there has been a recent renewed interest in, and understanding of the urgency of an enhanced paediatric and adolescent response. New initiatives, guidelines and targets hold promise for improved access and outcomes and provide crucial direction to ensure that programmes deliver the best prevention, treatment and care possible. However, many countries have yet to implement the guidance. At this juncture, it is critical to adapt global targets to local realities, translating discourse into action.

A ‘nuts and bolts’ approach – focused on service level activities and implementation models – is needed. While some health facilities have developed operational solutions in response to the unique needs of children and adolescents living with HIV, too often these initiatives are unreported, their impact limited to isolated facilities. Peer-to-peer sharing of these real world promising practices (‘practice-based evidence’) is a key strategy towards influencing policy and programmes.

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 across 24 countries who collectively care for over 200,000 children and adolescents on ART. The PATA network includes members from Southern, East and West/Central Africa, and comprises several cadres of health professionals and lay service providers, including doctors, nurses, pharmacists, counsellors, community health workers and peer supporters. 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.

Dr Irene Makui, Ministry of Health Kenya, welcomes participants to the country and provides an introduction to the paediatric treatment gap.
Promising practices: What does PATA mean?

- Pilot stage interventions that have not been systematically demonstrated, formally evaluated and/or scaled up
- May be new to the local setting (modified to address local circumstances), not necessarily to global context
- Interventions, activities or services that support children and/or adolescents living with HIV
- Potential for impact on treatment access, adherence, retention and/or virological suppression
- Operational rather than clinical
- Promising rather than best, in recognition of i) the limitations of pilot-stage, small-scale, time-bound intervention assessments, ii) the rapidly evolving context and emerging sector knowledge, and iii) different contexts across the continent

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 synchronized 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, create a gateway for two-way dialogue between civil society and policymakers and influence change. The PATA network provides access to valuable information and insights regarding effective service delivery models and potential solutions. This information has the power to drive policy change at the national and global levels.

PATA Strategy and Theory of Change
PATA forums are collaborative meetings where multiple cadres of health providers that serve clinical, psychosocial and operational functions\(^a\) from PATA focus countries\(^b\) convene for technical capacity-building, peer-to-peer exchange and the design of promising practice pilot projects. The academic programme consists of presentations of technical information and guidelines, peer workshops and health facility presentations of effective strategies and real world solutions. Forums culminate in health facility teams drafting *Promising Practice Grids* which articulate an intervention, activity or service that will be implemented over a 12-month period. PATA supports health facilities to implement their promising practice pilot projects through remote project management capacity-building, and – where available – site visits and the disbursement of small grants as a springboard for action. Annual PATA Continental Summits convene health providers for cross-fertilization and peer-to-peer exchange across the continent. PATA Local Forums bring together health providers from specific districts to develop strategies and solutions and form ‘communities of practice’ in local areas. PATA typically convenes six local forums each year, with participants drawn from specific partner-dense districts within a region or country. Since 2005, PATA has held 41 Continental Summits and Local Forums in Botswana, DRC, Ethiopia, Kenya, Lesotho, Malawi, Nigeria, Rwanda, Uganda, South Africa, Swaziland, Tanzania, Zambia and Zimbabwe for frontline healthcare teams from hundreds of health facilities.

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\(^a\) Clinical roles refer to those providing medical treatment, e.g. doctors, nurses, pharmacists. Psychosocial roles refer to those providing psychological or social support, e.g. counsellors, community health workers, peer supporters, psychologists, social workers. Operational roles refer to those managing or overseeing clinic services, including clinic managers, programme managers, director of services.

\(^b\) Burundi, Cameroon, DRC, Ethiopia, Kenya, Malawi, Nigeria, South Africa, Tanzania, Uganda, Zambia, Zimbabwe
PATA summit specific objectives are to:

I. Disseminate and popularise the latest paediatric and adolescent HIV treatment and care guidelines and technical updates

II. Mobilise the frontline to undertake local action to advance optimal paediatric and adolescent HIV services across sub-Saharan Africa

III. Share innovations, promising practices and models of service delivery in key programme areas across facilities and regions

IV. Enhance South-South solidarity and encourage linkages between professional roles, health facilities and regions

The PATA 2015 Continental Summit, themed *Promising practices in paediatric and adolescent HIV services: Adapting global targets to local realities* was held 6-9 December 2015 in Nairobi, Kenya.

The meeting brought together 125 participants, including 85 frontline health providers from 29 health facilities across 12 PATA focus countries. Together, these facilities care for 47,387 infants, children and adolescents living with HIV. Each attending health facility team was made up of three members who represented an operational, clinical and psychosocial role. They were joined by representatives from ministry of health, youth networks and organisations who are leading the response to paediatric and adolescent HIV in sub-Saharan Africa.

The summit focused on three overarching themes:

- Case identification of HIV-infected children
- Addressing SRHR in health facilities
- Caregiver support and family-centred HIV services

Simultaneous interpretation facilitated full Anglophone-Francophone participation.
Methodology

The 3-day meeting used a variety of session formats to achieve its aims.

*Plenary sessions*
Technical input was provided through evidence and programme reviews as well as policy updates. Plenaries also provided top-line recommendations and facility-level solution examples.

*Peer workshops*
Health providers and stakeholder groups (ministry of health officials and youth representatives) worked in parallel to discuss their particular bottlenecks, challenges, solutions and strategies.

*Stakeholder panels*
Cross-cutting themes emerging from peer workshops were discussed in a facilitated open fishbowl conversation.

*Promising practice world cafés*
Selected health facilities that had demonstrated real world responses to key issues provided rapid presentations and Q&A responses.

*Promising practice grid workshops*
Health facilities discussed effective strategies, solutions and practices, before brainstorming and prioritising an intervention, activity or service articulated as a *Promising Practice Grid*. Draft grids underwent peer-to-peer presentation and feedback, before being revised and finalised.

This report is based on summit presentations, discussions in plenary sessions, peer workshops, stakeholder panels, promising practice world cafés, and promising practice grid workshops.
Unlocking the key: Case identification of HIV-infected children

PLENARY UPDATES AND TECHNICAL INPUT

WHO’s new guidelines recommend that all people infected with HIV be initiated on ART at diagnosis, regardless of CD4 count. UNAIDS’ ambitious “90-90-90” targets set out that by 2020, 90% of people living with HIV will be diagnosed, 90% of those diagnosed will be on sustained ART, and 90% of those on ART virologically suppressed. Yet, paediatric treatment coverage lags behind that of adults, and globally, 32% of all children under age 15 years receive ART. In the absence of treatment, half will die by the age of two, and 75% by the age of five.

To resolve the treatment gap for children and adolescents, we must begin to understand the critical bottlenecks to their identification and diagnosis. Barriers exist at the levels of child, family, caregiver, health system and environment. Caregivers may be hesitant to test their children because they are afraid this will inadvertently disclose their own status, rendering both them and their children vulnerable to stigma and discrimination. Healthcare providers are also frequently reluctant to test – if the child is well, testing may not be seen as a priority; if the child is ill, there may be other priorities.

“Caregivers are not consenting to testing, healthcare workers are not comfortable recommending testing, healthcare workers are busy and even when it comes to counselling there isn’t any privacy. We need to find new solutions.”
— Dr Nandita Sugandhi
Clinical Advisor, Clinton Health Access Initiative and Assistant Clinical Professor, Icahn School of Medicine at Mount Sinai

“If you can’t unlock the first 90%, the others are irrelevant.”
— Dr Landry Dongmo Tsague, Senior HIV Specialist for PMTCT and Paediatric HIV Care, UNICEF Regional Office for Western and Central Africa
PLENARY RECOMMENDATIONS

• In order to find and test hard-to-reach children living with HIV, adopt a family-centred approach to testing. **Use the index client enrolled in any HIV service** to find out if they have children that haven’t been tested or aren’t accessing services. Test these children through facility- or home-based testing.

• **Look in the right places.** WHO guidance recommends that in generalised epidemic settings, provider-initiated testing and counselling (PITC) be used as a means of intensified case finding in inpatient wards, malnutrition services, outpatient services and immunisation clinics. Tuberculosis (TB) treatment centres in high prevalence settings like South Africa should also be considered. The yield is highest when children are already in contact with healthcare services, and these testing opportunities within routine encounters should not be missed. Finally, all children and adolescents receiving orphan and vulnerable children (OVC) services should be tested.

• **Engage and empower community stakeholders and members** such as community health workers and patient escorts to generate demand and promote health-seeking behaviour. Community sensitisation through information sharing at schools and churches, as well as print and broadcast media should be considered.

• **Provide adolescent-friendly health services** and address the unique needs of adolescents.

“Provider attitudes are what make a difference. It is important to be conscious and aware of what adolescents are looking for and to treat them in a non-judgemental way.”
– Dr Shaffiq Essajee, Medical Officer for the Prevention of Mother-to-Child Transmission, WHO

“We should have uniform implementation of strategies so that everyone walks with one common goal with one common method.”
– Ministry of health stakeholder group

Dr Nandita Sugandhi, CHAI and the Icahn School of Medicine Mount Sinai, provides an example of using a family tree to establish testing and HIV status of the index client’s family.
PEER AND STAKEHOLDER BOTTLENECKS AND STRATEGIES

Major case identification bottlenecks

- Limited caregiver understanding of the heightened risk of mortality in children and consequent importance of paediatric ART
- Weak referral systems and linkages with paediatric inpatient, TB and adult ART services
- Low male involvement and support for maternal and paediatric testing
- Shortage of test kits and long laboratory turnaround time (TAT)
- Poor inter-ministerial coordination, with insufficient harmonisation across policies, guidance and donors

Key case identification strategies

- Finding and testing children of HIV-infected adults through family facility-based or home-based testing
- Linkage to inpatient wards, EPI/under-5 clinics, malnutrition services, TB clinics and OVC services
- Building partnerships between the clinic and the community (through NGOs, CBOs and FBOs) to create demand
- Involving peer supporters to encourage and motivate testing at all service points
- Harnessing medical male circumcision (MMC) services and male-friendly extended hours as platforms and strategies to encourage family testing
- Sensitising communities through community spaces such as schools and churches, as well as print and broadcast media
- Information, education and communication (IEC) materials with clear messaging on why to test
- Lower age of consent for young people to access testing services
- Conduct detailed forecasting of HIV test kit requirements to avoid stock-outs
- Technical working groups to communicate and coordinate across sectors and stakeholders

“If you aren’t already doing it at the health facility level, you should develop the practice of looking at your data.”

— Dr Irene Makui, Ministry of Health Kenya

FACES, Kenya uses a Family Information Table (FIT) to identify and capture contacts of index clients at risk of HIV. In December 2015, they launched a tool for aggregating this data, called the Family Testing Cohort Register (FTCR), which combines index client and family member information and ensures longitudinal follow-up from identification to testing and linkage. More information is available here.
Baylor College of Medicine Children’s Foundation, Tanzania was challenged by low rates of paediatric enrolment at 5-11% of their patient base, and set out to improve case finding through Know your Child’s Status (KYCS) facility-based testing events throughout the year. Providers conduct family histories with adult patients and invite those with untested children to the facility on a specific day, while community health workers, home-based carers and peer educators sensitise communities in preparation for the event. On the appointed day, those testing positive are immediately enrolled or referred for enrolment. Since 2011, over 11,000 children have been tested. Some of the challenges encountered include test kit shortages, and – where staff engagement is poor – low event turnout. Resources needed to implement KYCS events are: test kits, testing staff, and refreshments and prizes (if provided).

Key messages from the facility:
- Test all children with known exposure to HIV
- Targeted testing has higher yield than community-wide testing
- Health provider attitudes to increased enrolment are critical in assuring buy-in and subsequent ownership of KYCS strategy
- Involvement of communities can greatly increase the turnout and yield for KYCS

TASO Gulu, Uganda was registering far higher rates of adults than paediatric patients, and began routine HIV testing for children of HIV-positive adults and siblings of HIV-positive children through home-based HIV counselling and testing (HBHCT). Index clients with young children are identified, and consent sought for HBHCT. Home visits include pre- and post-test counselling. To date, >90% of the facility’s adult patient base has tested all of their children. Challenges include lack of counselling space and compromised privacy in homes, missing family members at the time of the visit (e.g. due to boarding school attendance) and refusal to consent to home visit for fear of stigma and discrimination. TASO Gulu uses the following to implement HBHCT: staff training, staff travel time, airtime for coordination, transport and refreshments (if provided).

Key messages from the facility:
- HBHCT is a gateway to earlier diagnosis of HIV-infected children
- HBHCT eliminates costs for the patient and stigma associated with HIV testing at a health facility
- Ensure home address is correct before visit
- Avoid using vehicles labelled with ‘HIV’
- The index client should try to ensure that all children are present at the time of the visit
- Family may request medical care and advice from HBHCT tester that he or she is not qualified to provide
- Other community members may request testing, yet evidence shows targeted testing has higher yield than community-wide testing
- Ensure linkage to child-friendly services
USEFUL RESOURCES

- PEPFAR Strategies for identifying and linking HIV-infected infants, children, and adolescents to HIV care and treatment
- WHO and UNICEF Paediatric advocacy toolkit for improved paediatric HIV diagnosis, care and treatment in high HIV prevalence countries and regions
- PEPFAR Guidance for orphans and vulnerable children programming
- WHO Policy brief: Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection
- WHO Recommendations on the diagnosis of HIV infection in infants and children

"When you find that needle, pull on it because at the end of that needle is a thread connecting you to other needles in that haystack."
- Dr. Shaffiq Essajee, Medical Officer, WHO

"Timing is everything. A good system is necessary to find out which mothers are positive. Adequate numbers of trained staff are important."
- Dr. Shaffiq Essajee, Medical Officer, WHO

Dr. Shaffiq Essajee, Medical Officer for the Prevention of Mother-to-Child Transmission, WHO, presents new guidance on prevention, testing and treatment of HIV in children.
Focus on adolescents, not HIV: Addressing SRHR in health facilities

PLENARY UPDATES AND TECHNICAL INPUT

Poor sexual and reproductive health (SRH) outcomes among adolescents reflect the many barriers this group faces in accessing health appropriate health services. While programmes may seek to address adolescent SRH, they may lack a rights based perspective. Young people have the right to sexual health and satisfying and safe sex lives, including the right to express themselves as male or female and the freedom of sexual expression without coercion, violence or discrimination.

Integrating adolescent-centred sexual and reproductive health and rights (SRHR) and HIV services is critical for improved access and uptake. Yet, there is low availability of comprehensive adolescent-centred SRHR services, and where services are available, adolescent uptake tends to be low. This gap results in early sexual debut; high rates of unplanned pregnancies; young motherhood and termination of pregnancy (TOP); unsafe sex; late diagnosis of STIs; and high burden of cervical disease in young women. In many contexts, it remains taboo for health providers, caregivers and other adults to talk to young people about sex. There may be an explicit or implied expectation that young people should not be having sex and concern that if information and services are provided, early sex will be endorsed and even encouraged. Providers may struggle with the tension between protecting adolescents and supporting their autonomy, leading to adolescent reluctance to disclose to and request services from facilities.
When setting up adolescent-friendly, comprehensive HIV and SRHR services, Dr Ivy Kasirye, DFID, recommends considering:

- **Purpose and outcomes** — Are you setting out to improve access, adherence and/or retention? Do you want to reduce risk behaviour or adverse outcomes?
- **Activities** — Which activities can your facility offer to achieve these outcomes? When and how frequently?
- **Space and resources** — What is your patient volume? What is the availability, workload, interest and skill set of health providers? What level is your facility and how far are you located from other services?

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**PLENARY RECOMMENDATIONS**

- Addressing adolescent SRHR and providing adolescent-friendly health services (AFHS) is an approach tailored to the needs of adolescents. It is about creating equitable, accessible, acceptable, appropriate and effective services that serve a specific purpose and set out to achieve positive outcomes. An adolescent-friendly SRHR corner that offers quality services in a conducive environment will be more effective than the proverbial flat screen TV.
- HIV and SRHR services are often provided in parallel but should be integrated. The root causes of HIV and sexual and reproductive ill health are similar, as are counselling content, intended behavioural change and desired outcomes. SRHR services that meet the needs of adolescents should be provided in a one-stop shop model within facilities or through referrals and outreach.
- Programmes should deliver a comprehensive package of services, expanded to include family planning and modern contraceptives (short- and long-term); STI screening, testing and treatment; cervical cancer screening, testing and treatment; SRHR education and counselling; pregnancy testing and counselling; antenatal care (ANC), post-natal care and PMTCT; and MMC. Additionally, pre-TOP counselling and post-TOP care and support should be provided in line with national policies. Service provision should focus on depth as well as breadth of support.
- The service environment must be enabling and supportive. The facility itself should be welcoming, conducive, private and flexible, and health providers need to be sensitised to adolescent needs and communication strategies. The entry point is the adolescent, not their HIV status. Rather than telling adolescents what to do, we should listen to what they have to say.
- **Peer support and environments** allow young people to feel at ease and raise uncomfortable issues. Young peer supporters are well placed to lead services, serve as powerful role models and motivate clinic attendance, for instance through leading peer support groups. It is important to remember that young people are not all the same, with different stages of maturity and young key population status for example. For that reason, it is often beneficial to provide peer support for specific groups of adolescents at a time.

"It is about creating spaces for peers to share expertise, just facilitating what people know how to do themselves.”

— Dr Ivy Kasirye, Health Advisor, DFID
• Consider dedicated clinic times and operational flexibility. Attending to adolescent patients separately from children and/or adults, for instance by allocating a specific day or time to adolescent visits, may increase uptake and retention. Providing convenient clinic hours before or after school (such as 7-8 am and/or 3-4 pm) will also likely improve outcomes.
• A key strategy is to use creative rather than didactic methodologies. Avoid instruction and monotonous messaging in favour of drama, music, social media, WhatsApp and even involvement of local celebrities.
• Ensure meaningful participation of young people in the planning, delivery and monitoring of HIV and SRHR services. Incorporating young people within representative bodies and platforms is not enough to ensure legitimate engagement. One of the criteria for genuine participation is that when involved in decision-making fora, youth are empowered and feel able to disagree. We must ask, ‘How do we practically involve and empower young people?’
• Planning for young key populations is important. The needs and vulnerabilities of young men who have sex with men, young people who inject drugs, young people who sell sex and young transgender people must be addressed in a non-stigmatizing environment.

“Our stories are our biggest strength. It is our duty to change the story about living with HIV. We’ve come a long way in this epidemic. There are many beautiful things happening. We need to document stories of people living with HIV. We need to bring stories of hope. A child believes what you tell them. A child gathers value. Make children believe in themselves.”
— Florence Anam, Senior Manager Advocacy and Communication, ICW

“Young people know what they need.”
— Dr Cordelia Katureebe-Mboijana, Ministry of Health, Uganda
Several facilities recommended the Home, Education, Activities, Drug use and abuse, Sexual behaviour, Suicidality and depression (HEADSS) approach\textsuperscript{14} for talking with adolescents about issues that may affect their health. The methodology creates opportunity for challenges across the important spheres of adolescents to be discussed. The questions can be accessed \textcolor{blue}{here}. Regardless of the specific approach chosen, conversations with adolescents should always be supportive, respectful, empowering and confidential.

**PEER AND STAKEHOLDER BOTTLENECKS AND STRATEGIES**

**Major SRHR bottlenecks**

- Limited SRHR services and resources
- Adolescent unease at accessing SRHR services alongside adults
- Poor attitudes and stigma and discrimination by some health providers
- Insufficient health provider training, materials and guidelines
- Heavy health provider workload and patient burden
- Cultural and social norms, resistance, taboos, stigma and discrimination

**Key SRHR strategies**

- Peer-led services and meaningful participation of young people in planning, implementing and monitoring services
- Empowering peer supporters and networks to increase demand, educate their peers about available health services, serve as role models, encourage health-seeking behaviour and reduce stigma
- Working with communities and linking to CBOs for continuity of support
- Demand creation through IEC materials, social media and outreach events using the right messages, navigating culturally appropriate communication and engaging stakeholders
- Caregiver sensitisation on adolescent SRHR needs
- Creative engagement methodologies such as drama, music, sport, storytelling and debating
Newlands Clinic, Zimbabwe was concerned about the poor uptake of SRH services by young women, and resultant unplanned pregnancies, STIs and cervical disease. To mitigate these challenges, the facility set out to develop a comprehensive approach to SRHR issues facing adolescent girls and to create a conducive environment in which to deliver these services. Services and activities include: cervical cancer screening, family planning services, walk-in STI screening and treatment, couples counselling and testing for partners, support groups for young mothers and workshops. The intervention proved feasible and has led to a reduction in unplanned pregnancies, improved adherence, increase in skills and financial independence of the young women, improved self-confidence and awareness of sexual health matters. Some of the challenges encountered include transport costs to the facility and non-disclosure of HIV to partners. Resources used include staffing and commodities.

Key messages from the facility:
• Think outside of the box, be innovative!
• Incorporate adolescents in the planning of activities that affect adolescents
• Use locally available resources
• Consider psychosocial and cultural issues in addressing SRHR

MatCH, South Africa identified a high teenage pregnancy rate within the community and noted that adolescents were unhappy with services. Young people reported poor attitudes of health providers and provider discomfort in attending to young key populations. MatCH established health provider training on adolescent SRHR, values clarification, disclosure and peer counselling. MatCH also identified specific health providers as ‘youth champions’. They strengthened referral systems to various departments, began implementing fast queues for adolescents, convenient hours before and after school, counselling for TOP and appropriate referrals, support to pregnant teenagers at ANC visits, adolescent support groups, WhatsApp groups and youth-friendly corners. The interventions have resulted in improved staff attitude, skills and knowledge; strengthened inter-departmental referrals; and better linkages with schools. Challenges include initial resistance from health providers and school principal, continued health provider unease in supporting young key populations, limited space, gender-based violence and high staff attrition rates. Resources include training materials and staffing.

Key messages from MatCH:
• Ensure SRHR services are comprehensive, available and accessible to young people
• Appropriate referral systems
• Training results in clinic staff feeling more comfortable with adolescents - and increased attendance of adolescents at clinics
The International HIV/AIDS Alliance's Link Up project explains that there are several different approaches to service integration:

- **One-stop shop** provision of comprehensive and integrated services, such as drop-in centres or clinics that offer HIV services with SRHR services.

- **A referrals approach**, where an HIV service provides information and referrals to an SRHR service.

- **Physical and functional integration** can include a variety of combinations: different services in the same room; the same provider for both services; the same facility but a different room; the same provider but in different rooms or at different times; and a combination of services received in one visit.
The other 29 days: Caregiver support and family-centred HIV services

PLENARY UPDATES AND TECHNICAL INPUT

Caregivers and families play a central role in the wellbeing of children living with HIV. Children depend on care for treatment access and adherence, psychosocial support and the development of resilience.

Caregivers are uniquely placed to provide practical and psychosocial support to children living with HIV, as the child’s:

- Closest supporter for pill-taking, nutrition and positive living
- Gateway to a network of support within the family
- Best opportunity for age-appropriate disclosure, which builds trust and lifts the cloud of secrecy
- Shield and first line of defence against stigma
- Possibility for trusting, open relationships that facilitate intimate discussions about issues such as SRHR

But caregivers are not a homogeneous group. They may or may not be biologically related to the child, they might be living with HIV themselves, psychologically well or depressed. This may be their first encounter with the disease or they may have lost one or more people to HIV already. They could be ill, or healthy; a mother, father, grandparent or sibling. They might be young or old, manage with or without resources. Caregivers have their own unique needs and may or may not have reservoirs of physical and emotional strength to support wellness for the children in their care. Children too are not a homogeneous group, and may be girls or boys, infants up to age 18 years. They may have lost caregiver/s before, experienced abuse, be physically or cognitively delayed.

Caregiver support and family-centred services at a facility level are limited, without standardisation and low uptake. A narrow paradigm of individualised care at monthly clinic visits fails to maximise the potential of families to improve health outcomes and build resilience.

“Generally access to HIV care by children depends on caregivers. The engagement – how committed the caregiver is – goes a long way to contributing to the success of care and treatment. We need to start looking into how families should be supported together.”

– Dr Florence Fru Soh
Ministry of health, Cameroon

“The critical outcome of psychosocial support is resilience. Resilience is the ability to get up when life has knocked you down and still stand up and keep going. Sometimes that ability is internal strength. Very often, however, it is someone who reaches you and helps you to stand up. If you can imagine a child with enough hands reaching them, then in fact they never fall all the way to the ground. As life is knocking them, there are hands there to help them keep moving. And not just keep moving, but look up and see the stars and have hope that there is a better tomorrow and that, ‘I will reach that better tomorrow.’ Resilience is what enables us to face challenges and even to find the opportunity within those challenges. That the challenge is not greater than what I am. This is what we are working towards. The belief that will help children to take their medication, that will get them to that better tomorrow.”

– Lynette Mudekunye, Advisor, REPSSI
PLENARY RECOMMENDATIONS

- Facilitate caregiver support groups. This need not mean the formation of new groups, but rather draw on congregations or groups that already exist in local contexts, such as burial societies, coffee ceremonies or stokvels.
- Provide family services and case management.

PEER AND STAKEHOLDER BOTTLENECKS AND STRATEGIES

**Major caregiver support bottlenecks**

- Insufficient funding and human resource constraints
- Poor caregiver attendance
- Low caregiver health literacy levels
- Inconsistent caregivers
- Orphanhood
- Poor male caregiver involvement and participation

**Key caregiver support strategies**

- Family services, case management and counselling
- Caregiver support groups and peer support
- Caregiver skills-building and training on parenting, disclosure and treatment literacy
- Linkage and referral of caregivers to community partners for positive parenting, health services and psychosocial support
- Encourage male caregiver involvement in caregiver responsibilities through workshops and engaging community leader role models
- Build caregiver consistency through transition planning
- Caregiver economic support, income generation activities and referrals to social welfare as needed
- Health provider training and capacity-building to understand caregiver challenges and needs
- Identify child-headed families and build their capacity

“Mothers living with HIV are carrying a double burden. For some of us, we found out about our HIV status during our first pregnancies or later pregnancies. You are dealing both with your HIV diagnosis, but also your child’s HIV diagnosis.”
— Florence Anam
Advocacy and Communication Senior Manager, ICW

“Health is more than a CD4 count or viral load. Health is more than the one visit a month to the clinic, and the person who is there on the other 29 days is the caregiver.”
— Lynette Mudekunye
Advisor, REPSSI
Kilgoris District Hospital, Kenya was concerned about poor adherence and detectable viral loads in children, coupled with inconsistent caregiving. The facility reports that local culture asserts that taking care of orphaned children is a collective responsibility, meaning that children move homes frequently and are cared for by caregivers who may not be familiar with HIV management and adherence requirements. The facility set out to increase caregiver awareness of the management of the HIV-infected child in order to improve treatment outcomes and quality of life of the children. Kilgoris District Hospital initiated caregiver group sessions during clinic visits and caregiver retreats, all focused on treatment literacy. The intervention has led to a reduction in paediatric patients with detectable viral loads and improved visit attendance. Some of the challenges encountered include illiteracy and continued shifts in caregivers. Resources used are refreshments, transport and stationery.

**Key messages from the facility:**

- Caregiver engagement enables the clinic to understand challenges faced by our children.
- Caregiver group sessions during clinic visits do not require additional resources but still result in improved outcomes.

Referral Health Centre Ozubulu, Nigeria increasingly understood that placing excessive emphasis on facility-based support services for HIV-infected children meant potentially discounting the importance of everyday support and reassurance that children need and may receive from families and communities. They noted however that caregivers and families often need support to be able to provide these enabling conditions for the children in their care. The facility began to build the capacity of caregivers and families through life skills training; individual and group counselling; demonstration classes on local food sources, food preservation, growth monitoring and diet; money management classes; and a loans scheme. They also established a caregiver forum, which convenes monthly education and counselling services through a local CBO. Referral Health Centre Ozubulu reports improved paediatric nutritional status and growth, disclosure and quality of life. Challenges include inadequate resources, weak linkage and referral mechanisms, and limited staff capacity. Resources include training, stipends and refreshments.

**Key messages from the facility:**

- Facilities should explore providing caregivers of HIV households with the skills and knowledge needed to provide care and support services to the HIV-infected children in their care.
- When providing information, informal and practical approaches should be adopted for greatest impact.
USEFUL RESOURCES

- PATA Promising Practices: GOKidz
- REPSSI Mainstreaming psychosocial care and support within paediatric HIV and AIDS treatment
- Alliance Good practice guide for family-centred HIV programming for children
- An introduction to family-centred services for children affected by HIV and AIDS

- SAfAIDS Supporting parents and caregivers of children living with HIV: Training-of-trainers handbook
- Program P manual for engaging men in fatherhood, caregiving and maternal and child health

Dr Cordelia Katureebe, Ministry of Health Uganda and Ms Helen Phiri-Mwiinga, Ministry of Health Zambia discuss routine HIV testing.

“Instil in the child an ability to face challenges, keep moving and see the stars!”
– Lynette Mudekunye, Advisor, REPSSI
Cross-cutting opportunities

Several key messages are cross-cutting and apply across the three day themes.

- **Accelerate now.** It’s time to act. Set ambitious targets and don’t settle for mediocre results.
- **Share what works.** As the frontline of the HIV response, the solutions are within you. In your daily work, you have grappled with the issues and created solutions to meet them. Learn from each other – and then duplicate. Only through sharing promising practices, may we respond to the challenges facing us.
- **Integrate.** Provide services based on a one-stop shop model, or set up strong referrals and linkages.
- **Engage communities.** Working with others in your community is fundamental to accomplishing your objectives, especially when information and resources can be shared.
- **Involve young people.** Ensure relevance and look to adolescents and young people themselves for guidance.
- **Harness peer supporters.** Involving adolescents as peer counsellors, support group leaders, outreach workers and health providers may create opportunities for shared experiences and improve linkage to care, adherence, retention and psychosocial wellbeing in young people.
- **Innovate.** Get creative. Look for game changers for your context, and don’t wait for resources before you shift or re-organise.
- **Adopt an approach, tailored to need.** There is no silver bullet or one-size-fits-all response suitable for different epidemics, populations and resource contexts. Effectiveness is not about centres of excellence, but building relationships and offering quality services.
- **Focus on impact.** Know your data and concentrate on high yield activities. Place resources and efforts where you can best achieve your goals.
Summit outcomes and follow-up

The summit culminated in attending health facility teams drafting *Promising Practice Grids* which articulate an intervention, activity or service to be implemented across 2016. Each facility selected one of the three summit themes on which to base their project – case identification of HIV-infected children; addressing SRHR in health facilities; or caregiver support and family-centred HIV services.

Within the overarching themes, projects focus on the following intervention sub-categories:

- **Case identification of HIV-infected children** – family facility-based testing; home-based testing; linkage to inpatient settings, malnutrition clinics, immunisation clinics, TB clinics and OVC platforms
- **Addressing SRHR in health facilities** – peer-led services; creating enabling and supportive facility environments; health provider sensitisation; comprehensive, integrated package of services
- **Caregiver support and family-centred HIV services** – family services and case management; strengthening the capacity of caregivers to care for children living with HIV; and supporting caregivers to disclose to their children.

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Annah Sango from ICW representing youth and making it loud and clear, ‘Nothing for us, without us’
Throughout 2016, PATA is supporting summit facilities to implement their promising practice pilot projects through remote project management capacity-building, and – where feasible – site visits and small demonstration grants. Each project is being undertaken directly by the health facility team, does not require vast resources and is achievable within 12 months at health facility level. An example grid is included below.

<table>
<thead>
<tr>
<th>PATA 2015 Continental Summit, 6-9 December 2015, Nairobi, Kenya</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinic name</td>
</tr>
<tr>
<td>Model chosen</td>
</tr>
<tr>
<td>Project name</td>
</tr>
<tr>
<td>What challenge will be addressed by this project? Please describe the problem and how it has affected your health facility and/or its patients.</td>
</tr>
<tr>
<td>What is the project aim?</td>
</tr>
<tr>
<td>Please briefly describe your project.</td>
</tr>
<tr>
<td>How will you know if the project has been successful?</td>
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<tr>
<td>Who are the main beneficiaries?</td>
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<tr>
<td>What is the general age of the beneficiaries?</td>
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<tr>
<td>What do you expect the gender breakdown to be?</td>
</tr>
</tbody>
</table>

**Key project activities**

<table>
<thead>
<tr>
<th>When will this activity be completed?</th>
<th>Who will be responsible?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Start-up 6 months</td>
<td>On-going 12 months</td>
</tr>
<tr>
<td>1 Identification of 50 caregivers of school-aged children and 50 caregivers of HEI as “at risk”. (“At risk” caregivers include those whose children have documented adherence outside of the target range of 95-105%).</td>
<td>X</td>
</tr>
<tr>
<td>2 Schedule all 100 caregivers for the same appointment days during the month (one for school-aged and the other for HEI).</td>
<td>X</td>
</tr>
<tr>
<td>3 Play videos in waiting areas for caregivers based on the following topics: HIV Basics, adherence and nutrition, stigma and discrimination, children’s rights and early childhood development. One topic per month.</td>
<td>X</td>
</tr>
<tr>
<td>4 Facilitated discussions monthly for participants about the topic of the month.</td>
<td>X</td>
</tr>
<tr>
<td>5 Program evaluation based on indicators listed above.</td>
<td>X</td>
</tr>
</tbody>
</table>
References


# Annex 1: List of participating health facilities and ministry of health officials

<table>
<thead>
<tr>
<th>Country</th>
<th>Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burundi</td>
<td>Centre Hospitalo - Universitaire de Kamenge</td>
</tr>
<tr>
<td>Cameroon</td>
<td>Centre Hospitalier ESSOS</td>
</tr>
<tr>
<td></td>
<td>Chantal Biya Foundation</td>
</tr>
<tr>
<td>DRC</td>
<td>Hôpital Pédiatrique de Kalembelembe</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>Karalo Medium Clinic</td>
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<tr>
<td></td>
<td>St. Gabriel Catholic Health Center</td>
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<tr>
<td>Kenya</td>
<td>AMREF Kibera Community Health Centre</td>
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<td></td>
<td>Children of God Relief Institute-Lea Toto</td>
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<td></td>
<td>FACES CRDR Clinic</td>
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<td></td>
<td>FACES Mimosa Clinic</td>
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<tr>
<td></td>
<td>Kenyatta National Hospital Comprehensive Care Clinic</td>
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<tr>
<td></td>
<td>Kiambu County and Referral Hospital</td>
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<tr>
<td></td>
<td>Kilgoris District Hospital</td>
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<tr>
<td></td>
<td>Sunshine Smiles Clinic</td>
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<tr>
<td>Malawi</td>
<td>Chikowa Clinic</td>
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<td></td>
<td>Machinga Health Centre</td>
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<td></td>
<td>Rainbow Clinic</td>
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<tr>
<td>Nigeria</td>
<td>Ntasi Obi Specialist Hospital</td>
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<tr>
<td></td>
<td>Referral Health Center Ozubulu</td>
</tr>
<tr>
<td>South Africa</td>
<td>MatCH</td>
</tr>
<tr>
<td>Tanzania</td>
<td>Baylor College of Medicine Children’s Foundation</td>
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<tr>
<td>Uganda</td>
<td>Baylor College of Medicine Children’s Foundation</td>
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<tr>
<td></td>
<td>Bobi Health Centre III</td>
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<tr>
<td></td>
<td>Mjap ISS Clinic Ceo Mulango</td>
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<td></td>
<td>TASO Gulu</td>
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<tr>
<td>Zambia</td>
<td>Chazanga Clinic</td>
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<tr>
<td></td>
<td>Ipusukilo Clinic</td>
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<tr>
<td>Zimbabwe</td>
<td>Harare Children’s Hospital OI Clinic</td>
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<tr>
<td></td>
<td>Mpilo OI Clinic</td>
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<tr>
<td></td>
<td>Newlands Clinic</td>
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<tr>
<td>Country</td>
<td>Official</td>
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</tr>
<tr>
<td>Burundi</td>
<td>Richard Manirakiza</td>
</tr>
<tr>
<td>Cameroon</td>
<td>Dr Florence Soh</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>Dr Fethia Buser</td>
</tr>
<tr>
<td>Kenya</td>
<td>Dr Irene Mukui</td>
</tr>
<tr>
<td>Malawi</td>
<td>Ms Dalitso Midiani</td>
</tr>
<tr>
<td>Nigeria</td>
<td>Dr. Chukwuemeka Asadu</td>
</tr>
<tr>
<td>Uganda</td>
<td>Dr Cordelia Katureebe</td>
</tr>
<tr>
<td>Zambia</td>
<td>Ms Helen Phiri-Mwiinga</td>
</tr>
</tbody>
</table>

Jacquelyne Alesi, UNYPA, shares strategies on adolescent SRHR services with health providers.
**DAY 1: Monday 7 December 2015: Routine HIV testing for children of HIV-infected adults and siblings of HIV-infected children**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>08:00 – 08:30</td>
<td>PERFORMANCE: Sunshine Smiles Clinic and FACES (Kenya)</td>
</tr>
<tr>
<td></td>
<td>Welcome: Blessings Banda, Beyond our Hearts Foundation (Malawi)</td>
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<tr>
<td></td>
<td>National anthem of Kenya</td>
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<tr>
<td></td>
<td>PATA 2015 Continental Summit overview: Dr Daniella Mark, PATA (South Africa)</td>
</tr>
<tr>
<td>08:30 – 10:30</td>
<td>Plenary presentations:</td>
</tr>
<tr>
<td></td>
<td>Chaired by Dr Irene Njahira Makui, Ministry of Health (Kenya)</td>
</tr>
<tr>
<td></td>
<td>Dr Shaffiq Essajee, WHO (Switzerland)</td>
</tr>
<tr>
<td></td>
<td>New WHO guidance on prevention, testing and treatment of HIV in children:</td>
</tr>
<tr>
<td></td>
<td>What can you do to get to EMTCT and close the paediatric treatment gap?</td>
</tr>
<tr>
<td></td>
<td>Dr Landry Dongmo Tsague, UNICEF (Senegal)</td>
</tr>
<tr>
<td></td>
<td>Achieving 90-90-90 for children living with HIV by 2020: Unlocking the first 90 through innovative approaches in programming</td>
</tr>
<tr>
<td></td>
<td>Dr Nandita Sugandhi, Clinton Health Access Initiative and Icahn School of Medicine Mount Sinai (United States)</td>
</tr>
<tr>
<td></td>
<td>Finding needles in a haystack: The who, where and how of paediatric HIV case finding</td>
</tr>
<tr>
<td></td>
<td>Heleen Soeters, PATA (South Africa) and Blessings Banda, Beyond our Hearts Foundation (Malawi)</td>
</tr>
<tr>
<td></td>
<td>PATA clinic feedback on routine HIV testing for children of HIV-infected children</td>
</tr>
<tr>
<td>10:30 – 11:00</td>
<td>TEA</td>
</tr>
<tr>
<td>11:00 – 12:30</td>
<td>Peer workshop on routine HIV testing for children of HIV-infected adults and siblings of HIV-infected children (in professional roles and stakeholder groups)</td>
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<tr>
<td></td>
<td>Solutions and strategies</td>
</tr>
<tr>
<td>12:30 – 13:30</td>
<td>LUNCH</td>
</tr>
<tr>
<td>13:30 – 15:00</td>
<td>Stakeholder panel: Chaired by Dr Patrick Oyaro Owiti, FACES (Kenya)</td>
</tr>
<tr>
<td>15:00 – 15:30</td>
<td>TEA</td>
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<tr>
<td>15:30 – 17:00</td>
<td>PATA Promising Practices World Café on routine HIV testing for children of HIV-infected adults and siblings of HIV-infected children</td>
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</tbody>
</table>

**DAY 2: Tuesday 8 December 2015: Adolescent sexual and reproductive health services**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>07:50 – 08:00</td>
<td>PERFORMANCE: Songea CTC (Tanzania)</td>
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<tr>
<td>08:00 – 10:00</td>
<td>Plenary presentations:</td>
</tr>
<tr>
<td></td>
<td>Chaired by Dr Cordelia Katureebe-Mboijana, Ministry of Health (Uganda)</td>
</tr>
<tr>
<td></td>
<td>Dr Ivy Kasirye, DFID (Uganda)</td>
</tr>
<tr>
<td></td>
<td>Providing adolescent SRH services in the clinic: Practical aspects</td>
</tr>
<tr>
<td></td>
<td>Dr Margret Elang, Community Health Alliance (CHAU) and Link Up (Uganda)</td>
</tr>
<tr>
<td></td>
<td>andJacquelyne Alesi, Network of Youth People Living with HIV (UNYPAD) and</td>
</tr>
<tr>
<td></td>
<td>Link Up (Uganda)</td>
</tr>
<tr>
<td></td>
<td>Adolescent SRHR services: Best practices, lessons learnt &amp; emerging strategies</td>
</tr>
<tr>
<td></td>
<td>Arsene Ngombe, PATA (South Africa) and Abigail Dreyer (South Africa)</td>
</tr>
<tr>
<td></td>
<td>PATA clinic feedback on adolescent sexual and reproductive health services</td>
</tr>
<tr>
<td>10:00 – 10:30</td>
<td>TEA</td>
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</tbody>
</table>
### DAY 3: Wednesday 9 December 2015: Caregiver engagement and support activities

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>07:45 – 08:00</td>
<td>PERFORMANCE: Kamengue Hospital (Burundi)</td>
</tr>
<tr>
<td>08:00 – 09:30</td>
<td>Plenary presentations: Chaired by Dr Florence Fru Soh, Ministry of Health (Cameroon)</td>
</tr>
<tr>
<td></td>
<td>Lynette Mudekunye, Regional Psychosocial Support Initiative (REPSSI) (South Africa) Psychosocial support for caregiver engagement towards improved health outcomes</td>
</tr>
<tr>
<td></td>
<td>Florence Anam, International Community of Women living with HIV (ICW) (Kenya) HIV-positive parents; HIV-positive children: Experiences of parents/ guardians raising children and adolescents living with HIV</td>
</tr>
<tr>
<td></td>
<td>PERFORMANCE: Rainbow Clinic (Malawi) Short play on adherence</td>
</tr>
<tr>
<td></td>
<td>Lebogang Montewa, PATA (South Africa) and Charity Maruva, Africaid Zvandiri (Zimbabwe) PATA clinic feedback on caregiver engagement and support activities</td>
</tr>
<tr>
<td>09:30 – 11:00</td>
<td>Peer Workshop on caregiver engagement and support activities (in professional roles and stakeholder groups) Solutions and strategies</td>
</tr>
<tr>
<td>11:00 – 11:30</td>
<td>TEA</td>
</tr>
<tr>
<td>11:30 – 13:00</td>
<td>PATA Promising Practices World Café on caregiver engagement and support</td>
</tr>
<tr>
<td>13:00 – 14:00</td>
<td>LUNCH</td>
</tr>
<tr>
<td>14:00 – 15:30</td>
<td>PATA 2016 Promising Practice Grid Workshop (in facility teams) Quality improvement planning and drafting of 12-month health facility grids</td>
</tr>
<tr>
<td>15:30 – 15:45</td>
<td>GROUP PHOTOGRAPH</td>
</tr>
<tr>
<td>15:45 – 16:00</td>
<td>TEA</td>
</tr>
<tr>
<td>16:00 – 17:00</td>
<td>PERFORMANCE: Kabangwe Creative Initiative (Zambia) Wrap up and key messages: Luann Hatane, PATA (South Africa) Formal closure: Dr Daniella Mark, PATA (South Africa) Certificate ceremony</td>
</tr>
</tbody>
</table>
The 11th PATA Continental Summit was kindly supported by The ELMA Foundation, M-A-C AIDS Fund, Sidaction and Miracle Corners of the World.