**Expert Patient Programme**

**Improving antiretroviral treatment access and quality of care for infants, children and adolescents**

Zambia & Zimbabwe

The Expert Patient Programme (June 2014 - March 2017) aims to improve access and quality of treatment and care services for HIV+ infants, children and adolescents in Zambia and Zimbabwe, by implementing a facility-based peer support model. It provides people living with HIV the opportunity to learn new skills while helping their peers to access information and services, adhere to treatment and develop resilience in the face of adversity.

Peer Supporters also help build facility capacities and strengthen systems to deliver treatment and care at health facilities. 16 participating facilities recruited 62 adults and young people who live openly and positively with HIV to be facility-based Peer Supporters.

“Peer Supporters are very friendly and we understand each other. If I have a problem I feel more comfortable to share it with a Peer Supporter than with a nurse.”

- Young person living with HIV, Kwekwe General Hospital (Zimbabwe)

“Helping people live positive in my community has made me realise that it’s not the big things we need to do for people to appreciate our services.”

- Peer Supporter, Chikoka Health Post (Zambia)
BACKGROUND

In 2014, approximately one-third (32%) of the world’s 2.6 million children living with HIV received antiretroviral therapy (ART). Coverage is especially low in sub-Saharan Africa, which accounts for 90% of the global paediatric HIV population.\(^1\) AIDS has thus become the leading cause of death for adolescents in Africa, with 1 out of every 6 deaths being HIV-related.\(^2\)

Infants, children and young people living with HIV (YPLHIV) require specialised support from healthcare providers and communities to undertake treatment and stay in care.\(^3\) Overburdened health facilities, however, often are unable to offer YPLHIV the psychosocial support they need. It is important to find innovative ways to expand such services to improve paediatric ART access and ensure that quality care is delivered in a sustainable and holistic manner for infants, children and adolescents living with HIV.

Country-wide health initiatives in Zambia and Zimbabwe have reduced HIV incidence and expanded ART access for children (0-14 years old), but their uptake remains disproportionately low when compared to adults (see Table 1).

In light of these figures, Zambian policymakers stipulated that their services are inadequately ‘meeting the needs of adolescents’ (10-19 years old), and their Zimbabwean counterparts have promised to ‘[i]ntensify programming’ for youth by removing ‘barriers to service access’. HIV-associated stigma and discrimination from families, communities and health providers are seen as major barriers that deter young people from seeking, uptaking and adhering to treatment and care programmes.\(^6\)

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<tr>
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<th>Zambia</th>
<th>Zimbabwe</th>
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<tr>
<td>Adults</td>
<td>62.6%</td>
<td>63.4%</td>
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<tr>
<td>Children</td>
<td>45.5%</td>
<td>55%</td>
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Only 50% of children living with HIV in Zambia\(^4\) and Zimbabwe\(^5\) were on antiretroviral treatment in 2014.

Table 1
Percentage of adult and children HIV population accessing ART in Zambia\(^4\) and Zimbabwe\(^5\) in 2014.
PROGRAMME IMPLEMENTATION

Collaborative planning and networking:

- One to One Children’s Fund and PATA established a partnership to pilot a facility-based peer support programme. A formal agreement outlined the partners’ mutual vision, project objectives and roles and responsibilities.

- PATA worked with its network to identify potential facility and NGO participants. Participants were selected from a pool of applicants most in need of assistance to increase YPLHIV access and quality of services. Facility locations were also considered to ensure a mix of rural and urban sites.

Memorandum of Understanding (MoUs):

- PATA, One to One Children’s Fund, facilities and NGOs signed MoUs that set expectations with time-bound deliverables on an annual basis.

- Facilities or NGOs received quarterly grant disbursements to contribute towards the costs of Peer Supporter stipends, their supervision, and advocacy activities and programme administration.

Recruitment and Integration of Peer Supporters:

- 4 Peer Supporters were recruited per site against criteria that included: being over the age of 18, living openly with HIV, adhering successfully to treatment and already being actively involved at facilities as volunteers.

- Each Peer Supporter signed a contract that detailed their conditions of service and the range of activities they would undertake at the facilities (see ‘Results, outputs and impacts’). They also were assigned a Supervisor who provided them with on-the-job training and mentorship.

Capacity Building:

- A Simple Toolkit for Community Health Workers and Peer Supporters was developed and distributed.

- Annual trainings (based on the toolkit’s content) were provided to the Peer Supporters and Supervisors.
  - The Peer Supporter trainings especially centred on improving treatment literacy, adherence counselling, and disclosure and psychosocial support, as well as the significance of self-care.
  - The Supervisor trainings focused on improving their supervisory skills and improving YPLHIV ART access and care by integrating Peer Supporters at facilities.
Supervisors and Peer Supporters receive continual support through:
- A multi-country Whatsapp Community of Practice.
- Monthly telephonic check-ins and occasional site visits from PATA.
- Regular access to additional tools and guidance on YPLHIV treatment and care at PATA’s Resource Hub.

RESULTS, OUTPUTS AND IMPACTS

- Peer Supporters (ages 18-57) work an average of 56 hours a month.
- Peer Supporters assist in a range of treatment, care and support tasks, including the following:

### Peer Supporters’ Tasks

<table>
<thead>
<tr>
<th>Task</th>
<th>% of Time Spent</th>
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<tbody>
<tr>
<td>Adherence counselling and treatment literacy</td>
<td></td>
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<tr>
<td>Palliative care</td>
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<tr>
<td>Psychosocial care and support</td>
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<tr>
<td>Pill counts</td>
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<tr>
<td>Family engagement and sensitization</td>
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<tr>
<td>Health promotion and community sensitization</td>
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<tr>
<td>Follow-up and tracing</td>
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</tbody>
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### Testing, enrolment and treatment

- Prevention of Mother to Child Transmission
- HIV counselling and testing
- ART initiation
- Disclosure support
- Sexual and reproductive health (SRH) education
- Clinic administration

### Adherence and care

- Adherence counselling and treatment literacy
- Palliative care
- Psychosocial care and support
- Pill counts
- Family engagement and sensitization
- Health promotion and community sensitization
- Follow-up and tracing

### Dedicated children/adolescent services

- Income generation activities/vocational
- Dedicated space or day
- Support groups
- Children’s play supervision
- Teen clubs/camps
Integrated facility-based peer support models:

- 100% of Peer Supporters have contractual agreements, a dedicated Supervisor and are involved in multidisciplinary staff meetings.
- 100% of facilities in Zambia said Peer Supporters are ‘vital’ to their operations. Their counterparts in Zimbabwe similarly noted that they are ‘highly beneficial’ (62%) or ‘vital’ (38%).

Increased capacity of Peer Supporters to help young people living with HIV:

- All 62 Peer Supporters received a toolkit and attended a health worker training.
- 100% of facilities in Zambia and 88% in Zimbabwe reported that the toolkits are ‘useful’.
- 95% of Supervisors (n = 64) have rated the performance of Peer Supporters as ‘good’ or ‘very good’ since baseline.

**Peer Supporter gender breakdown (n=62)**

- Male 31%
- Female 69%

**Facility locations (n=16)**

- Rural 25%
- Urban 25%

**Patient population (n=18,191)**

- Infants: 1,461 (8%)
- Children: 6,630 (36%)
- Adolescents: 10,100 (56%)

**Patient gender breakdown (n=18,191)**

- Male 45%
- Female 55%

**Expert Patient Programme statistics**

Peer Supporters aid a diverse population of paediatric patients in rural and urban areas.
Peer Supporters helped overburdened staff and improved service delivery:

“Peer Supporters have helped immensely on task-shifting of less technical tasks and activities from trained health care workers to Peer Supporters. Health workers, particularly nurses and doctors, now have more time to provide clinical support to HIV-positive children and adolescents, while Peer Supporters help with following up mainly on adherence to treatment through pill counts. Furthermore, the Peer Supporters demonstrated how they contributed to an improved referral system in which, children and adolescents who are HIV-positive have issues identified and referred early and are subsequently receiving appropriate support.”

- Clinician, Harare Children’s Hospital (Zimbabwe)

“With my HIV-positive status, Peer Supporters helped to have my baby born HIV-negative through their counselling on [Prevention of Mother to Child Transmission].”

- Patient, Ndeke Clinic (Zambia)
Promoted facility-based peer supporter models to gain buy-in:

- 100% of facilities in Zambia and 62% in Zimbabwe have a designated advocacy representative and advocacy plan in place.

- These representatives have promoted peer support programmes at 26 local, provincial and national-level meetings in Zambia and Zimbabwe.

- PATA has promoted this programme at 6 meetings and amongst 3 HIV working groups at a global level. Programme data also informed the World Health Organization’s forthcoming Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection among adolescents.

Spotlight: Chikoka Health Post, Zambia

Broadening facility outreach and disclosure support in communities:
Facility-based Peer Supporters are instrumental in community outreach.

“I am a 13-year-old double orphan adolescent who has been living with HIV since my birth. I never used to take my medicine because my grandmother did not disclose to me. I thought I was not sick and had no reason to take the drugs. But after the intervention of Peer Supporters, I have now accepted my HIV status. My grandmother also has now accepted her role and she supports me in every way. This has given me every reason to take my drugs accordingly.”

- Young Chikoka Patient

Peer Supporters have nurtured community-clinic relationships and engaged caregivers:

“They link community and health workers together.”

- Clinician, Ndeke Clinic (Zambia)

“Caregivers are becoming more involved in the care and treatment of their charges.”

- Clinician, Mpilo Clinic (Zimbabwe)
**KEY FINDINGS**

- HIV+ Peer Supporters are positive role models, because they specially relate to the fears and concerns of HIV+ children, adolescents and their families.

- Their participation has expanded psychosocial support services at clinics and vitally linked health facilities and communities.

- Peer Supporters also assisted health professionals through task shifting and providing additional capacity in overburdened facilities.

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**Spotlight: Glenview Clinic, Zimbabwe**

Empowering and supporting youth with dedicated services: Peer Supporters inspire and support children and adolescents struggling to live positively with HIV through peer-to-peer counseling and support groups.

"Before she met PATA Peer Supporters, my daughter was afraid of nurses and counsellors. She couldn’t accept her status. She was always saying “why was I born positive and why only me?” PATA Peer Supporters counselled her and she accepted for the first time that she could live with HIV as she realised she was not the only one."

- Glenview Caregiver

The Expert Patient Programme is inspiring and empowering people living with HIV to think about their futures and give back to their communities:

"...Being HIV+ is not a death sentence."
- A 16-year-old male living with HIV, Ndeke Clinic (Zambia)

"It helps me remember to take my medication and helps me plan my future."
- Peer Supporter, Beatrice Road Hospital (Zimbabwe)

"I have been recognized in my community as someone that helps people and have earned respect and honour in my community. I would love to continue helping people in any way I can manage."
- Peer Supporter, Chikoka Health Post (Zambia)

"I have learned a lot, I have been empowered by my peers in the community. I now have confidence to advocate for adolescents and children in the community and clinics."
- Peer Supporter, Glenview (Zimbabwe)
The Expert Patient Programme has demonstrated that an integrated community health worker (CHW) model that situates Peer Supporters at facilities is feasible and can enhance service provision, increase staff capacity and contribute to positive patient outcomes.

Zambia and Zimbabwe's governments have increasingly recognised the potential of formalising and strategically utilising the services of CHWs to improve health services and systems. Both governments, however, struggle to adopt this as practice due to their having limited resources to address a diverse range of health priorities. In light of this, policymakers should consider facility-based peer support models as inexpensive but cost-effective means of increasing capacity and expanding much needed support services for infants, children and adolescents living with HIV.

The sustainable integration of facility-based CHWs also requires facilities to establish mechanisms that continue to build the capacities of Peer Supporters while involving them in planning, delivery and monitoring of patient services.

The programme’s advocacy outputs will focus on sharing lessons from the pilot with health departments and HIV stakeholders, by continuing to support Peer Supporters on-the-ground and disseminate knowledge through PATA’s Resource Hub.

CONCLUSION: POTENTIAL IN POLICY AND PRACTICE

Integration into national health programmes
Ndeke’s Peer Supporters work with health staff and government officials to increase voluntary HIV counselling and testing in Zambia.

Resources & links
- PATA Resource Hub:
  http://www.teampata.org/publications-resources/pata-partner-resources
Spotlight: Mpilo Opportunistic Infections Clinic, Zimbabwe

Making clinic environments friendlier to patients and families:
Peer Supporters make facilities easier to navigate and help personalise service delivery.

“Peer Supporters help us with our files, advise us where to go at the clinic and always remind us of our appointment days. Whenever we want help, they are there for us. Any questions we ask, they answer us well and politely.”
— Mpilo Caregiver (Zimbabwe)

Patients say peer-to-peer support is very effective in children and adolescent HIV treatment and care:

“The Peer Supporters are approachable because they are our age mates. They are well informed on issues that affect us, be it HIV/AIDS information or [adolescent sexual reproductive health issues], we can freely discuss with them. They are trained to uphold confidentiality in all our discussions.”
— Adolescent living with HIV, United Bulawayo Hospital (Zimbabwe)

“After I was introduced to a Peer Supporter at the clinic, I could not believe that there are people out there who are like me, who are living a healthy happy life. This day was a turning point for me as I realized that I am not alone... My Peer Supporter is my pillar of support. She has also introduced me to Zvandiri support group where I have made so many friends.”
— Adolescent living with HIV, Rutsanana Clinic (Zimbabwe)

REFERENCES

6. UNICEF Zimbabwe, Stakeholders meet to discuss the “All In” initiative to end adolescent AIDS. Media Centre: Newsnote, 2016. Available at: http://www.unicef.org/zimbabwe/media_16553.html.
Thank you to the following health facilities and NGOs for their participation in this pilot:

**ZAMBIA**

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<td>• Chikoka Health Post</td>
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<td>• Chanyanya Rural Health Centre</td>
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<td>• Chazanga Health Post</td>
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<td>• Chikupi Clinic</td>
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<tr>
<td>• Estates Health Facility</td>
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<td>• Kafue District Hospital</td>
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<td>• Ndeke Clinic</td>
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<td>• Shifwankula Health Post</td>
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**NGOs: Pride Community Health Organisation and Kabangwe Creative Initiatives Association**

**ZIMBABWE**

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<td>• Glenview Poly Clinic</td>
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<td>• Harare Children's Hospital</td>
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<td>• Kwekwe General Hospital</td>
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<td>• Mpilo Opportunistic Infections Clinic</td>
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<td>• Rutsanana Clinic</td>
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<td>• United Bulawayo Hospital</td>
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**NGO: Africaid - Zvandiri**

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[www.teampata.org](http://www.teampata.org)
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