REALITY CHECK
IN PAEDIATRIC AND ADOLESCENT HIV
The here and now of service delivery on the frontline in sub-Saharan Africa
And thank you to the donors who support the PATA network’s daily efforts on the ground.

This situational analysis represents evidence and information gathered by PATA and does not necessarily reflect the views of partner or donor organisations.
### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABCD</td>
<td>Ask, Boost, Connect, Discuss Programme</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>AYPLHIV</td>
<td>Adolescents and Young People Living with HIV</td>
</tr>
<tr>
<td>C³</td>
<td>Clinic-CBO Collaboration Programme</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-based organisation</td>
</tr>
<tr>
<td>CIPHER</td>
<td>Collaborative Initiative for Paediatric HIV Education and Research</td>
</tr>
<tr>
<td>DSD4A</td>
<td>Differentiated Service Delivery for Africa Programme</td>
</tr>
<tr>
<td>P2Z</td>
<td>Peers 2 Zero Programme</td>
</tr>
<tr>
<td>PATA</td>
<td>Paediatric-Adolescent Treatment Africa</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission of HIV</td>
</tr>
<tr>
<td>REACH</td>
<td>Re-Engage Adolescents and Children with HIV Programme</td>
</tr>
<tr>
<td>READY+</td>
<td>Resilient and Empowered Adolescents &amp; Young People Programme</td>
</tr>
<tr>
<td>SRHR</td>
<td>Sexual and reproductive health and rights</td>
</tr>
<tr>
<td>YPLHIV</td>
<td>Young People Living with HIV</td>
</tr>
</tbody>
</table>

### Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>FOREWORD</td>
<td>5</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>6</td>
</tr>
<tr>
<td>About PATA and the Situational Analysis</td>
<td></td>
</tr>
<tr>
<td>ISSUE OVERVIEW</td>
<td></td>
</tr>
<tr>
<td>Children in the age of HIV optimism: What happens when the glass is 46% full?</td>
<td>11</td>
</tr>
<tr>
<td>GAP 1: THE PRACTICE TO POLICY GAP</td>
<td>13</td>
</tr>
<tr>
<td>Local to global: Health provider voices</td>
<td></td>
</tr>
<tr>
<td>GAP 2: THE SERVICE GAP</td>
<td>20</td>
</tr>
<tr>
<td>In practice: Lessons in delivery</td>
<td></td>
</tr>
<tr>
<td>GAP 3: THE COMMUNITY GAP</td>
<td>28</td>
</tr>
<tr>
<td>The linked response: Harnessing the power of communities</td>
<td></td>
</tr>
<tr>
<td>GAP 4: THE INFORMATION GAP</td>
<td>34</td>
</tr>
<tr>
<td>Where there are no p-values: Patient outcomes</td>
<td></td>
</tr>
<tr>
<td>LAST WORDS</td>
<td>37</td>
</tr>
</tbody>
</table>
Our increased capacity and the opportunity before us does not mean that our potential victory is certain. For paediatric and adolescent HIV in particular, we require an unblinking appraisal of today’s reality.
FOREWORD

Urgent and ambitious 2020 global targets are on the horizon, yet there has been insufficient progress in paediatric and adolescent HIV to date. Scaling up HIV services for all HIV-infected women, children and adolescents is in alignment with the UNAIDS super-fast-track framework, Sustainable Development Goals and global guidance on Universal Test and Treat, yet midway through 2018 we are not where we need to be. To make our goals a reality and ensure that nobody is left behind, we require a clear and unfiltered understanding of implementation gaps and barriers, and must, with urgency, scale up promising practices and home-grown solutions available to us.

**Reality check in paediatric and adolescent HIV: The here and now of service delivery on the frontline** is a unique situational analysis of routine service delivery at health facilities across sub-Saharan Africa, together with perspectives from the health providers at the centre of the HIV response.

The HIV landscape has changed dramatically for children and adolescents since PATA formally began its work a decade ago. This publication consolidates PATA’s lessons over the past three years and provides a series of valuable insights into what is happening – and what is still not happening – at the frontline of the response. It highlights barriers and inefficiencies in everyday service delivery whilst also featuring innovative, promising practices in hospitals, clinics and communities across the continent.

**Reality check** addresses four important shortfalls which shape the treatment gap for children and adolescents:

- **The practice to policy gap**
- **The service gap**
- **The community gap**
- **The information gap**

Following this first edition, PATA will produce **Reality check** biennially, capturing the shifting landscape of the paediatric and adolescent HIV response on the ground in order to inform regional and global efforts as service delivery evolves on the road to 2030.

Luann Hatane and Team PATA
INTRODUCTION TO PATA AND THE SITUATIONAL ANALYSIS

The PATA network

As the world embarks on a fast-track strategy to end AIDS by 2030, Paediatric-Adolescent Treatment Africa (PATA) and its partners are on a mission to bridge the gap and realise a vision where all children and adolescents living with HIV in sub-Saharan Africa receive optimal treatment, person-centred care and support and live long healthy lives.

PATA is a network of health providers and facilities on the frontline of paediatric and adolescent HIV service delivery in sub-Saharan Africa.

PATA grew as a knowledge-sharing network of paediatric HIV health facility teams, originally inspired by the learning ground offered by Groote Schuur Hospital in Cape Town, South Africa. As one of the first paediatric antiretroviral therapy (ART) sites on the continent, the hospital attracted visiting health teams from across the region. This engagement was of such benefit, that health teams sought to maintain contact, linkage and peer-to-peer learning. This led to the first PATA Forum in 2005, followed by the organisation’s formal registration in 2007.

THE PATA NETWORK

PATA has worked with over 400 health facilities across sub-Saharan Africa who collectively care for over 200,000 children and adolescents on ART

PATA’S GOALS

- Build and support an engaged network of health providers and facilities
- Facilitate platforms for linking and learning to share knowledge and practice
- Champion innovative and targeted paediatric and adolescent HIV responses and practices
- Generate, collate and disseminate evidence and collaborate in joint advocacy initiatives and partnerships
The PATA network has since grown to include health providers at over 400 health facilities across sub-Saharan Africa which collectively care for 200,000 children and adolescents on ART. With a wide footprint across Africa and a unique ear-to-the-ground presence through its frontline health provider membership, the PATA network provides valuable information and insights into real-time challenges and effective paediatric and adolescent HIV service delivery models. This information is invaluable for driving policy and programme change.

PATA hosts local and regional forums and continental summits. These are platforms for multiple cadres of health providers, policy-makers, programme managers and adolescents and young people living with HIV to convene to share promising practices and plan immediate actions. This ‘link and learn’ approach is central to PATA’s work.

While these PATA forums and summits take on different themes and objectives, their consistent aim is to identify and highlight key lessons from the frontline, placing health providers at the centre of service delivery. This is based on the belief that at the heart of HIV management lies one very critical entry point to patient-centred care: the health provider.

PATA’s summit and forum methodology has been refined through 12 years of experience in bringing stakeholders together to build regional action around paediatric and adolescent HIV treatment, care and support. These meetings support health providers, policy-makers, partner organisations and youth from across the region to link and learn, share experiences, access global guidance and technical input and discuss solutions to service delivery challenges. PATA summits and forums are a place for reflection by health providers, who then commit to refining or redesigning specific health service areas on their return to their home countries. PATA then supports facilities to strengthen implementation, document and evaluate some of these emerging promising practices.

PATA’S CURRENT INITIATIVES

PATA’s current portfolio of multi-country incubation projects and programmes includes:

» Clinic-CBO Collaboration (C3)
» Peers 2 Zero (P2Z)
» Re-Engage Adolescents and Children with HIV (REACH)
» Resilient and Empowered Adolescents & Young People (READY+)
» Leading Loud
» Differentiated Service Delivery for Africa (DSD4A)
» Ask, Boost, Connect, Discuss (ABCD)

Click or visit our website, www.teampata.org to learn more about each initiative.
PATA is engaged in various global and regional working groups and coalitions and uses these platforms to advocate for best practice in paediatric and adolescent HIV care. This is underpinned by sharing the health provider experience at the centre of service delivery.

PATA also aims to acknowledge health providers who are going above and beyond the call of duty to make HIV health services, treatment and care more child- and adolescent-friendly. The PATA 2017 Continental Summit, for example, allowed PATA the opportunity to acknowledge and celebrate the valuable contribution of our unsung health provider heroes at an awards evening where several nominees were honoured for their dedicated and selfless service.

While each summit and forum employs a variety of session formats, each are informative, interactive and oriented toward moving discussion from policy to practice and practice to policy. It is an opportunity to amplify the voices of health providers, while creating enabling and engaging service environments that motivate and accelerate action.

A ‘link and learn’ approach is central to PATA’s work.
The situational analysis

**Reality check** shares a snapshot of routine service delivery, together with frontline health provider perspectives on major challenges, barriers and solutions.

### ABOUT THE SAMPLES

<table>
<thead>
<tr>
<th>FULL SITUATIONAL ANALYSIS</th>
<th>SUB-ANALYSIS</th>
<th>PATA PROGRAMME DATA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic routine reporting from PATA network health facilities across 2015-2017</td>
<td>Detailed routine reporting from a sub-set of PATA network health facilities in 2017</td>
<td>Focused reporting from health facilities in specific PATA programmes and/or PATA research studies across 2015-2017</td>
</tr>
<tr>
<td>282 health facilities</td>
<td>115 health facilities</td>
<td>Characterisitics vary by programme</td>
</tr>
<tr>
<td>24 countries</td>
<td>15 countries</td>
<td></td>
</tr>
<tr>
<td>40% urban, 28% peri-urban, 32% rural</td>
<td>51% urban, 24% peri-urban, 25% rural</td>
<td></td>
</tr>
<tr>
<td>50% primary, 33% secondary, 17% tertiary</td>
<td>50% primary, 30% secondary, 20% tertiary</td>
<td></td>
</tr>
<tr>
<td>66% government services</td>
<td>64% government services</td>
<td></td>
</tr>
</tbody>
</table>

The health facilities in this analysis provide treatment and care for 16,419 infants; 82,142 children; 70,267 adolescents; 44,054 young people; and 221,659 adults on ART. Total on ART is 333,377

*Young people and adults not disaggregated

To contextualise these findings, **Reality check** draws on implementation data and lessons from PATA’s 2015-2017 programmes and research portfolio. These data further explore gaps, identify promising practices, amplify voices from the ground and field-test global trends for regional resonance.

---

**Defining age groups (WHO):**

- **Young person:** A person aged 10-24 years
- **Adolescent:** A person aged 10-19 years
- **Child:** A person 19 years or younger
- **Infant:** A child younger than one year of age

---

2018 Reality Check | 9
Reality check is divided into four sections:

**GAP 1: THE PRACTICE TO POLICY GAP**

LOCAL TO GLOBAL: HEALTH PROVIDER VOICES provides perspectives from health providers across the continent, harnessing experiences at the coalface to share upwards to policy-makers, programme managers and advocates who may be removed from direct service provision. Providers share the biggest challenges they face today in implementing HIV services for children and adolescents living with HIV. Many of these can be addressed through policy action at the global level. It also shares unique insights around the promising and innovative strategies and services that are working well on the frontline, despite limited resources.

**GAP 2: THE SERVICE GAP**

IN PRACTICE: LESSONS IN DELIVERY presents a snapshot of HIV service provision across health facilities in the PATA network, highlighting the services that providers are struggling to implement as well as those they are implementing routinely.

**GAP 3: THE COMMUNITY GAP**

THE LINKED RESPONSE: HARNESING THE POWER OF COMMUNITY showcases the phenomenal potential of engaging community-based organisations and community health workers, or peer supporters, to accelerate and expand prevention of mother-to-child transmission of HIV (PMTCT), paediatric and adolescent HIV services. The feature provides evidence as well as implementation considerations.

**GAP 4: THE INFORMATION GAP**

WHERE THERE ARE NO P-VALUES: PATIENT OUTCOMES presents patient outcomes from health facilities across the PATA network, while examining the challenges of monitoring and utilising data at facility level.
Children in the age of global HIV optimism: What happens when the glass is 46% full?

A decade ago, the HIV response looked very different for children. In sub-Saharan Africa, the key focus was making lifesaving ART for pregnant women living with HIV available for the first time in countries where regulatory frameworks, patents and pricing rendered widespread access to antiretrovirals complicated, if not unrealistic. For paediatric patients, highly centralised diagnostics, inconvenient formulations and weak supply chains prohibited access to treatment.

Since then, countries have made renewed commitments to serving women, children and young people in the context of the Millennium Development Goals, and later the Sustainable Development Goals.¹ It is estimated that around two million new HIV infections among children have been averted by PMTCT programmes since 2000.² Governments, in partnership with various stakeholders, are now working towards universal health coverage to realise the Global Strategy for Women’s, Children’s and Adolescents’ Health and meet ambitious fast-track and super-fast-track targets.³

The extraordinary progress of the treatment era has fuelled the global narrative that the end of AIDS is in sight. It is true that AIDS-related deaths have plummeted. We have new diagnostic technologies, improved access to better treatment regimens, promising implementation strategies and broad political will. But our increased capacity and the opportunity before us does not mean that our potential victory is certain. For paediatric and adolescent HIV in particular, we require an unblinking appraisal of today’s reality.

Progress in scaling up ART has been uneven across age groups and a sizeable treatment gap exists for children and adolescents living with HIV. While one of the AIDS Free super-fast-track targets is to treat 95% of all children living with HIV by 2018, by June 2017 only 46% of children living with HIV were on treatment.⁴ The proverbial glass is filled just under the halfway point. Without timely ART, the impact on paediatric morbidity and mortality is devastating, with 52% of perinatally infected children dying within one year of infection without treatment.⁵ At a time when HIV-related deaths are decreasing in all other age groups, it remains the leading cause of death among adolescents aged 10-19 in Africa. With this in mind, it would be irresponsible to project the best possible outcome. Our plans and strategies must be grounded in the reality of what we know to be true today: children and adolescents remain critical but are inadequately served in the HIV response.
While the treatment gap between children and adults continues to receive deserved attention, chasms in other critical aspects of our efforts go unnoticed. It is these less obvious gaps that hold the key to a grounded and accelerated response.

1. The practice to policy gap
2. The service gap
3. The community gap
4. The information gap

In the age of ending AIDS, identifying gaps in the paediatric and adolescent HIV response is sobering. Pausing to identify and recognise areas of weakness, however, can open new doors of opportunity to strengthen our resolve, focus and efforts. Areas of deficiency provide a pathway to solution. The more we mind these gaps, the closer we will be to realising our goals.

Beyond the treatment gap: The four intangible gaps in the paediatric and adolescent HIV response
GAP 1: THE PRACTICE TO POLICY GAP

Local to global: Health provider voices

The gap between policy and practice is often spoken about in the global discourse around HIV and AIDS – specifically around how practice on the ground needs to keep pace with national policy and international guidance. This gap between policy and practice, however, is bidirectional. In many cases, it is in fact policy that needs to catch up to the leading edge of practice.

Health providers at the frontlines of the HIV response bear witness to everyday and long-range successes and failures in real-world settings. Across the continent, health providers and programme implementers are confronting and overcoming barriers, developing solutions and testing innovations every day in creative and resourceful ways. With patients in line today, they must make care work. They are in the trenches of the HIV response and an inimitable source of information.

These approaches and insights, however, do not reach the global level because the evidence and rigour required to shape formal guidance excludes lessons that have not been drawn using specific scientific methodologies. Providers and implementers cannot produce rigorous controlled trial or implementation science data without strong investigator partnerships and intensive capacity-building which, while important, will take time and investment. As a result, global guidelines, recommendations and protocols do not integrate many of the key lessons learned in practice. National programme managers, implementing partners and health providers are left only partly informed – often unaware of what is working well or poorly in neighbouring districts or countries – but required to make informed decisions in delivering services. They must act today. At the same time, because policy-makers must rely on rigorous studies to develop implementation guidance, they are limited by the strength of evidence available to them.

When normative guidance cannot respond quickly, we – unconstrained by the requirement to state only that for which there is rigorous evidence – must share what our experiences teach us to be true. We must adopt a different paradigm that identifies and showcases local learnings, harnessing and crystalizing the collective knowledge from those at the frontlines: programme implementers and health providers themselves.

This section presents a window into this collective wisdom by providing the perspectives of health providers across sub-Saharan Africa. Providers share the biggest challenges that they are currently facing in providing HIV care, treatment and support services for infants, children, adolescents, and young people living with HIV. They also share unique insights around what is working well on the frontline and the promising strategies, models and services that they see are improving access to, and quality of, HIV service delivery and care.

“We get new protocols all the time without anyone ever coming to ask or see what is working well in our clinic – we have found our own solutions to make things work here. These new guidelines come long after we have already made changes on the ground.”

– Nurse, PATA Continental Summit, 2017
The biggest challenges health providers face today

**Infants and children**

59% of health providers say that the biggest challenge they face in providing HIV services for infants and children living with HIV is insufficient parent and caregiver support for the child’s treatment.

“Multiple caregivers with different parenting skills are involved in child care. Not all have attained the same level of health literacy. As a result, adherence support at home becomes erratic. Children are often represented at the facility by caregivers, who may pick up the antiretrovirals and get information, but hand over to another person who will supervise drug administration.”

- Fort Portal Regional Referral Hospital, Uganda

Moreover, the second and third most common challenges health providers reported were also recounted as caregiver-related: non-adherence, loss to follow-up and treatment failure (40%); and delayed disclosure to children (16%).

“The biggest challenge is that these children live with their guardians and they are not disclosed to, so they don’t know why they are taking the drugs and the importance of adhering to the drugs.”

- Tisungane Clinic, Malawi
The other 29 days

Caregivers play a crucial role in the wellbeing of a child. Caregivers are a child’s first line of defence, best placed to disclose to a child and build support within the family and beyond. A caregiver’s attendance at a clinic visit provides an opportunity for health education and counselling that can maximise the potential of a family to improve health and development between clinic visits.

The World Health Organization (WHO) guidelines emphasise the importance of health provider support to parents and caregivers of children living with HIV. WHO recommendations for this support include:

- Adequate preparation, education and discussions prior to ART initiation
- Reinforcing to caregivers the importance of the process of disclosing to the child
- Appropriate counselling and support to stay in care

Despite this guidance, health providers continue to struggle to ensure that parents and caregivers remain informed, aware and actively engaged in the care of their children living with HIV. Providers must be trained and have at their disposal up-to-date tools, job aides and educational material to communicate effectively with parents and caregivers. Services should be structured to be more accessible to working parents and caregivers – including integrated family care models, differentiated care approaches, after-hours or weekend clinics and home visits. To support health providers to address the persistent challenge of parent and caregiver engagement, these approaches require more detailed implementation guidance and support from the national and global level.

The WHO and Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) global research agenda for paediatric HIV prioritised three caregiver-related research areas as top priorities:

- Psychosocial and family support strategies or interventions
- Strategies or interventions to improve and support parents, caregivers and healthcare providers to facilitate HIV disclosure to children, as well as factors that impact their success
- Strategies or interventions to reduce stigma and discrimination experienced by children and their caregivers

The agenda will guide research efforts on the road to 2030. We expect to see alignment with the agenda in the coming years, and with it, emerging evidence around best practice in improving parent and caregiver support for paediatric treatment.

One of the key foci of the PATA Expert Patient Programme (June 2014 – March 2017) was caregiver engagement, which included supporting and equipping caregivers to navigate the health system and disclose to their children.

Family-centred care in action

Providing family-centred services should go beyond caregiver support and be evident in a health facility’s protocols, systems and activities. Operationalising family-centred care in the context of HIV means providing comprehensive coordinated care for a family unit, including family index case testing to identify missed children as well as harmonised family clinic visits and/or family ART refills.

“We want to build caregiver resilience so that families can support children to stay in care... But it’s important for us to realise that once-off psychosocial support interventions don’t work. What works is ongoing support. There are no quick fixes when it comes to psychosocial support for sustained wellbeing.”

- Noreen Huni, REPSSI at the PATA 2017 Continental Summit
Adolescents and young people living with HIV

45% of health providers say that the biggest challenge they face in providing HIV services for adolescents and young people living with HIV is non-adherence and loss to follow-up.

This is in line with existing evidence that, compared with adults, adolescents living with HIV have higher rates of loss to follow-up and lower rates of adherence.10,11,12

The second most prominent challenge reported by 37% of health providers was stigma, discrimination and peer-pressure. Providers referred to stigma and discrimination in households, schools (particularly boarding schools), broader communities and health facilities. This is in line with existing research which has found discrimination directed at adolescents living with HIV accessing sexual and reproductive health services.13

Adolescent-friendly health services and an adolescent-friendly environment are critical in supporting adolescent HIV and sexual and reproductive health outcomes. Health provider knowledge, attitudes and practices are at the core of quality service provision and central to adolescents’ experience of care. Health providers must adopt a human rights-based approach to adolescent healthcare, and display non-discriminatory, non-judgemental and respectful attitudes towards adolescent clients.14 To achieve this, providers – and support staff – must be provided with training and sensitisation to gain awareness of their own attitudes, values and any prejudices that may interfere with their ability to provide this care.

The third most commonly reported challenge was non-disclosure (27%). Health providers referred to a variety of disclosure-related challenges, including difficulty disclosing to the adolescent or young person, as well as supporting the client’s onward disclosure to parents and caregivers, partners, boarding school nurses and other health providers. Providers explained how both discrimination and non-disclosure contribute directly to non-adherence and loss to follow-up.

While the challenges of stigma, discrimination and disclosure have been well documented throughout the history of the fight against HIV,15,16 albeit less so for children and adolescents, our findings highlight these as enduring challenges that have yet to be overcome. As global dialogue shifts towards new science, breakthrough innovations and updated models of care, let us not forget the persistent challenges that continue to undermine our efforts.

With limited reporting on young key populations and little evidence for these populations, health providers are not always orientated towards the diversity of young people. Not only are these populations facing multiple transitions and developmental tasks, such as establishing identity, but they are also facing these changes in particular contexts that may be challenging and unsupported (take it on themselves). Young key populations include young men who have sex with men (MSM), people who inject drugs, sex workers and transgender people. Youth can also belong to multiple groups at one time.17 These factors increase vulnerability, and contribute to the invisibility of many youth. In the HIV response, they should not remain unseen and under-served.

---

Top 5 challenges health providers face in providing HIV services for adolescents and young people living with HIV

1. Non-adherence and loss to follow-up
   - 45%

2. Stigma, discrimination and peer pressure
   - 37%

3. Non-disclosure
   - 27%

4. Insufficient caregiver support
   - 17%

5. No dedicated space
   - 12%

---

“The biggest challenge we face is trying to maximise consistent adherence in light of social, psychological and clinical challenges faced by youth and adolescents.”

- WhizzKids United, South Africa

---

2018 Reality Check
The blind spot of stigma and discrimination towards young people in healthcare settings

UNAIDS warns that HIV-related stigma and discrimination in healthcare settings discourage adolescents and young people from accessing HIV services. Confronting marginalisation in HIV care is critical to ensuring service access and positive treatment outcomes for these age groups.

87% of providers reported training in care and support for adolescents and young people living with HIV, and 85% of providers reported that younger clients do not receive inferior care. 98% of providers reported being comfortable talking about sexual and reproductive health with adolescents and young people. Yet, 41% of adolescents and young people receiving services reported that they fear discussing sexual and reproductive health with providers. While 76% of providers reported that they did not scold young people for requesting sexual and reproductive health services, 41% of young people reported that they had been scolded.

These results indicate a discrepancy between health provider versus adolescents and young people’s accounts of youth services. Providers seem to have little awareness of young people’s experience of services as discriminatory. Fundamentally there remains a blind spot in providers’ insight and willingness to provide services without judgement. To mitigate stigmatising health provider attitudes and practices, we recommend urgent and intensified health provider education, sensitisation and training on people-centred healthcare and the rights of adolescents and young people, as well as routinised engagement with youth themselves. In particular, integration of young peer supporters within health facility teams and active adolescent client feedback and dialogue mechanisms build trust between youth and providers, improve client service experiences and increase provider confidence.

ABOUT THE SAMPLE
54 health providers
68 adolescents and young people living with HIV
8 countries
2016-2017 data

“Disclosure to family members, boarding school nurses, to partners is a big concern in this age group. As a result, adherence is affected negatively. The needs of adolescents and young people for support in the community cannot be met due to stigma.”
- Fort Portal Regional Referral Hospital, Uganda

“Adolescents tend to default treatment because of stigma and discrimination from agemates and the community.”
- St. Paul’s Health Centre, Lesotho
Where are global efforts placing too much attention?

As critical as it is to recognise providers’ most reported challenges, it is also striking to examine the challenges that, whilst objects of considerable global interest, did not emerge as major issues in provider reporting.

Just 5% of providers mentioned stock outs as their biggest challenge in providing HIV services for infants and children, 1% for adolescents and young people. This is a notable change from a decade ago, and suggests that the supply chain for antiretrovirals has strengthened as the epidemic has matured and formulations have simplified.

Just 1% of providers reported transition as the biggest challenge in providing HIV services for adolescents and young people. In many ways this is not surprising given the context of how healthcare is delivered in sub-Saharan Africa. In many facilities, in particular rural clinics, all age groups receive services in a common space and often it is the same provider/s attending to all age groups. The continuity of place and providers means that transitioning is more fluid than in other parts of the world.

What’s working?

PATA invited health providers to report on best practices and models from their own facility that they believe are working best to treat and care for infants, children, adolescent and young people living with HIV.

INFANTS AND CHILDREN

Harmonised mother-infant and family visits: Evidence shows that family visits can improve retention rates as they reduce the number of times a family or family member is required to attend the clinic.19

“Seeing mother-baby pairs on the same day as well as children having refills done at the same time with their caregivers has helped in retention.”

- Queen II Hospital, Lesotho

Child-friendly space including play area and special activities

“Setting up the paediatric playground has really motivated the children to come to the clinic. We have received feedback from caregivers that their children are the ones reminding them to attend clinic so that they can have the opportunity to utilise the play station. This has greatly improved clinic attendance for both HIV-positive parents and their children.”

- Muhoroni Country Hospital, Kenya

Specific clinic days or times dedicated to children: Providers highlighted various benefits for paediatric patients and their families, including shorter visit and queue times as well as non-conflict with school hours.

“Having children seen on a specific clinic day has improved age-specific services.”

- Fort Portal Regional Referral Hospital, Uganda
ADOLESCENTS AND YOUNG PEOPLE LIVING WITH HIV

Peer support models, including peer supporters providing services, peer support groups, and youth camps.

“Peers are the best teachers.”
- Zalewa Clinic, Malawi

56% of providers

Adolescent-friendly space and services: This is in line with existing evidence that adolescent-friendly services can reduce loss to follow-up.20

The adolescent resource centre, where they not only interact with their peers, but have a learning and social environment where they can interact freely has helped to reduce stigma.
- Muhoroni County Hospital, Kenya

33% of providers

Specific clinic days or times dedicated to adolescents and young people, including weekends.

“There is an adolescent-specific clinic once a month which offers services comprehensively packaged for adolescents...this has helped improve their clinic attendance.”
- TASO Soroti, Uganda

29% of providers
IN PRACTICE: Lessons in delivery

It is the age of best practice. Academic publications, job aides and conferences abound with a proliferation of best practice case studies. But in the context of global AIDS optimism and the narrative of ending AIDS, there is danger of exaggerating our collective progress by harbouring the illusion that these best practice examples represent the broad reality on the ground.

The question remains as to how our ambitious global targets will be reached in the context of sub-Saharan Africa’s overstretched health systems. To achieve our targets, we must routinise the exceptional. Best practice services and systems must become the new normal.

Yet the service and outcomes data that we do have for paediatric and adolescent HIV services show extreme deficiencies. In 2016, just 43% of HIV-exposed infants were tested by the recommended age of two months. While HIV testing is the entry point to the HIV treatment, care and support cascade, only 33% of adolescent girls and 20% of adolescent boys in Africa report having ever been tested for HIV.

A key objective of Reality check is to take stock of what services are being offered on the ground for children and adolescents living with HIV. This section provides a snapshot of everyday service provision.

**GAP 2: THE SERVICE GAP**

**Case finding**

Active paediatric HIV case finding outside of PMTCT programmes is critical to identifying children living with HIV whose mothers did not access – or were not retained in – PMTCT programmes. However, despite the fact that WHO guidance has recommended active case-finding and provider-initiated testing and counselling in children since 2007, our data show that these are not being optimally implemented.

41% of facilities are not actively case finding outside of clinic doors. This means that children not engaged with the health system are being missed.
In the context of global AIDS optimism and the narrative of ending AIDS, there is danger of exaggerating our collective progress by harbouring the illusion that best practice examples represent the broad reality on the ground.
Promising practices in case finding and treatment

CASE FINDING

Promising practices in case finding from the PATA 2017 Continental Summit centred around the need to expand the narrow scope of an elimination agenda focused on PMTCT in order to reach all children and adolescents living with HIV. The major barriers to finding and linking children and adolescents living with HIV included:

- HIV-related stigma in families
- Communities and health facilities
- Reluctance of some caregivers to test their children
- Health providers not suspecting or testing for HIV in older children
- High age of consent for testing and guardianship issues
- Testing not being allowed in schools
- Test kit shortages

- Lengthy turnaround time for HIV test results to reach families
- Poor data quality and monitoring
- Human resource constraints
- Limited capacity for community testing
- Adult-centred and inflexible health systems
- Clinic operating times conflicting with school hours and incomplete referral systems.

More detail on FIND, TREAT & CARE can be found in the PATA 2017 Continental Summit Report.

TREATMENT

Treatment is another critical area where there is a shortfall in child- and adolescent-centred service delivery. WHO global guidance to treat all people living with HIV has now been taken up by almost all countries in the region. It is no longer about whom to treat or when to treat but how to treat.

Treatment barriers

- Suboptimal formulations and increasing levels of drug resistance
- ART stock outs
- Coinfections that require staggering the initiation of both treatments
- Heavy workload of health providers
- Lack of confidence on the part of health providers to initiate and manage ART in children
- Poor treatment literacy and treatment readiness
- Laws criminalising HIV transmission

Actions

- Use simplified initiation processes and consider same-day test and start, but ensure treatment readiness
- Don’t delay the start of ART
- Promote nurse-initiated management of ART
- Provide the best treatment available and advocate for better paediatric formulations and ART optimisation
- Differentiated treatment and care approaches

ART optimisation

- Low toxicity
- Well tolerated and easy to take/administer
- High generic barrier to resistance/durable
- Improved sequencing-switching options
- Can be harmonised across special populations
- Reduced cost

More detail on FIND, TREAT & CARE can be found in the PATA 2017 Continental Summit Report.
Psychosocial support

Psychosocial support services are generally provided more frequently for adolescents living with HIV than children living with HIV.

While more than three quarters (78%) offer adolescent support groups separated by age, fewer separate by gender (34%), perinatal versus horizontal infection (30%) and time since diagnosis (29%). Reporting is however unable to capture quality, scope and consistency across varying support group activities. This is an area to watch over the next few years with the proliferation of differentiated models of care.

<table>
<thead>
<tr>
<th>Psychosocial support services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual counselling</td>
</tr>
<tr>
<td>75%  97%</td>
</tr>
<tr>
<td>Family counselling</td>
</tr>
<tr>
<td>77%  90%</td>
</tr>
<tr>
<td>Peer support groups</td>
</tr>
<tr>
<td>64%  89%</td>
</tr>
</tbody>
</table>

Digging deeper into quality of counselling

To support WHO’s 2016 consolidated guidelines on ART, PATA undertook a facility-level situational analysis of adolescent HIV treatment and care services in 23 sub-Saharan African countries. As part of this analysis, PATA interrogated the substance of routine adolescent adherence counselling. In addition to content focused on general descriptions of adherence and ART regimens, providers also reported voicing the negative implications of non-adherence, such as the development of drug resistance. Discussions about repercussions, however, sometimes took the form of scaremongering, as demonstrated by a nurse in Namibia who noted that health providers “counsel on the danger of resistance and the scare of opportunistic infections as well as death.”

To find out more, click or visit www.teampata.org.za.

Spotlight on mental health

There is little research on the effects of mental health challenges for young people living with HIV and even fewer evaluations on interventions that address them in this population. Yet these challenges exist and can impact all aspects of HIV prevention and treatment, especially in areas where resources are scarce.

Thus the promotion of mental health is a critical role for health providers – a role that must be proactive. In the absence of cost-effective solutions and adequate research and support for mental health, action can still be taken. Mental health screening can be improved, with increased attention needed for standardised and quality driven mental health screening and treatment with linkage to psychosocial support services.
### Operational modifications for children and adolescents

Operational modifications are less prevalent.

<table>
<thead>
<tr>
<th>Operational modifications</th>
<th>Percentage</th>
<th>Children</th>
<th>Adolescents</th>
<th>Both</th>
</tr>
</thead>
<tbody>
<tr>
<td>After-hours services on evenings and weekends</td>
<td>44%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced waiting times</td>
<td>72%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dedicated clinic space</td>
<td>52%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dedicated clinic time</td>
<td>78%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Monitoring and data

<table>
<thead>
<tr>
<th>Monitoring and data</th>
<th>Percentage</th>
<th>Children</th>
<th>Adolescents</th>
<th>Both</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pill counts for adolescent clients</td>
<td>92%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home visits to track mother-baby pairs</td>
<td>84%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Linked records for mother-infant pairs</td>
<td>80%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electronic medical records</td>
<td>78%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The mean turnaround time from sending a viral load sample for testing to providing the result to a patient is 35 days.

“The time frame to receive results for infants is too long. This has resulted in major complications, even deaths.”

- Nurse, Zambia at the PATA 2017 Continental Summit
Sexual and reproductive health services for adolescents and young people

Sexual and reproductive health services are widely provided, but there is scope for improvement in several service areas.

Of major concern is the poor integration of prenatal and postnatal services for adolescents within HIV services. In many cases, pregnant adolescents lose access to adolescent-specific HIV services on pregnancy: in 35% of facilities, when an HIV-infected adolescent becomes pregnant, she is transitioned to adult HIV services within the same facility and a further 3% to another facility entirely.

Those that remain in adolescent services for their HIV treatment do not receive a full spectrum of integrated services that cater to their needs. Less than two-thirds access PMTCT (62%), antenatal care (57%) and sexual and reproductive health services (55%) at the same time as their HIV services. Less than half access support groups (45%) and social services assistance (24%). This is an area needing urgent attention.
Meaningful engagement of adolescents living with HIV

Notably, only 59% of facilities had mechanisms in place for children and adolescents living with HIV to provide input and feedback to inform service design, planning and delivery. These mechanisms are not always applied or integrated consistently across health facilities. The provision of responsive services requires the active involvement and engagement of youth.

Peers 2 Zero Programme

PATA’s Peers 2 Zero (P2Z) Programme, in partnership with the African Young Positives network (AY+) provides a platform that brings health providers, national networks of YPLHIV and young peer supporters together to jointly plan, deliver, and evaluate adolescent-friendly health services.

In 2016, P2Z held a Youth Summit. For peer supporters and national networks engaged in the programme. The summit aimed to create a safe space for young people to engage and learn from one another, share barriers and strategies for improving peer-led services and adolescent-friendly health services, and collectively identify and advance service delivery priorities though a Call to Action, the The Dar es Salaam Peer Supporter Declaration.

The Youth Summit served as a catalyst to inspire peer supporters and showcase the power of peer-led strategies in the HIV response for children and adolescents.

Resilient & Empowered Adolescents & Young People Programme

PATA’s Resilient & Empowered Adolescents & Young People (READY+) Programme, implemented as part of a consortium led by the International HIV/AIDS Alliance prioritises improved HIV and SRHR service integration for AYPLHIV.

READY+ seeks to ensure that adolescents and young people are resilient, empowered and knowledgeable and have the freedom to make healthier choices and access services and commodities related to their sexual and reproductive health and rights. Its aim is for youth to become ready to make informed decisions about their health, with parents and caregivers ready to support young people to talk about sexuality, health providers ready to provide youth-friendly services, and decision-makers ready to champion youth access to information, services and commodities.

As part of READY+, the Global Network of Young People Living with HIV has developed a health facility scorecard that young clients can complete at clinic visits.

Taken together, these service data show that while progress has certainly been made on several fronts to increase access to services, much remains to be done to bridge the service delivery gap. The following section explores an avenue for this change in greater depth.
With these actualities in mind, it would be irresponsible to project the best possible outcome. Our plans and strategies must be grounded in the reality of what we know to be true today: children and adolescents remain critical but are inadequately served in the HIV response.
To achieve universal paediatric and adolescent ART coverage, efforts must extend beyond clinic doors and professional health providers. Community-based organisations (CBOs) and lay providers such as peer supporters can play a pivotal role in accelerating, expanding and improving the quality of services.

Recently, differentiated service delivery has been propounded as a strategy to increase treatment access and meet diverse patient needs. Differentiated approaches rely heavily on community-led activities across the "Where" and "Who" building blocks of differentiated ART delivery.

However, for the contribution of CBOs and community health workers to be amplified, they must be engaged as integral implementing partners with shared responsibility for service delivery.

Engaging community-based organisations to deliver PMTCT and paediatric HIV services

Community-based service delivery – including HIV testing, ART distribution and psychosocial support – can help countries to scale up universal access by reducing unnecessary burdens on the health system. CBOs also have the potential to sensitise, educate, drive demand and identify pregnant women, children and adolescents who are outside of the traditional health system. Tracing and support to mother-infant pairs to improve post-partum loss to follow-up and PMTCT is a critical service area for CBOs who can undertake home visits and combat stigma. However, close collaboration and linkage between CBOs and local health facilities are essential for effective service coordination and continuity of care.

Despite this, CBOs and health facilities tend to operate in isolation, relying primarily on informal arrangements that do not provide structures or mechanisms to facilitate and coordinate meaningful and sustainable partnerships between them.

Referrals and linkages

Where health facilities are referring children and adolescents living with HIV to CBOs, feedback loops are weak. Only 38% of facilities communicate directly with the referral organisation to ensure referrals are completed.

Various barriers prevent these linkages, including mistrust, poor perceptions, miscommunication, differing work cultures, poorly aligned funding arrangements and inadequate data sharing between CBOs and health facilities.
Clinic-CBO Collaboration Programme

To strengthen linkages between health facilities and CBOs, PATA and the Positive Action for Children Fund established the Clinic-CBO Collaboration (C³) Programme to form 36 clinic-CBO partnerships across nine countries in 2014-2016.

Recognising the value of linking clinic and community, these partnerships worked together to mobilise demand for services, sensiti se communities, undertake active outreach, provide care and support and create enabling service environments. Lessons from C³ highlight the importance of investing in and strengthening these linkages. The C³ Toolkit and accompanying Be Connected e-learning course were developed, setting the stage for strengthening this linkage over time across the continent.

Phase II of the C³ Programme is now in operation and looks to both deepen and scale up the C³ model.

THE EVIDENCE

C³ results showed improved relationships between clinic-community partners and a 38% reduction in loss to follow-up. The five major domains for effective clinic-community collaboration were: community sensitisation; demand mobilisation; patient outreach; care and support; and enabling environments.

The programme demonstrated that clinic-community partnerships are feasible, acceptable and can result in joint ventures that positively impact services. Also, if well implemented, collaboration may improve retention in care.

KEY LESSONS FROM C³

To forge and sustain CBO and health facility partnerships, a systematic approach embedded in district planning is required:

- Systematic national and sub-national mapping
- Formal agreements that identify partnership coordinators
- Terms of reference that define responsibilities, lines of accountability and division of human and financial resources
- Strategies for regular communication, including joint planning, data sharing and monitoring
- Including CBO-health system linkage as a key performance area within annual operational plans

Without investment into a bold, empowered and linked community response, the health system, operating in isolation, will not succeed in breaking down the barriers preventing access to and retention in HIV programmes.
Peer support models for adolescents living with HIV

Adolescents living with HIV face unique challenges and have specific needs when accessing HIV and sexual reproductive health services, to which health services must be responsive. Health facilities in Africa also face critical health worker shortages, with only 2.3 health providers per 1,000 people. Peer supporter models have gained recent attention as a promising scalable intervention to improve adolescent linkage, adherence and retention. Over the past few years, the global landscape has seen the proliferation and increased adoption of the adolescent peer support model within various sub-national, and in some cases national, HIV programmes. Case studies and early programme data reflect the promise of peer support for young populations. Continuity of these programmes and research studies are expected to generate more robust evidence for the model over time.

Trained and supervised peer supporters are both a pragmatic response to improve efficiency of an overburdened health system as well as to provide responsive, community-linked and client-centred care that addresses the unique and multidimensional needs of adolescents living with HIV.

Young peer supporters who are living with HIV and engaged at health facilities to promote the health and wellbeing of their peers:

- Draw on their own lived expertise to provide psychosocial support
- Provide relevant and context-specific services for this age group
- Help to redress stigma and discrimination in healthcare settings
- Facilitate linkage amongst peers and mobilise joint action

THE EVIDENCE

In the first known multi-country analysis of the impact of facility-based adolescent peer support on viral suppression, PATA measured past-year adolescent (10-19 years) viral suppression rate per facility in relation to facility-level characteristics in a subset of situational analysis data. We used logistic regression to measure the impact of ≥1 facility-based adolescent peer supporter on adolescent viral suppression rate, controlling for: country, urban/rural location, public/private facility, level of facility (primary/secondary/tertiary) and physician/non-physician care. This analysis revealed that facility-based adolescent peer support was associated with an almost seven-fold increase in the likelihood of aggregate adolescent viral suppression above that of the UNAIDS Eastern and Southern Africa regional viral suppression rate of 50% (adjusted OR 6.95, p=0.02, CI 1.28-37.59).

These findings suggest that peer support should be a key service component of the facility-based health response for adolescents living with HIV in sub-Saharan Africa, regardless of where facilities are located, their level of care or health provider profile.

ABOUT THE SAMPLE

- 71 health facilities
- 160 peer supporters
- 13 countries
- 2017 data
REACH Programme

PATA’s REACH Programme is a simple, health facility-based, low-cost adolescent peer support model to improve HIV treatment and care services for, and treatment outcomes in, adolescents living with HIV. REACH harnesses the lived expertise of young people living with HIV (age 18-24 years) as lay community health providers who are fully integrated into the health facility team to support their adolescent peers (10-19 years). The model also places emphasis on building the capacity, resilience and agency of supporters themselves through training, mentorship, peer-peer engagement and livelihood strengthening. REACH is implemented in 18 health facilities across six countries.

KEY LESSONS FROM REACH

- Peer supporters should be recruited from within the facility’s client pool, adherent to ART, actively involved in support groups and comfortable to disclose their status.
- Peer supporter roles and responsibilities should be clearly outlined in a job description, communicated and understood by health staff and clients.
- Peer supporters should be included within health facility structures and activities such as meetings and committees so that they can learn, be integrated and build relationships with staff.
- Training, supervision, skills development and psychosocial support for young peer supporters requires careful planning and investment.
- Peer supporters must be remunerated, with salary where possible (stipend at minimum) and expenses covered including transportation, and be provided with opportunities for career development and capacity-building.
- As role models, peer supporter well-being is important and requires an enabling and supportive environment.
- Engage more than one peer supporter per clinic to enable collaboration, mutual support and task-sharing, with the option of matching different levels of experience, gender and age.

“As a young adolescent living with HIV, life has not been easy for me...I am working to mobilise money for school fees because my goal is to achieve a high level in counselling. It always has been my goal to help millions of young positive children to have a healthy, positive life.”

- Faswiha, peer supporter, Mulago ISS Clinic, Uganda

PATA has active peer support programmes in eight countries: Cameroon, DRC, Ethiopia, Malawi, Tanzania, Uganda, Zambia, Zimbabwe.
However, several barriers prevent integration of peer supporters into the health system response. These include policy and legal barriers to task-shifting and community-based service delivery. In addition, fiscal commitments to adopt this cadre at national level are largely absent. As a primarily volunteer-based workforce, there is no standardised scope of work and peer supporter efforts often go unrecognised and unpaid, despite their contribution.

Peer support models also have inherent operational complexities related to the integration of a lay cadre of young people living with HIV into the health system across varying contexts in the region, especially in low-resource and already overburdened settings. Operationalising peer support requires careful consideration and planning, as well as the requisite capacity and sensitivity from health service management and staff to implement meaningfully and effectively. This will ultimately determine the effectiveness, scalability and sustainability of peer support programmes in the region.

For a health facility-based peer support model to be prioritised, scalable and sustainable it needs to be simple, low cost and replicable across settings, whilst still meeting minimum quality standards.

Across 2018-2020, PATA will be developing a user-friendly package of accessible tools to support facilities to implement peer support services that adhere to quality standards while still being feasible in low-resource environments. These tools will be imperative to optimise the power of peers for the wellbeing of adolescents living with HIV.

PEER SUPPORTER VOICES

Peer Supporter Olive, Chikowa Health Centre

Olive is 23 years old and married with three children. Before joining REACH, Olive was unemployed and very worried about her HIV status. She thought she was without value and her outlook on life was hopeless. Olive now champions adolescent-friendly services for her peers at Chikowa Health Centre and in her community. She also often goes beyond her peer supporter responsibilities, by offering her assistance to health workers in Chikowa’s maternity and malaria programmes. Her desire to help other people encourages her to do more. She loves her job.

“Being a peer supporter has helped me overcome self-stigma, personal fears and low self-esteem. I feel freer and stronger, and have plans for my future.”
As global dialogue shifts towards new science, breakthrough innovations and updated models of care, let us not forget the persistent challenges that continue to undermine our efforts.
GAP 4: THE INFORMATION GAP

WHERE THERE ARE NO P-VALUES: Patient outcomes

Evidence to support optimal delivery of services to children and adolescents is lacking. An information gap exists around which service delivery models are effective and how implementation challenges can be overcome.

Across the data quality control and analysis for Reality check, PATA found that – of all data points reported by health facilities – data on patient outcomes was weakest. In particular, loss to follow-up and viral suppression reporting had the highest volume of missing data and error rates.

For example, 34 of the 115 facilities in our outcomes analysis (30% of the sample) were not able to provide age-disaggregated data for viral suppression rates. Facilities reported that viral suppression rates are unknown, unavailable or not recorded. This large proportion of facilities therefore had to be excluded from our calculation.

We may be justified in inferring that those health facilities able to report accurate numbers are likely to have better data records and monitoring practices such as attendance registers. This would mean that our analysis excludes facilities likely to have the poorest tracing and tracking, and therefore lowest viral suppression and highest loss to follow-up rates.

The data challenges illustrated here are not unique to PATA. The health facilities included in Reality check are located in urban (40%), peri-urban (28%) and rural (32%) settings. They operate at primary (50%), secondary (33%) and tertiary (17%) level and are primarily government healthcare facilities (66%). They span 15 countries in Southern, East, West and Central Africa. As such, they represent a range of sub-Saharan Africa’s health centres treating and caring for children and adolescents living with HIV. The data challenges reflected here represent similar difficulties across the continent.

To support evidence-informed policy and programmes, new and better data are required. We can only determine which programmes and services work best for children and adolescents living with HIV if we have quality data disaggregated by age. Routine national monitoring systems, however, often do this insufficiently and electronic medical records are not universally implemented. While randomised controlled trials are critical, they are also expensive and lengthy and big cohort collaborations tend to be limited in scope. These challenges limit our understanding of how best to implement and upscale services to improve paediatric and adolescent HIV outcomes. Without this evidence, policy-makers are left to extrapolate from adult cohorts to children and adolescents, which may not be appropriate and often does not directly translate to addressing the particular challenges faced by these age groups.

“We have to get to the last 90% for everybody. We can’t just get to 90% for the total patient population. We need to get to 90% for each population group.”

– Nandita Sugandi, ICAP
A total of 502,954 children, adolescents and young people tested for HIV in the past year.

Of these, 5% tested positive for HIV.

Health facilities reported a total of 86,872 HIV-pregnant women to have initiated ART in the past year.

Of these, 5% were reported to be lost to follow-up.

About the sample:
115 health facilities
15 countries
51% urban, 24% peri-urban, 25% rural
50% primary, 30% secondary, 20% tertiary
2017 data

HIV+ children, adolescents and young people

HIV-pregnant women

Loss to follow-up by age group
Children 10%
Adolescents 5%
Young People 8%

Viral suppression by age group
Children 58%
Adolescents 69%
Young People 61%

* Loss to follow-up was defined using the World Health Organization definition of 90 days since last scheduled appointment.
Not only does the routine collection of disaggregated data need to be improved to inform provincial, national and global policy, but the increased use and engagement with this disaggregated data at the facility level is required. Data utilisation by health providers is key to shaping facility operations and service delivery to be more responsive and efficient in real-time. It also allows providers to deliver services in a way that is more nuanced and context-specific. Countries, provinces, districts and facilities are not homogenous and each has localised challenges, in addition to those that are pervasive.

In the absence of rigorous data and p-values, and with the stakes so high in the sprint to 2020, we urgently need a pragmatic understanding both of the operational barriers to optimal paediatric and adolescent HIV outcomes and the interventions and service delivery models that will get us where we need to be – quickly. Health providers are an invaluable source and key audience for this information, and PATA will continue to amplify their voices in shaping the global HIV response in years to come. As a global community, there is also a need to continue to invest in strengthening systems for electronic medical record keeping, routine data monitoring, reporting and use.

**LACK OF DATA**

Adolescents and young people living with HIV have been identified as inadequately served populations, yet how do we begin to respond effectively when age-disaggregated data is not available? In 2016, only 84 countries reported data on ART coverage for 10- to 14-year-olds to the UNAIDS Global AIDS Monitoring Programme.
Last words

With 2020 in sight, there is no time to waste in making our goals a reality and ensuring that children and adolescents are not left behind. For PATA, placing health providers at the centre of the response is the first step in overcoming the enduring barriers to the targets we have set ourselves.

Achieving global super-fast-track targets requires urgent upskilling of health providers. High-impact, innovative approaches must be implemented at each step of the HIV prevention, treatment and care cascade to meet the unique and diverse needs of children and adolescents living with HIV.

Community linkages need to be harnessed. PATA’s role is in facilitating this linking and learning to achieve its vision that all children and adolescents living with HIV in sub-Saharan Africa receive optimal treatment, patient-centered care and support and live long, healthy lives.

By understanding the barriers on the frontline and truly grappling with the perspectives of those at the centre of service delivery – health providers – there is an opportunity to bridge the gaps in practice to policy, service delivery, community and information. Only then will we be able to achieve an AIDS-Free generation in sub-Saharan Africa.
References


23 Sughandi, N. Optimizing Paediatric and Adolescent ART: Challenges and Opportunities. Presented at the PATA 2017 Continental Summit; October, Johannesburg.


With 2020 in sight, there is no time to waste in making our goals a reality and ensuring that children and adolescents are not left behind.