PATA-PACF 2016
Continental Summit Report

Clinic-Community Collaboration (C³): Linking health facilities and communities to deliver services together

5 - 7 DECEMBER 2016, ENTEBBE, UGANDA
Acknowledgements

PATA thanks the many participants and contributors to the PATA-PACF 2016 Continental Summit. Special thanks go to all attending and contributing clinic-CBO partnerships and the Ministry of Health from the host country, Uganda.

We acknowledge the meeting’s generous donor partners, The ELMA Foundation and the Positive Action for Children Fund (PACF).

We are also grateful to the academic institutions, multilaterals, civil society networks and development organisations for their participation and contribution to the programme: PACF, Baylor College of Medicine Children’s Foundation – Uganda, Elizabeth Glaser Pediatric AIDS Foundation and Project ACCLAIM, STOP AIDS NOW!, Towards an AIDS Free Generation in Uganda (TAFU) programme, Engender Health, People in Need Agency (PINA), and the Uganda Network of Young People Living with HIV (UNYPA).

Special thanks must also be extended to Team PATA and PACF who contributed to the development, facilitation and organisation of the Summit.

Summit programme and facilitation
- Luann Hatane
- Dominic Kemps
- Daniella Mark
- Tanya Jacobs
- Lebogang Montewa
- Gerard Payne
- Heleen Soeters
- Noluthando Xagxa
- Carly Davies
- Lina Taing
- Daphne Mpofu

PATA logistics
- Glynis Gossman
- Margail Brown
- Liz Sineke
- Matthew Davids

Communications
- Leilahn Albertyn
Contents

Acknowledgements 2
Glossary of Acronyms 4
Introduction 5
The Clinic-CBO Collaboration (C³) Programme 7
Summit purpose and objectives 9
Methodology 11
Coordinated action for improved case finding and linkage to care 12
Spotlight Presentations: Community approaches in improving PMTCT and Paediatric HIV treatment outcomes 16
The clinic-CBO relationship – underpinning community engagement 20
Key messages and lessons in clinic-CBO relationship building 22
Talking is tough – communication in partnership is key 25
Meeting in the middle – formalising partnerships and creating an enabling environment 26
The bigger picture – C³ sustainability 29
Images from the Summit 30
Summit evaluation 33
In Conclusion – the value of clinic-CBO collaboration 36
Annex 1: Summit programme 39
Annex 2: C³ Joint Activation Projects 42
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACCLAIM</td>
<td>Advancing Community Level Action for Improved Maternal and Child Health and PMTCT</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal Care</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</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-based organisation</td>
</tr>
<tr>
<td>DMHT</td>
<td>District Health Management Team</td>
</tr>
<tr>
<td>EGPAF</td>
<td>Elizabeth Glaser Pediatric AIDS Foundation</td>
</tr>
<tr>
<td>eMTCT</td>
<td>End mother to child transmission</td>
</tr>
<tr>
<td>EID</td>
<td>Early Infant Diagnosis</td>
</tr>
<tr>
<td>HCT</td>
<td>HIV counselling and testing</td>
</tr>
<tr>
<td>LTFU</td>
<td>Loss to follow-up</td>
</tr>
<tr>
<td>MCH</td>
<td>Mother child health</td>
</tr>
<tr>
<td>M&amp;E</td>
<td>Monitoring and evaluation</td>
</tr>
<tr>
<td>MNCH</td>
<td>Mother Neonatal Child Health</td>
</tr>
<tr>
<td>MoU</td>
<td>Memorandum of understanding</td>
</tr>
<tr>
<td>MOH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>OVC</td>
<td>Orphans and vulnerable children</td>
</tr>
<tr>
<td>PACF</td>
<td>Positive Action for Children Fund</td>
</tr>
<tr>
<td>PATA</td>
<td>Paediatric AIDS Treatment for Africa</td>
</tr>
<tr>
<td>PIF</td>
<td>Partnership Initiation Forum</td>
</tr>
<tr>
<td>PLHIV</td>
<td>People living with HIV</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission</td>
</tr>
<tr>
<td>SRHR</td>
<td>Sexual and reproductive health rights</td>
</tr>
<tr>
<td>TAFU</td>
<td>Towards an AIDS Free Generation</td>
</tr>
<tr>
<td>UNYPA</td>
<td>Ugandan Network of Youth People Living with HIV</td>
</tr>
<tr>
<td>UTT</td>
<td>Universal Test and Treat</td>
</tr>
<tr>
<td>VSLA</td>
<td>Village Savings and Loans Association</td>
</tr>
</tbody>
</table>
Introduction

Clinic-community collaboration and linkage has played a vital role in the Global Plan to eliminate new HIV infections among children and keep their mothers alive. Newly established Fast Track Targets and Sustainable Development Goals, together with global guidance on Universal Test and Treat (UTT) will require rapid scale-up and integration of differential service delivery models. Achieving these targets will require shifting away from individualised and care intensive service delivery to that of an expanded public health approach; evidenced by decentralisation, simplification, task shifting and extended community-based service delivery.

Delivering 90-90-90 as well as updated Fast Track Targets for 2030 will require clinics and the communities they serve to partner with each other. A Fast-Track approach, which includes; increasing demand, connecting children and families to care, supporting retention, combatting stigma and discrimination, monitoring quality, advancing human rights and building stronger local health systems — can only be achieved with increased collaboration with communities. There is however limited evidence and guidance available on the factors that contribute to effective community engagement strategies and how these strategies should be undertaken within a jointly established clinic-community partnership. Health facilities (clinics) and community-based organisations (CBOs) often continue to operate in isolation, relying mostly on informal arrangements that do not provide the needed structure or mechanism to facilitate and coordinate meaningful and sustainable engagement between them over time.

In 2015, an estimated 150,000 children (aged 0–14 years) were newly infected with HIV globally, and nearly 85% of them live in sub-Saharan Africa. Half of the 1.8 million children (aged 0–14 years) living with HIV globally did not receive antiretroviral HIV treatment in 2015. For those children able to receive ART, it came too late, at an average age of initiation of 3.8 years in sub-Saharan Africa. Without timely treatment, one third of children with HIV will die by age 1, and half by age 2.

Source: [http://childrenandaids.org/programme-area/first-decade](http://childrenandaids.org/programme-area/first-decade)
As noted in the 2015 UNICEF Community Facility Linkage Report, community-facility linkage is defined as a formalised connection between a health facility and the community it serves in order to support improved health outcomes. The following guiding principles are offered for all efforts to engage with communities in health, including community-facility linkages in support of prevention of mother-to-child transmission (PMTCT) and lifelong antiretroviral therapy (ART):

- Tailor community strategies and activities to the local context
- Align with and support national plans and frameworks
- Adopt the human rights-based approach
- Involve people living with HIV (PLHIV)
- Build on existing structures and resources
- Strengthen accountability for health
- Encourage greater integration of health services
- Ensure quality of community-level health communication and services

The Clinic-CBO Collaboration (C³) programme was conceptualised and implemented within this context and is making an important contribution to promoting clinic-community collaboration as a key strategy in the elimination of mother-to-child transmission, improved access to early infant diagnosis and paediatric treatment for children living with HIV. The C³ programme supports clinic-community partnerships across nine sub-Saharan countries to investigate bottlenecks and develop recommendations. Using case learning, the C³ programme provides a central entry point for exploring health system-community linkage complexities within the clinic and CBO relationship.
The Clinic-CBO Collaboration (C³) Programme

The C³ Programme is a partnership between PATA and the PACF. The partnership initiated 36 clinic-community partnerships across nine focus countries (Ethiopia, Nigeria, Malawi, Zambia, Uganda, DRC, Cameroon, Kenya and Zimbabwe) over a three-year period. The C³ programme set out to develop, incubate and disseminate clinic-community implementation models and partnership strategies, as well as provide recommendations for effective clinic-CBO collaboration. The three-year programme used a localised model – establishing four clinic-community partnerships per country to gather and learn lessons.

C³ aims to promote and strengthen clinic-CBO collaboration for:

- improved PMTCT and paediatric HIV service delivery;
- greater community engagement in PMTCT and paediatric HIV service delivery;
- increased health partnership and linkage between clinic and CBO; and
- documentation and dissemination of challenges, lessons and promising practice from clinic-CBO partnership and joint activation.

The culmination of the first three-year phase was to host all C³ partners together in a PATA-PACF Continental Summit, offering a learning platform to share promising practices and provide a collective contribution of clinic-CBO linkage experience. This joint experience and learning across the programme will inform the development of a C³ Toolkit. The toolkit will become a critical vehicle for consolidating and building on C³ methodology as new facilities continue to refine the methodology and new clinic-CBO partnerships are initiated in the future. The toolkit intends to be a ‘How to Guide’ on clinic-CBO linkage, with a focus on structural arrangements, mechanisms and tools needed to build partnership. Clinic-CBO partnership will be contextualised through sharing joint activation projects and strategies with the established purpose of expanding access to treatment for pregnant and breastfeeding women living with HIV and improving access to early infant diagnosis and paediatric treatment for children. The toolkit will be grounded in lessons from the C³ programme, incorporating additional tools and case studies from strategic partners in the sector.

“C³ is not coming to do anything differently. We are already working in the communities. C³ is a programme that just helps build our capacity.”

- CBO partner, Ethiopia
Figure 1. The C³ Cascade illustrates key programme interventions undertaken between 2014 and 2017.
Summit purpose and objectives

The purpose of the 2016 PATA-PACF Continental Summit entitled, ‘Clinic-Community Collaboration (C³): Linking health facilities and communities to deliver services together’ for improved PMTCT and paediatric HIV care was to create a platform to:

- disseminate and popularise global and regional updates and best practices on how health facilities and communities can collaborate to deliver services together
- share challenges, lessons learned and best practice models for clinic-CBO collaboration as experienced in the C³ programme
- enhance regional solidarity and networking for improved clinic-CBO linkage across the region

The summit brought together 115 participants including 61 frontline health providers representing 31 health facilities, and 34 CBO representatives across the nine focus countries. Attending clinic-CBO partners were joined by 11 other guests, comprising of international guest speakers, donors and a representative of the Ugandan Ministry of Health.

The Summit programme was designed to highlight and share clinic-CBO activation plans and promising practices that address barriers and advance improved linkage and retention along the PMTCT prevention, treatment and care cascade.

“I see this summit as a valuable opportunity to link health facilities and communities to deliver services together. I see the opportunity we have, and especially want to note and mention, we’ve had previous forums where CBOs were not involved. C³ is a very welcome innovation.”

- Dr. Cordelia Katureebe-Mboijana - Ministry of Health in Uganda
The programme placed special interest and focus on the clinic-CBO relationship, defining structural arrangements as well as establishing indicators for effective clinic-CBO linkage and partnership.

The Summit was held over three days with the programme organised around a daily theme.

**DAY 1:**
Coordinated action for improved case finding and linkage to care

**DAY 2:**
Keeping connected for outreach and support

**DAY 3:**
Creating the context for an enabling environment

“We want honest conversation about what’s worked and what’s happened. Because if we are going to get others on board and bring C³ to scale, we need to go in with our eyes open with what the experiences of this group have been.”

- Dominic Kemps, PACF

“C³ is about how we are going to work together more effectively as partners to deliver services and how our joint activations can address barriers that may deter or delay mothers and their children from being tested, initiated on treatment and retained in care”

- Luann Hatane, PATA
Methodology

The C³ Summit provided an opportunity for participants from partnering clinics and CBOs to interact and share their experiences and lessons of working together and undertaking joint activation plans. The three-day forum used a variety of session formats that were interactive to achieve the Summits purpose and objectives. The three-day Summit also included a formal dinner where participants could interact and network in a relaxed environment.

This report is based on summit presentations, discussions in plenary sessions and workshops as well as evaluation feedback from participants.

PLENARY SESSIONS
The start of each day provided an overview and introduction to the day’s theme and programme. Day 1 started with a formal opening session with Day 2 and 3 focusing on technical input and guidance. Plenaries provided a platform to share regional case studies as well as promising practices emerging from within the C³ programme.

WORKSHOPS
A series of seven workshops were held over the course of the Summit. The workshops provided a platform for C³ partners to present and discuss how they work together and apply strategies for effective partnership, whilst also share the barriers and challenges experienced.

PANEL SESSIONS
Daily panel sessions provided feedback to the plenary on reflections from workshop sessions and created interactive discussion highlighting what worked well and what worked less well in the programme to date.

ROLE PLAYS
Role plays were included in workshops as a way of show-casing various experiences within the clinic-CBO partnership and provided a valuable and fun tool to extract and demonstrate communication challenges and lessons.

TEAM PRESENTATIONS
Clinic-CBO teams presented their experiences and joint activation projects through a world café format as well as a whirlpool poster process. Clinic-CBO teams could move around and engage with each of the posters, creating an interactive “whirlpool” effect. This allowed participants to share practical strategies and solutions learnt within C³ and encouraged opportunity for peer review across the programme.

“The purpose of C³ was never to introduce new programmes; but rather about doing business-as-usual in a different way, clinic-community collaboration is a methodology, it’s the way we want to do our work - together.”

- Luann Hatane, PATA
Coordinated action for improved case finding and linkage to care

Dr. Cordelia Katureeb-Mboijana from the Ministry of Health in Uganda opened the Summit and highlighted that despite recent improvements and performance against global targets, serious challenges continue to undermine efforts to link pregnant HIV positive mothers, children and adolescents into care. Early infant diagnosis coverage remains low with many children being lost in the PMTCT cascade following birth. Associate Professor Adeodata Akekitiiinwa from Baylor College of Medicine – Uganda, highlighted key barriers and bottlenecks within the cascade that limit linkage, access and utilisation of services across the domains of supply, demand and service quality.

In the context of costly and ineffective testing for infants and children, where children are solely dependent on caregivers to be tested, and provider initiated counselling and testing (PICT) is often initiated too late; in many instances after children have already presented with illness. Stigma and discrimination as well as gender relations, unsafe norms and cultural factors heavily influence how communities seek and engage with health services. Health system challenges such as limited human and financial resources, as well as ineffective and inefficient strategies to optimally involve the community can create further barriers.

“90-90-90 is an issue that involves the community and we must sensitise the community so they can have the buy-in and work with us.”

- Asstt. Prof Adeodata Akekitiiinwa, Baylor College of Medicine

Children’s Foundation-Uganda

Figure 2.
Key barriers and bottlenecks - limiting access and utilisation in relation to supply, demand and quality, extracted from Asstt. Prof Adeodata Akekitiiinwa’s presentation.
The involvement of the community is a central strategy to drive case finding and linkage to care with clinic-CBO partnerships offering an important entry point for coordinated action.

Strategies for identification and case finding of children lie in their connection to adults and other children living with HIV in the family. Assct. Prof Adeodata Akekitinwa presented a core package of service for improved linkage that includes: community mobilisation, regular PMTCT follow up with early infant diagnosis, index-based HIV testing, orphans and vulnerable children (OVC) and family testing.

Once children are linked to care, initiation of ART may be delayed further due to health providers who view paediatric regimens as being more complex to manage. Once initiated, caregivers are also challenged with logistical difficulties related to storage requirements, dosage and resistance due to poor palatability of paediatric ARVs. Getting to the second and last 90 will require urgent treatment optimisation for children, and is centrally reliant on the engagement and support of caregivers.

“In terms of the start free, stay free, AIDS free strategy, how can you keep children free from HIV if you do not include the communities where they are born?”

- Assct. Prof Adeodata Akekitinwa, Baylor College of Medicine Children’s Foundation - Uganda

“I stopped taking my medication at one point, efavirenz gave me bloating and nausea. It was difficult to concentrate – I often felt drunk. Being at boarding school also made it difficult as nobody knew my HIV status. Even in my family it was not spoken about. My twin sister and I were just told to take our medication – we only found out when we were much older. Family members were also very negative and we never really got the chance to have the family we had dreamt of. These family issues also affected us kids and how we took our medication. That’s why I became a peer supporter, I don’t want other children to have to go through this

- Young peer supporter, Eva Babyire, PINA Uganda
Keeping connected for outreach and support

Participants and presenters highlighted several barriers to being retained in care and adherence to treatment that extended from basic health systems issues (staff shortages, drug supply, long waiting times to getting results or being seen at the facility), service accessibility (transport costs, distance and poverty), community-level stigma and fear of disclosure to partners, as well as weak community structures that can effectively support, link and return mother-baby pairs who have been lost to follow up (LTFU).

Towards an AIDS free generation in Uganda (TAFU) presented different barrier levels:

- Household: awareness, stigma, economic challenges and peer support
- Community: stigma, awareness and linkage with health centre
- Health facility: linkage, staffing levels, stock outs and loss to follow up

“Adherence is paramount to any successful ART program. Clinicians and counsellors have big workloads, to ensure ART programme goals, clinics and communities must work together. Medication has to be taken for life, so we need to engage our patients as we are making treatment plans, we need to involve them at all levels. If patients don’t adhere, we all know what happens”.

– Asia Mbajja, PINA Uganda
KEY STRATEGIES TO STRENGTHEN CLINIC-CBO COLLABORATION FOR IMPROVED LINKAGE TO CARE

Several presentations and discussions at the Summit explored innovative strategies in joint clinic-CBO collaboration that highlighted how clinics and CBOs can work together in a more structured and systematic way. The key message being that of building and supporting LINKAGE into testing, treatment and care.

Linkage:
- bringing together stakeholders and community leaders, CBOs, health providers and district focal point persons to develop, implement and monitor one coordinated response plan
- build upon and strengthen the capacity of key resource persons, organisations and structures in the community as key entry points to link community and health service delivery
- use approaches that include models of community health work, peer support, community sensitisation and mobilisation to generate service demand

10 C’s of community mobilisation

- **Which, what Community?** Know the community and how it views itself
- **Consult the community** on what they see as their burning burden / issue
- **Challenges** are overcome successfully if solutions are driven from within the community, by the community
- **Codes of Conduct**—all communities have unwritten but living rules and regulations and Culture and Customs: Respect, respect and respect
- **Coordinate:** with existing services, role players, government
- **Collaborate:** do not compete with local heroes, other funders, service providers
- **Communicate:** be transparent, say what you will do, do what you said you will do and report on what you have done
- **Community Counselling:** All interactions provide opportunities to counsel and be counselled by individuals, segments of the community and sometime the whole community
- **Capacity building:** work yourself out of that job, allow the community to build its capacity to continue without your meddling

Figure 4.
The community strengthening model used by TAFU, extracted from Merian Musinguzi’s presentation.
COMMUNITY APPROACHES IN IMPROVING PMTCT AND PAEDIATRIC HIV TREATMENT OUTCOMES

Community approaches towards access, uptake and retention in the mother child health (MCH)/PMTCT cascade undertaken by the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) tested and evaluated a package of community-level PMTCT interventions designed to overcome key social barriers in three African countries: Zimbabwe, Swaziland and Uganda (Project ACCLAIM, EGPAF).

Interventions focussed on building community engagement for maternal and child health and were undertaken at three levels:

LEADERSHIP: Empowerment and action:
- Community Leaders Intervention
- Training and mentoring
- Community Action Plans (CAPs)

COMMUNITY: Opening the public dialogue
- Community days
- Structured dialogues for men, women, adolescents

INDIVIDUAL: Information and attitudes
- Peer groups for men
- Antenatal classes for women

Results shared at the Summit indicated that community perceptions, attitudes and beliefs improved in response to planning for safe delivery, mobilising community resources for MCH and working with others to solve community MCH problems. In addition following the intervention an improvement was seen in retention in PMTCT and early infant diagnosis at eight weeks with increasing numbers of pregnant women completing at least four ANC visits.
Linked community and facility-based health promotion services through building the capacity of community resources and encouraged health facilities to work with community structures in linkage and follow up.

**Interventions:**

- Mobilised and educated communities on paediatric HIV and eMTCT through training, home visits and community dialogues.
- HIV testing through strengthened provider initiated and routine testing as well as referral of pregnant women to facilities for testing
  - Enroll in care through improved referral and linkages between communities and health centres, treatment support, health facility information sessions, community and school mobilisation and sensitisation work
  - ART initiation through capacity building of health workers in paediatric HIV care, the provision of training materials and support aids for adherence counselling and support, strengthened supply management for drugs
  - Retention in care through initiation of treatment support groups for children and caregivers, linkage to community resource persons for follow up with income generating village saving schemes and ongoing community dialogues
- Results shared at the Summit indicated an increased number of children tested, children and women referred for testing and enrolled into care. New strategies included the establishment of 33 child peer support groups, 34 Village Saving and Loan Associations (VSLAs) formed/supported and 542 households linked to existing VSLAs.
Engender Health shared its work in strengthening facility-community linkages for fistula prevention, detection, treatment, and reintegration. The programme consists of both community cadre training for Village Health Teams (VHTs) as well as Site Walk-Through (SWT) engagements. SWTs were described as a promising approach for improving access, availability, acceptability, quality, and choice of service. This is undertaken through providing a “guided tour” of a health facility focusing on demonstrating and explaining health services to community members, discussing service statistics, identifying joint barriers to access and developing action plans. The SWTs build greater awareness and address misconceptions about family planning methods, women’s lack of decision-making power (gender norms) and concerns about health provider attitudes and interpersonal dimensions of care.

UNYPA highlighted the need for youth-friendly service for young positive parents and described how young mothers are often transitioned to adult services without sufficient preparation or support. Young mothers are vulnerable and require youth-friendly services that are tailored to their needs. Services need to include: ANC, safe delivery, breastfeeding and nutritional support, ongoing treatment literacy, adherence counselling and parenting support and skills building with regular follow-up visits and home visits. This will assist in early infant diagnosis (EID) and initiation of paediatric ART if required, as well as retaining mother baby pairs in care. Negative attitudes from health workers, lack of treatment literacy, poor family planning counselling and limited provision or safe conception options for young positives were highlighted as key barriers to be overcome.

“Attitude is a service...Your attitude should be one of the services you provide”

- Jacquelyne Alesi, UNYPA
KEY MESSAGES AND LESSONS IN CLINIC-CBO COLLABORATION FOR IMPROVED LINKAGE ACROSS THE PMTCT AND PAEDIATRIC HIV TREATMENT CASCADE

- In achieving global targets linkage between clinics and the communities they serve will need to be maximised at each step of the HIV prevention, care and treatment cascade.
- Political commitment to PMTCT and paediatric treatment scale up is needed at all spheres of government and amongst all key stakeholders.
- District level planning must facilitate civic participation to develop home grown solutions and maximise local assets to address linkage along the PMTCT and paediatric treatment cascade.
- Develop and share tools to facilitate planning, sharing of data, decision-making and implementation of locally appropriate community engagement activities.
- Identify key barriers to access, linkage and retention collectively – plan appropriate responses to remedy such barriers.
- Promote joint planning that is informed by local evidence and data.
- Consult cultural and traditional leaders as a key strategy to drive sensitisation on community-level barriers that include stigma and discrimination; or traditional beliefs that may promote unsafe norms.
- Advocate for and apply local and global guidance for optimal paediatric HIV treatment options.
- Improve funding mechanisms and strategies to develop organisational capacity of CBOs.
- Strengthen opportunities and resources for joint action and regular engagement between community based structures and health facilities.
- Promote peer-to-peer involvement and support through mothers’ groups, adherence clubs, mom and baby pair play groups and male partners’ involvement.
- Promote community driven communications and joint activities that address male involvement, partner disclosure, early antenatal care attendance, facility delivery, and early infant diagnosis.
- Develop clear indicators for ongoing monitoring and evaluation of community engagement impact in the PMTCT and paediatric treatment cascade.

“Community interventions require significant upfront investment (time, planning and funding) to ensure that community cadres are effective. They need training and mentoring. And I think that’s why we are all here, because this is critical for any community intervention.”

- Daphne Mpofu, EGPAF
The clinic-CBO relationship – underpinning community engagement

Partnership is key in clinic-CBO collaboration and underpins all community engagement. Summit participants discussed what worked well and what worked less well in their partnership. The table below provides a summary of key areas that were mentioned from both clinic and CBO perspectives. These were then themed into: understanding clinic-CBO collaboration (the what), structural arrangements to make it work (the how) and strategic areas of intervention and collaboration (the plan).

From the clinic perspective:

<table>
<thead>
<tr>
<th>What worked well – ‘the good’</th>
<th>What worked less well - ‘the bad’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding clinic-CBO Collaboration</td>
<td></td>
</tr>
<tr>
<td>• Mutual understanding</td>
<td>• Poor understanding of what is meant by collaboration</td>
</tr>
<tr>
<td>• Common goal</td>
<td>• Hinderance and burdensome to existing work – undermined partnership</td>
</tr>
<tr>
<td>• Valuing each others strengths</td>
<td>• Participation only for reward</td>
</tr>
<tr>
<td>Structural Arrangements – the how</td>
<td></td>
</tr>
<tr>
<td>• Work close together – in close proximity</td>
<td>• Not compatible, mistrust and poor perception of the other</td>
</tr>
<tr>
<td>• Working together, joint planning, budgeting and implementation</td>
<td>• Lack of data sharing between partners</td>
</tr>
<tr>
<td>• Formalise MoU – each partner had a defined role to play in implementation</td>
<td>• Different work schedules and different demands and roles that were not complementary</td>
</tr>
<tr>
<td>• Written into workplans</td>
<td>• No clear defined roles with an informal arrangement that was not well understood by all and was not measured or evaluated</td>
</tr>
<tr>
<td>• Written into key performance areas</td>
<td>• Occasional, infrequent, reliant on one or two people</td>
</tr>
<tr>
<td>• Clinic-CBO collaboration discussed at team meetings, placed on weekly agenda and measured as part of operational planning</td>
<td>• Not consistent or well maintained</td>
</tr>
<tr>
<td>• Communication</td>
<td>• No communication plan</td>
</tr>
<tr>
<td>• Two-sided</td>
<td>• Responsibility and accountability was not equally shared between the CBO and clinic</td>
</tr>
<tr>
<td>• Regular meetings held between clinic-CBO</td>
<td></td>
</tr>
<tr>
<td>• Whatsapp as a medium to facilitate communication</td>
<td></td>
</tr>
<tr>
<td>• Power sharing in implementation: “By sitting down and planning together there was some form of power sharing.”</td>
<td></td>
</tr>
<tr>
<td>Areas of joint intervention and collaboration (the what)</td>
<td></td>
</tr>
<tr>
<td>• Support from community health workers who are able to reach out, engage and sensitise communities</td>
<td>• Insufficient stipend amounts - could not sustain community health workers, who were volunteers</td>
</tr>
<tr>
<td>• Involvement of cultural and traditional leaders, oftentimes with the CBOs or community leaders as facilitators of joint activities</td>
<td>• Lack of support or interest from political, community or traditional leaders</td>
</tr>
<tr>
<td>• Clear plan on joint activities</td>
<td>• Plan not clear</td>
</tr>
<tr>
<td>• Sharing of resources</td>
<td>• Limited resources and lack of transparency between CBO and clinic</td>
</tr>
<tr>
<td>• Joint community engagement</td>
<td>• Staff attrition with insufficient hand over</td>
</tr>
<tr>
<td>• Effective documentation and shared reporting</td>
<td>• Lack of sufficient documentation and reporting</td>
</tr>
</tbody>
</table>
From the CBO perspective:

<table>
<thead>
<tr>
<th>What worked well – ‘the good’</th>
<th>What worked less well - ‘the bad’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding clinic-CBO collaboration</td>
<td></td>
</tr>
<tr>
<td>• Good understanding and common goal</td>
<td>• Poor understanding – seen as a burden</td>
</tr>
<tr>
<td>• Transparency</td>
<td>• Lack of transparency - different understanding on how the funds should be managed. Seen as an “interference”</td>
</tr>
<tr>
<td>• Leadership from both clinic and CBO in place</td>
<td>• No joint ownership</td>
</tr>
<tr>
<td>• Physical proximity</td>
<td>• Lack of commitment and lack of interest</td>
</tr>
<tr>
<td>• Both clinic-CBO committed</td>
<td>• Different responsibilities and timeframes</td>
</tr>
<tr>
<td>• Building trust</td>
<td>• No focal person – no accountability</td>
</tr>
<tr>
<td>• Have a central driver and focal person</td>
<td></td>
</tr>
</tbody>
</table>

Structural Arrangements – the how

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Having MoU between clinic and CBO</td>
<td>• No continuity plan, especially in light of staff turnover</td>
</tr>
<tr>
<td>• Specified roles</td>
<td>• Lack of commitment</td>
</tr>
<tr>
<td>• Accountability structure</td>
<td>• Clinics have their goals and patients to attend to, while the CBOs have other projects to attend to</td>
</tr>
<tr>
<td>• Having decision-makers in management at the clinic involved and committed</td>
<td>• Conflicting priorities</td>
</tr>
<tr>
<td>• Regular review meetings: discuss progress, whether targets are reached, problem solving and ongoing planning</td>
<td>• Insufficient management buy in</td>
</tr>
<tr>
<td>• Involving MOH officials</td>
<td>• Lack of data sharing and delays in accessing data from the MOH</td>
</tr>
<tr>
<td>• Joint implementation on the ground</td>
<td>• Bureaucracy and hierarchy of clinics makes partnering with CBOs challenging</td>
</tr>
<tr>
<td>• Engaging all the stakeholders such as headmen and key women of influence in the community</td>
<td>• Not enough capacity and skill to deal with joint implementation or deal with emerging conflict</td>
</tr>
<tr>
<td></td>
<td>• Lack of dedicated volunteers to reach out and implement</td>
</tr>
</tbody>
</table>
Key messages and lessons in clinic-CBO relationship building

There were many similarities between clinics and the CBOs perceptions of what worked well and what worked less well. Key recommendations for both partners to take into consideration are outlined below:

- Clinics and CBOs collaborate each from their sector perspective and organisational reality, and do not automatically understand each other’s challenges.
- Relationship building is key and requires ongoing commitment to work together with appreciation for open dialogue.
- Before initiating partnership, each partner needs to conduct and assess the best ‘match’ in partner.
- Invest in careful planning to establish joint priority areas and plan together.
- Engage with data to determine where partnership opportunities exist and make most sense.
- Develop a plan of action that is regularly reviewed, monitored and measured.
- Develop agreements and provide clear terms of reference with defined roles, responsibilities and lines of accountability.
- Provide clarity and transparency upfront on available human and financial resources.
- Ongoing communication is needed to optimise each other’s strengths and build improved understanding on different working styles and schedules.
- Joint commitment and ownership – integrate clinic-community engagement as a key performance area within both the clinic and CBOs annual operational plan with monitored progress and feedback.
- Identify central leaders and drivers and hold them accountable.
- Identify and build the capacity of key entry points such as: community resources, peer support groups, community health workers, community and faith based structures as well as traditional leadership.

“We want honest conversation about what’s worked and what’s happened. Because if we are going to get others on board and bring C3 to scale, we need to go in with our eyes open with what the experiences of this group have been.”
- Dominic Kemps, PACF

“Poor communication between CBO and clinic is a problem. There needs to be leadership on both sides to drive the work forward regardless of resources but out of a will to do so.”
- CBO

“It needs to be a partnership with a purpose. We have seen that this functional partnership with CBO is working. It has helped the clinic to help sensitise traditional birth attendants about the importance of going to a clinic, and it has resulted in a decrease in homebirths.”
- health worker

“Dealing directly with health management makes it easier to make changes at the clinic and working with CBOs as well.” (i.e. not just nurse!)
- CBO
Clinic-CBO Partnership Spotlight:
Chazanga Clinic and Kabangwe Creative Initiative Association (KCIA) (Zambia)

Chazanga Clinic is an outpatient clinic located in a peri-urban area called Chazanga with a population of over 44122. The clinic attends to 450-500 clients daily (TB, MCH, OPD, ART) and has eight nurses, two clinicians, three pharmacists and four counselors. It sees an average of 300 patients per day. The Kabangwe Creative Initiative Association is a CBO undertaking community awareness, defaulter tracing for mother-baby pairs, referrals and community support.

**AIM OF THE C³ PARTNERSHIP**
The aim of the partnership is to improve retention in care of HIV-infected pregnant women and specifically, re-engage half of the 183 women who had been LTFU.

**METHODS**
- Set up a Women’s Savings Club to incentivise women to re-engage in care
- Weekly Women’s Savings Club meetings, with PMTCT discussions
- Provision of birth packs

**HOW WE PARTNER**
The partnership has been informed and guided by a formal MoU. KCIA was invited to the clinic’s annual planning meeting and both clinic and CBO were able to integrate into one another’s action plans. Briefing meetings, weekly Women’s Savings Club meetings, peer supporter supervision and monthly case discussion and review meetings were held jointly.

“**We should do needs assessment of partners to see who is compatible and a good match together, especially around a common goal, involving decision-makers, and also develop a sustainability plan for continuity of projects**”

- participant/delegate

“A well-functioning relationship is important because it strengthens capacity and efficiency. Resources are scarce – if we work together, even with fewer resources, we can realise greater outcomes. The impact is far greater when working together than when working in isolation”

- Eugene Mupakile, Kabangwe Creative Initiative Association
SHARE INFORMATION & DATA
KCIA provides monthly report to Chanzanga, while Chanzanga Clinic reciprocates with quarterly and annual data.

SUCCESSES
The facility reported an increase in the number of women who had been LTFU that have now been returned to care and increased male involvement at womens savings clubs. 40 new Women's Savings Club meetings, with a focus on PMTCT discussions, were established. An increased number of children testing HIV-negative at 6 weeks was reported.

CHALLENGES
• Health workers are busy, and this creates delays
• Not every member of staff recognises the CBO as an important partner
• Failure to recognise the role of clinic-based peer supporters by some health workers

KEY MESSAGES AND RECOMMENDATIONS
• Signed MoU between clinic and CBO
• Planning together
• Constant communication
• Transparency
• Geographical proximity (neighbours)
• Human capital (peer supporters from CBO working in the clinic)

“One size does not fit all. One lesson is that the C³ partnership is around a methodology, it’s around the way we work. The project was a way to get partners to work collaboratively, to practice working together, to facilitate a more formal structure and formal arrangement between the clinic and CBO. Its important that we do not see C³ not as a once off project, but as a methodology and principle in how we work consistenly over time.”

– Luann Hatane, PATA

“Effective and ongoing communication is the glue in C³”

- CBO partner, Malawi
Talking is tough – communication in partnership is key

The creative use of role plays explored referral, linkage and joint meeting scenarios between the clinic and CBO. Central themes emerged across all the role plays, illustrating real life C³ partnership experiences and challenges.

KEY MESSAGES AND LESSONS:

• Communication is central successful clinic-community collaboration

• The most common cause of communication breakdown highlighted by the role play scenarios were:
  » One-way discussions or dialogues
  » Poor listening skills
  » Lost-in-translation: bias influencing what a person wants to hear or overuse of jargon dilutes messaging and mutual understanding
  » Reliance on one mode of communication: e.g. Whatsapp being more prevalent, but not everyone has a smartphone or data access
  » Reliance on one key communicator – relationship compromised due to high turnover of staff

• Referral systems and associated tools and procedures between the clinic and CBO need to be developed further, and communicated to all parties clearly and be consistently monitored and reviewed

• C³ communication strategies and general operating procedures need to be more clearly defined, agreed to and monitored

• Some of the communication tools C³ partners used were:
  » Face-to-face meetings
  » E-mail
  » Letters – including referrals letters or slips
  » WhatsApp
  » HIV information and education communication tools for various campaigns, such as:
    ▪ Pamphlets and posters
    ▪ Radio
    ▪ Drums/music/performing arts, etc.

“C³ behaves like human beings in love. It needs attention, it has feelings. If you don’t do the little, little things for it, it dies; if you nourish it, it thrives.”

  - CBO partner, Malawi

“C³ partnership is like a relationship. There are issues of love; today it’s on the brink, tomorrow it falls down. You need to maintain it.”

  - CBO partner, Malawi
Meeting in the middle – formalising partnerships and creating an enabling environment

One of the key discussions that was focussed on was how C³ partnerships can be formalised and whether the introduction of increased structural arrangements and a joint agreement between the clinic and CBO could be beneficial to the partnership and its purpose. Examples of helpful structural arrangements that were undertaken by C³ partners are as follows:

<table>
<thead>
<tr>
<th>Who</th>
<th>Action, strategy or tactic</th>
<th>Who else to involve</th>
<th>Mechanisms for accountability</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBO Health facilities DHMT</td>
<td>Joint agreement - MOU with detailed terms of reference</td>
<td>Other facility staff Other CBO staff All DHMT</td>
<td>MOU reviewed and guidelines on implementation provided</td>
</tr>
<tr>
<td>CBO Clinic</td>
<td>Awareness meetings conducted jointly by C³ partners Develop a communications brief</td>
<td>All community stakeholders</td>
<td>Review of communication brief</td>
</tr>
<tr>
<td>CBO Clinic</td>
<td>Face to face meeting Telephonic contacts Skype Setting regular meeting dates with established agenda</td>
<td>Local leaders Heads of departments</td>
<td>Minutes of Meetings Integrated into key performance area</td>
</tr>
<tr>
<td>CBO Clinic</td>
<td>Appointing focal persons</td>
<td>HIV counsellors</td>
<td>Written documents</td>
</tr>
<tr>
<td>CBO Clinic</td>
<td>Joint activation plans MOU</td>
<td>Community leaders Beneficiary representatives</td>
<td>Reports</td>
</tr>
<tr>
<td>Clinic CBO</td>
<td>Share resources for joint activity Training workshops Toolkits or IEC materials</td>
<td>Clinic staff providing clinical care Continual review of the work plan</td>
<td>Trained staff Shared account Condoms IEC materials Test kits</td>
</tr>
<tr>
<td>Clinic CBO</td>
<td>Joint supervision and or mentoring</td>
<td>Clinic provides technical support to CBO</td>
<td>Ensuring that all activities are carried out Supervision reports</td>
</tr>
</tbody>
</table>

“Initially it didn’t work due to different understandings, so we set-up a joint bank account, which improved the relationship and partnership.”

- Health provider, Zambia
KEY MESSAGES AND LESSONS:

- Prior to formalising the partnership, conduct a systematic mapping exercise to ensure optimal selection of clinic – CBO partners
- Formalise the C³ partnership with a clear MoU or agreement that provides terms of reference, roles, responsibilities and lines of accountability
- Jointly develop an implementation plan with established indicators
- Establish clearly defined monitoring and reporting mechanisms
- Integrate joint implementation plans into both clinic and CBO operational work plans
- Integrate C³ principles as a key strategy and way of working
- Promote mutual respect and undertake activities that build and maintain partnership
- Agree upon and implement arrangements and structure from the onset that facilitate scheduled meetings and communication
- Undertake regular monitoring, reporting, review and planning sessions together
- Measure and report against relationship-building and active working together
- Involve and secure buy-in from key stakeholders and gate keepers
- Secure technical support and capacity building for planning, coordination and evaluation
- Establish forums for dialogue and joint team building to address power differentials and manage conflict
- Secure district level coordination and responsibility for ongoing sustainability
- Facilitate ongoing learning forums that contribute toward building C³ evidence and regional collaboration

“To sustain our partnership we need to keep working on it to iron out some things, including continual negotiation when partners diverge from the existing MoU.”

- CBO partner, Malawi
How to build and drive C³ as a learning network and community of practice

What process, people and context builds the work clinics and CBOs do together

What process, people and context breaks down the work clinics and CBOs do together

How to optimise the value of the C³ partnership

How to build C³ accountability and leadership
The bigger picture – C³ sustainability

Taking the learnings from C³ forward in a sustainable way will require an approach that it is grounded in district-level planning, human and financial resource allocation, implementation and evaluation. Across all contexts where C³ is being implemented, more needs to be done to ensure that leadership within the health system and community work together to plan and deliver service in a coordinated and collaborative manner. A favourable and supportive national and district policy environment is needed for global directives to be translated into operational plans that are resourced and equipped to measure and report on community engagement. Community engagement must be informed by local information and data to ensure that resources and collaboration is leveraged to scale up quality services where most needed and impactful.

C³ plays a central role in creating a growing community of practice with clinic-CBO collaboration becoming an important entry point and methodology in community engagement.

KEY MESSAGES AND LESSONS:

- Involvement of external partners for technical assistance, training and linkage to opportunities
- Joint fundraising and mobilising of resources
- Defining clear roles and responsibilities from the onset and holding each other accountable
- Integration into district-level planning and financing
- Investments and resource to be allocated to both project areas (e.g. PMTCT, male involvement etc) as well as ongoing partnership building (planning, meetings etc)
- Be committed to continuous review, learning and implementation of lessons
- Create a C³ learning and networking platform
- Sharing best practices as documented in the C³ Toolkit and expand clinic-CBO collaboration initiatives
- Undertake operational research to generate more evidence on the impact of clinic-CBO collaboration
“What we will do differently going forward is increased lobbying and advocacy with the DMO (District Medical Officer) to ensure that demand is created in the community and to ensure that the demand can be met by the clinic.”
- Health provider, DRC

“C3 has really added value in strengthening community clinic collaborations and we will continue to strengthen this after the Summit”
- Health provider, Zambia

“We invested more on the project and not the relationship. Going forward we will pay more attention to the relationship as well as reviewing our shared objectives and activities”
- Health provider, Cameroon

“Going forward it is important to have open communication and continuous involvement of all stakeholders”
- CBO partner, Uganda

“C3 provided the opportunity where we never thought that young people would come forward and declare their status, and that health providers would provide opportunity to reach out more and be more engaged and active in the community”.
- CBO partner, Nigeria
Summit evaluation

The Summit received positive evaluative feedback from participants. All respondents agreed that the plenary presentations shared relevant and useful information and the Summit highlighted both the successes and challenges of their C³ partnership. The workshop formats provided an interactive space to share lessons and experiences across different countries. The summit evaluation shows that participants found the sharing of local lessons and experiences as a valuable contribution to improving and formalising relationships based on a central C³ methodology moving forward.

- Learning from other partner’s experiences
- Inputs from different presenters, sharing of experiences, both successes and challenges
- Partnership strengthening
- Meeting other C³ partners and networking across countries and regions
- Innovative methodology such as poster sharing and the world café process
- Combination of plenary and workshop sessions
- Consultation and contributing into the development of a Toolkit

“The group sessions were very useful because it involved discussions and lots of interactions.”

- Health provider, Nigeria

![Survey Results](image-url)
Certificates of Attendance

All participating health facility- and CBO representatives received certificates of attendance for engaging and providing frontline experiences from the C³ programme. Certificates were delivered by PATA's Lebogang Montewa and PACF’s Carly Davies.
Participant feedback

“C³ is good tool to do community work especially in involving communities.”
- Health provider, Ethiopia

“I appreciate the collaboration between the CBO and the clinic and I thank PATA and PACF for making it possible for us to share with other countries.”
- CBO partner, Zambia

“Ways of strengthening partnerships was the reality that most partnerships needed.”
- CBO partner, Kenya

“Thanks for the teamwork spirit, together we can have a HIV free generation.”
- CBO partner, Uganda

“I have learnt that neither the CBO nor the clinic owns the C³ programme and that only partnership and effective communication helps in achieving good results”
- Health provider, Zimbabwe

“We always thank PATA and PACF for building our capacity to work together to end paediatric AIDS and for the opportunity to visit another country and experience regional networking”
- CBO partner, Malawi

The C³ summit was a great learning platform. Thank you for bringing the part about “the good, the bad and the ugly” it provided opportunity to learn from mistakes.
- Health provider, Kenya

“‘We always thank PATA and PACF for building our capacity to work together to end paediatric AIDS and for the opportunity to visit another country and experience regional networking’”
- CBO partner, Malawi
In Conclusion – the value of clinic-CBO collaboration

Collaborations between community and clinics, with clinic-CBO partnerships being the key entry point across C3-generated rich and diverse insights and learnings that will directly contribute to achieving improved community engagement in support of reaching the UNAIDS Fast Track targets. With stronger evidence from an emerging community of practice, together with implementing the toolkit, PATA and partners will be in a stronger position to advocate that additional capacity and investments are needed to strengthen clinic-community collaboration for improved access and retention along the PMTCT and paediatric HIV treatment cascade.

<table>
<thead>
<tr>
<th>DOMAIN</th>
<th>STRATEGIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service demand mobilisation</td>
<td>Leaders and peer support counselling, sociocounse etc</td>
</tr>
<tr>
<td></td>
<td>Education and awareness</td>
</tr>
<tr>
<td></td>
<td>Demand creation</td>
</tr>
<tr>
<td></td>
<td>Community HCT</td>
</tr>
<tr>
<td>Community sensitisation</td>
<td>Break down socio-cultural barriers</td>
</tr>
<tr>
<td></td>
<td>Combat stigma &amp; discrimination</td>
</tr>
<tr>
<td></td>
<td>Promote male involvement</td>
</tr>
<tr>
<td></td>
<td>Engage community &amp; religious leaders</td>
</tr>
<tr>
<td></td>
<td>Campaigns, sporting events, meetings, champions</td>
</tr>
<tr>
<td>Active patient outreach</td>
<td>Tracking &amp; follow-up</td>
</tr>
<tr>
<td></td>
<td>Home visits</td>
</tr>
<tr>
<td></td>
<td>Community case management</td>
</tr>
<tr>
<td>Treatment, care and support</td>
<td>Peer support groups</td>
</tr>
<tr>
<td></td>
<td>Peer counselling</td>
</tr>
<tr>
<td></td>
<td>Food assistance</td>
</tr>
<tr>
<td></td>
<td>Transport support</td>
</tr>
<tr>
<td></td>
<td>Income generation</td>
</tr>
<tr>
<td>Enabling facility environment</td>
<td>Clinic service times &amp; space</td>
</tr>
<tr>
<td></td>
<td>Privacy</td>
</tr>
<tr>
<td></td>
<td>Sensitized health workers</td>
</tr>
</tbody>
</table>
Clinic-CBO linkages are feasible, accepted by both clinics and CBOs and can result in joint ventures that can positively impact services. Clinic-CBO linkages have a tangible impact on patient outcomes. Various entry points to find, test, link and support retention are created through clinic-CBO collaboration. Community remains a key agent for mobilising access and linkage to services. Clinic-CBO collaboration and joint activation works best in the key domains of service mobilisation (education and awareness, demand creation, community HCT, health days), community sensitisation (breaking down socio-cultural barriers, combatting stigma and discrimination, engaging leaders), active patient outreach (tracking and following up, home visits etc), treatment, care and support (peer support, mobile services, community ART, counselling, transport and food assistance, income generation and VSLA) and creating an enabling environment (clinic times, well trained and sensitised staff etc).

Clinics and CBOs have different workspaces, responsibilities and accountability structures but have similar goals and interests – working together can make both stronger. Community engagement and clinic-CBO collaboration is context specific – one size does not fit all. Clinic-CBO collaboration must be rooted in district planning, resourcing and coordination. Joint planning and shared accountability is key. Processors and mechanisms with checks and balances to support teamwork must be adopted and integrated into operations. Clinic – CBO collaboration is about a plan (what is done together) and a relationship (how it is done together).

“From the start, when we first started conceptualising C3, I always thought of language. We are rethinking our health response, thinking about where our health systems are weak. Community workers are our extension into the community, where we don’t have doctors or nurses... I hope that clinicians can see that community workers can help facilitate your work. C3 is about us working together to create a new language in our local health responses, and get rid of this distinction around ‘your responsibility, my responsibility’. There’s only ‘our responsibility’.”

- Dominic Kemps, PACF
PATA believes in the principle of developing sustainable interventions that are integrated with the work of government, civil society and other stakeholders. PATA works to extend the horizons of care for each of its affiliated health facility teams by encouraging information sharing and support through monthly forums, extensive programming, and vibrant network communication platforms. These activities and channels enable PATA health facility teams to share learning, experiences and promising practices to improve the treatment and care they are able to provide for children and adolescents living with HIV. PATA supports health facility teams to reach out to neighbouring clinics and other partners to improve quality of care and extend the ‘PATA effect’ through leadership and mentoring.

For more information about PATA, and to subscribe to the PATA newsletter, please visit our website www.teampata.org or contact the PATA Secretariat, Building 20, Suite 205, 5A, Waverly Business Park, Wyecroft Rd, Mowbray, South Africa. Tel: +27 21 447 9566 Fax: +27 86 619 1623 Email: info@teampata.org

Resources & links

- UNICEF (2015) Community-Facility Linkages to Support the Scale Up of Lifelong Treatment for Pregnant and Breastfeeding Women Living With HIV
- UNAIDS and STOP AIDS ALLIANCE (2015) Communities Deliver. The critical role of communities in reaching global targets to end the AIDS epidemic
Annex 1: Summit programme

**DAY 1: Monday 5 December 2016: Coordinated action for improved case finding and linkage to care**

06:00 – 08:15  **BREAKFAST**  
Hotel restaurant

08:30 – 10:15  **Opening session: Chaired by Dominic Kemps, PACF (United Kingdom)**  
*Victoria Hall*

Welcome: Dr Cordelia Katureebe-Mboijana, Ugandan Ministry of Health (Uganda)

Summit overview: Luann Hatane, PATA (South Africa)

90:90:90 for children and adolescents – a global clinical and community perspective:  
Progress and barriers: Dr Adeodata Akekitiinwa, Baylor College of Medicine Children’s Foundation-Uganda (Uganda)

Project ACCLAIM: Community approaches towards access, uptake and retention in the MCH/PMTCT cascade: Dephin Mpofu, EGPAF (Swaziland)

10:15 – 10:45  **TEA**

10:45 – 12:00  **Workshop 1: The good the bad and the ugly – reflections on C³**  
*Clinic representatives to Victoria Annex & Pearl Hall*  
*CBO representatives to Grill Room*

12:00 – 13:00  **LUNCH**  
Hotel restaurant

13:00 – 14:00  **Clinic-community conversations: Chaired by Tanya Jacobs, PATA (South Africa)**  
*Victoria Hall*

14:00 – 16:00  **Workshop 2: C³ World Café of C³ projects**  
*Malawi, Zambia and Zimbabwe to Victoria Annex*  
*Ethiopia, Kenya and Uganda to Pearl Hall*  
*Cameroon, DRC and Nigeria to Grill Room*

16:30  **TEA AND GROUP PHOTOGRAPH**

18:30 – 21:00  **DINNER AT LEISURE**  
Hotel restaurant
DAY 2: Tuesday 6 December 2016: Keeping connected for outreach and support

06:00 – 08:15  BREAKFAST  
Hotel restaurant

08:30 – 10:00  Morning session: Chaired by Lebogang Montewa, PATA (South Africa)  
Victoria Hall

Patient retention in care and treatment: The role of clinic-community partnerships: Asia Mbajja, PINA (Uganda)

Communities taking the lead to improve paediatric HIV care: Merian Natukwatsa Musinguzi, ICCO Cooperation and Stop AIDS NOW (Uganda)

C³ partnership spotlight: Chazanga Clinic and Kabangwe Creative Initiative Association (Zambia)

10:00 – 10:30  TEA

10:30 – 12:30  Workshop 3: Critical connections – whirlpool of C³ projects  
Victoria Hall

12:30 – 13:30  LUNCH  
Hotel restaurant

13:30 – 14:45  Workshop 4: Talking is tough – communication in partnership  
Malawi, Zambia and Zimbabwe to Victoria Annex  
Ethiopia, Kenya and Uganda to Pearl Hall  
Cameroon, DRC and Nigeria to Grill Room

14:45 – 15:45  Workshop 5: Meeting in the middle – formalizing partnership  
Malawi, Zambia and Zimbabwe to Victoria Annex  
Ethiopia, Kenya and Uganda to Pearl Hall  
Cameroon, DRC and Nigeria to Grill Room

15:45 – 16:00  TEA

16:00 – 16:30  Closing activity: Creating connections  
Victoria Hall

18:30 – 21:00  PATA Gala Dinner, with special performance by PINA  
Hotel restaurant
## DAY 3: Wednesday 7 December 2016: Creating the context for an enabling environment

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
</table>
| 06:00 – 08:15 | **BREAKFAST**  
                Hotel restaurant                                                  |
| 08:30 – 09:15 | **Morning session: Chaired by Dr Daniella Mark, PATA (South Africa)**  
                Victoria Hall  
                Lessons learned from EngenderHealth’s work in strengthening facility-community linkages – creating an enabling clinic, community and care environment: Molly Tumusiime, EngenderHealth (Uganda)  
                Youth-friendly service for young positive parents: Jacquelyne Alesi, UNYPA (Uganda) |
| 09:15 – 10:30 | **Workshop 6: Building our toolkit**  
                2014 launch countries (Ethiopia, Malawi and Nigeria) to Victoria Annex  
                2015 launch countries (Cameroon, Uganda and Zambia) to Pearl Hall  
                2016 launch countries (DRC, Kenya and Zimbabwe) to Grill Room |
| 10:30 – 11:00 | **TEA**                                                               |
| 11:00 – 13:00 | **Workshop 7: The bigger picture – strategies for sustainability**  
                2014 launch countries (Ethiopia, Malawi and Nigeria) to Victoria Annex  
                2015 launch countries (Cameroon, Uganda and Zambia) to Pearl Hall  
                2016 launch countries (DRC, Kenya and Zimbabwe) to Grill Room |
| 13:00 – 14:00 | **LUNCH**                                                             |
| 14:00 – 16:30 | **Formal closure and way forward**                                    |
### Annex 2: C³ Joint Activation Projects

<table>
<thead>
<tr>
<th>CLINIC &amp; CBO</th>
<th>PROJECT TITLE &amp; AIM</th>
<th>PROJECT DESCRIPTION</th>
<th>ACHIEVEMENTS OF THE COLLABORATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>St Gabriel Catholic Health Centre and CAPOD</td>
<td>Enhancing Community Clinic Linkage (ECCH)</td>
<td>To create functional clinic-community referral linkages and feedback mechanisms to enhance PMTCT uptake and reduce LTFU through community outreach campaign.</td>
<td>Following the campaigns, the ECCH collaboration reported a 10% increase in community mobilisation and ANC uptake. No defaulters were reported during this period. Of the 435 clients who tested during the community HTC Campaign, five tested positive and were successfully linked to the health facility.</td>
</tr>
<tr>
<td>Selam Health Centre and National Network of Positive Women (NLKN-Neqem Lela Ken Kew)</td>
<td>Neqem Selam Tinerat/ Tomorrow, Peace &amp; Network</td>
<td>To increase uptake of PMTCT and expand Paediatric HIV services at Selam health centre by strengthening counselling services through refresher trainings for volunteers and HC professionals.</td>
<td>The number of HIV+ Pregnant mothers initiated on ART and clients accessing HTC services were reported to have doubled. Mom to mom discussion groups were initiated and 40 moms participated and delivered in health centres.</td>
</tr>
<tr>
<td>Karola Medium Clinic and Walta Mothers and children Health Care Organization</td>
<td>The WAKA Partnership Project</td>
<td>To increase the number of new HIV+ pregnant mothers utilising and retained in ANC services by training health education workers, instituting monthly service meetings and establishing joint platforms with support group leaders and the local DOH.</td>
<td>Six health extension workers were trained on effective and continuous referral linkage systems and 5460 mothers/adolescents were reached through the joint platforms.</td>
</tr>
<tr>
<td>Mekdim Ethiopia National Association Clinic and Addis Ababa Network of PLHIV’s Association (ANOPA+)</td>
<td>C³ Innovative Project at Arada Sub City</td>
<td>To strengthen clinic CBO referral linkage by promoting community dialogues for male involvement, couple testing, and retention.</td>
<td>Four volunteers and 2 healthcare workers were trained on standard paper referral system and through these healthcare workers, 80 HIV positive pregnant Mothers and their partners were referred</td>
</tr>
<tr>
<td>SRGDI-Chikowa Health Centre</td>
<td>Chikowa HTC Partnership Project (CHPP)</td>
<td>To increase access to HTC through recruiting and training two additional counsellors from the community.</td>
<td>Two additional counsellors were trained. The number of hours for HTC services were extended from morning to include afternoons with HCT being offered over five days versus three days. The number of HTC services were reported to have doubled following the intervention.</td>
</tr>
<tr>
<td>Project Child Malawi-Makhetha Clinic</td>
<td>The Impact of Collaboration in Promoting PMTCT</td>
<td>Employing certified HTC counsellors in order to increase the number of pregnant women accessing HTC services.</td>
<td>Following the hiring of HTC Counsellors, the facility reported an increase in the number of exposed infants tested.</td>
</tr>
<tr>
<td>SEEED Malawi-Malukula Health Centre</td>
<td>Malukula PMTCT Male involvement Project</td>
<td>To increase male participation in PMTCT and paediatric HIV care from three couples to six couples per week through community sensitisation campaigns on male participation in PMTCT and recruitment of male champions.</td>
<td>Two of the villages benefitted from 3 Community sensitisation campaigns and 1 community male champions was identified to advocate on PMTCT resulting in increased number of men escorting spouses/partners to ANC visits.</td>
</tr>
<tr>
<td>Youth Impact Malawi-Machinga Health Centre</td>
<td>Enhancing Male Involvement in PMTCT</td>
<td>To decrease LTFU through partner/male involvement in PMTCT through advocacy meetings on male involvement on PMTCT targeting local and religious leaders.</td>
<td>As a result of men being involved in PMTCT with their partners, the number of women reported as LTFU decreased from 18 to zero.</td>
</tr>
<tr>
<td>Victorian Clarion Foundation (VICLAF) / Referral Health Centre Ozubulu</td>
<td>Community Health Facility Referral &amp; Linkages Strengthening (CHERLES)</td>
<td>To improve health facility and community linkage in Ozubulu state through instituting a strong referral system and increased community sensitisation.</td>
<td>Through the community sensitisation intervention, 80 people were reached and 117 pregnant women were referred for ANC services through the referral system.</td>
</tr>
<tr>
<td>Widows and Orphans Empowerment Organization (WEWE) / Abia specialist hospital</td>
<td>Strengthening collaboration between WEWE, GH</td>
<td>To strengthen referrals for testing, enrolment and retention of HIV positive pregnant women, infants and children through advocacy outreach campaign.</td>
<td>The number of pregnant women that tested positive and were initiated on PMTCT/ART at clinic increased from three to six.</td>
</tr>
</tbody>
</table>

- Community mobilisation
- Enabling environment
- Active patient outreach
- Service demand mobilisation
<table>
<thead>
<tr>
<th>Women’s Rights and Health Project (WRAHP) / Primary Health Clinic Uromi</th>
<th>Strengthening local response to loss to follow up.</th>
<th>The project addresses loss to follow up in the PMTCT service delivery associated with traditional beliefs of health workers and the community through community outreach campaigns.</th>
<th>Hundred and fifty community members benefitted from two community sensitisation meetings. However, despite this intervention, the number of women initiated on PMTCT decreased by 37.5%.</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Saharan Development Organization SSDOI / Uzodimma maternity</td>
<td>Strengthening two-way referral of PMTCT cases to ensure retention in care</td>
<td>The project was designed to create a referral tracking system for PMTCT uptake by introducing customised documentation.</td>
<td>The number of HIV pregnant or breastfeeding women tracked and initiated on PMTCT/ART was reported to have increased from four to eight.</td>
</tr>
<tr>
<td>Hope and Peace for Humanity and Bobi Health Centre III</td>
<td>Improving retention of mother-baby pairs at Bobi HCIII</td>
<td>The project aimed to increase retention of MBPs from 49% to 80% through combined appointment scheduling for mothers and babies at Bobi Health Centre III.</td>
<td>Ninety three percent of MBPs were retained in care and of the MBPs who had been LTFU, 89% were successfully tracked and brought back to care and supported through regular home visits.</td>
</tr>
<tr>
<td>Kalamba Community Development Centre and Kibibi Nursing Home</td>
<td>Increasing demand for family planning for HIV+ mothers in care</td>
<td>The project is intended to increase the uptake of family planning services by 20% among HIV+ clients by empowering couples to utilize family planning.</td>
<td>Following the intervention, the number of mothers referred from CBO to clinic and accessed family planning services more than tripled (increased from 11 to 47). The clinic adopted Family planning as part of the ART enrolment.</td>
</tr>
<tr>
<td>Karambi Health Centre &amp; Youth Empowering Initiative</td>
<td>&quot;STAY CONNECTED&quot; Project</td>
<td>The project addressed the key challenge of LTFU by strengthening the capacity of volunteers in the community to follow-up through training and instituting home visits as part of follow-up.</td>
<td>Through home visits 29 HIV+ clients who had been LTFU were brought back into care (11 infants and 18 adolescents) and additional 46 siblings of those followed up were tested for HIV.</td>
</tr>
<tr>
<td>Youths and Women in Action (YAWIA) &amp; Sigulu Healthcare Centre III</td>
<td>Addressing Loss to follow up in PMTCT services</td>
<td>Through home visits, the project strengthened the network between the community and the health facility to track HIV+ mothers that had been LTFU.</td>
<td>Though the number of clients LTFU increased from one to seven, the number of women delivering in health facility increased from 49% to 96% following this intervention also contributing to increased number of HIV+ infants enrolled in the clinic for care and treatment by 67% (37 to 53).</td>
</tr>
<tr>
<td>Lolodorf District Hospital and For Impacts in Social health - FIS</td>
<td>&quot;Mamans Lumières&quot; Partnership with Community to increase PMTCT results in Lolodorf health area.</td>
<td>Using home visits, this project focused on strengthening community tracking systems for PLWH to improve retention of women / children and their partners in local PMTCT services by 80%.</td>
<td>The number of HIV+ children initiated on ART increased by 83% (from 3 to 8). Retention was increased to 90% with only 10% LTFU.</td>
</tr>
<tr>
<td>ESSOS Hospital and ACAPFAS</td>
<td>Monitoring and retention of pregnant women and their children exposed through breastfeeding support groups.</td>
<td>The goal is to improve breastfeeding practices of new HIV+ mothers by tracking them telephonically and linking them to breast feeding support groups.</td>
<td>A total of 95 follow up calls were made to HIV+ breastfeeding mothers and 57 were tracked. Ten groups of 30 pregnant women benefitted from best breastfeeding practices support from the breast-feeding support groups.</td>
</tr>
<tr>
<td>Hôpital District de la Cité Verte and Positive Generation</td>
<td>Community engagement for good management in the health district of the city green</td>
<td>To mobilize communities to track a hundred pregnant women through home visits in the district of the green city hospital for initialisation on PMTCT.</td>
<td>Hundred home visits were effectively carried out in the community and 242 patients that were lost to follow up were reached. Fifty-two HIV+ pregnant women and 13 children were followed up by call or SMS and enrolled into ART.</td>
</tr>
<tr>
<td>Zoetele District Hospital and Mengbwa: Actions Jeunes (MAJE)</td>
<td>Facilitating Youth Engagement / adolescents in the use of PMTCT services Zoetele District Hospital</td>
<td>This project seeks to increase HIV knowledge and perceptions of post-natal youth /adolescent involvement in sexual and reproductive rights using performing arts as a tool to deliver the message.</td>
<td>Four theatre performance pieces reached secondary schools and 4010 adolescents benefited from these theatre performances.</td>
</tr>
</tbody>
</table>

- **Community mobilisation**
- **Enabling environment**
- **Active patient outreach**
- **Service demand mobilisation**
<table>
<thead>
<tr>
<th>CLINIC &amp; CBO</th>
<th>PROJECT TITLE &amp; AIM</th>
<th>PROJECT DESCRIPTION</th>
<th>ACHIEVEMENTS OF THE COLLABORATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chazanga Clinic and Kabangwe Creative Initiative Association</td>
<td>Beyond ANC Horizons</td>
<td>This project aimed to improve retention of HIV+ pregnant mothers in care and support through informal HIV discussions support groups and incorporating saving schemes as a retention strategy.</td>
<td>Eighty one percent (n=118) of HIV+ mothers who were traced were returned into HIV care. Forty-three babies born during this period tested negative at 6 weeks and continue to be monitored until 18 months. Nine mothers received birth packs after delivery and 32 mothers were enrolled in the savings club. For groups revolving fund model nine mothers received top up funds of K300 each.</td>
</tr>
<tr>
<td>Chipulukusu Clinic and Mapalot Support Group</td>
<td>Infant Follow-up to Paediatric Care</td>
<td>This partnership aimed to reduce LTFU by tracking exposed infants and their mothers who are LTFU by offering a PMTCT refresher training course to the volunteers to empower them for home visits follow up.</td>
<td>10 volunteers were identified and were provided a two-day refresher course in PMTCT. Peer support groups for HIV+ mothers were established in 12 zones. Sixty-two mothers were enrolled on support groups. Hundred and six out of 136 mothers were referred to the clinic to access PMTCT.</td>
</tr>
<tr>
<td>Chikupi Rural Health Facility and Pride Community Health Organization</td>
<td>Men for Transformation in PMTCT Campaign</td>
<td>The aim of this project was to raise awareness on the need for male involvement and active partipation in ANC, PMTCT and Paediatric HIV Treatment and care through a community led awareness campaign using drama performances, and role plays.</td>
<td>A community sensitisation meeting reached community leaders such as headmen/women, gate keepers, teachers, and religious leaders. Following this intervention an increase in women accessing PMTCT and infants initiating ARVs was reported. Seven infants were initiated on ARV’s and 22 women initiated on PMTCT.</td>
</tr>
<tr>
<td>Ipusukilo Clinic and Prolife Advancement and Education Partners (PLAEP)</td>
<td>Ipusukilo Children Care Project</td>
<td>The project addressed HIV testing and care of HIV+ children, their parents / guardians by creating demand for ART services through community discussions and engagement with various community groups.</td>
<td>The clinic dedicated Wednesday morning for paediatric ART service and 44 infants and adolescents were initiated on treatment and care. However, 6 HIV+ pregnant women initiated on PMTCT were LTFU.</td>
</tr>
<tr>
<td>Hopital General De Reference De Bunyakiri and SACICONGO</td>
<td>Mobilisation of pregnant women for community outreach in Bunyakiri Health Zone</td>
<td>This project aimed to increase the percentage of pregnant women who have access to the PMTCT from 53% to 65% in the Bunyakiri Health Zone through community outreach and home visits.</td>
<td>Seventy-two home visits were conducted and 75% of pregnant women that had been LTFU were successfully tracked. The number of HIV+ infants enrolled in clinic for HIV care and treatment increased from four to nine. However, HIV+ pregnant or breastfeeding women initiated on PMTCT/ ART dropped by 53% (from 15 to 8).</td>
</tr>
<tr>
<td>Nundu General Referral Hospital and EPF</td>
<td>Tracking of LTFU pregnant women seen in the Nundu health zone in Fizi territory</td>
<td>The project aimed to reduce the number of pregnant women that were LTFU by 50% by providing a 2 day PMTCT training workshop to 9 women leaders to enable them to do home visits follow up.</td>
<td>A total of 150 pregnant women LTFU were mapped, resulting on 37 being initiated on PMTCT. However, the number of HIV+ infants enrolled for HIV care and treatment decreased by 70% (27 to 19).</td>
</tr>
<tr>
<td>Kampemba hospital and Troupe des Filles Mères (TFM)</td>
<td>Together against community HIV mother to child transmission</td>
<td>This project was designed to increase community knowledge on the benefits of PMTCT through community awareness campaign so that pregnant and breastfeeding women can utilise ANC services.</td>
<td>At project initiation only 2 HIV+ infants were reported to be enrolled in the clinic for HIV care and treatment. No Progress report regarding intervention outcomes was received despite requests.</td>
</tr>
<tr>
<td>Ruzizi General hospital and ‘MGM’H</td>
<td>MGM partnership -HGR Ruzizi for PMTCT</td>
<td>The project worked towards community sensitisation on discrimination and stigmatization of HIV+ pregnant women, leading to failure to utilize PMTCT services. The campaign target areas were churches, refugee camps and military camps for women.</td>
<td>Three hundred women in the community, refugee and military camps were reached through advocacy meetings. An increase from 44.7% to 64% on the uptake of PMTCT services was noted and no LTFU were reported.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Community mobilisation</th>
<th>Enabling environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active patient outreach</td>
<td>Service demand mobilisation</td>
</tr>
<tr>
<td>CLINIC &amp; CBO</td>
<td>PROJECT TITLE &amp; AIM</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Homa bay teaching and referral hospital &amp; Maisha Development trust</td>
<td>“Sixty to ninety initiative”</td>
</tr>
<tr>
<td>Ambira Sub County hospital &amp; Soteni Village of Hope</td>
<td>“Ambiso”</td>
</tr>
<tr>
<td>Migosi sub county hospital &amp; Kisumu Youth Olympic centre</td>
<td>“Keep me healthy”</td>
</tr>
<tr>
<td>Moise Bridge Medical Centre &amp; Moise Bridge Community Welfare Association</td>
<td>“Joint initiative to improve access to PMTCT in the community”</td>
</tr>
<tr>
<td>Waterfalls Clinic and Chiedza Child Care Center</td>
<td>“THE HUB - Building understanding to embrace peer support in HIV care retention.”</td>
</tr>
<tr>
<td>Maboleni Clinic and Jointed Hands Welfare Organisation.</td>
<td>“Maboleni Accelerated Institutional Delivery Encouragement Initiative (MAIDEI)”</td>
</tr>
<tr>
<td>Morgenster Mission Hospital (MMH) and MACOBAO</td>
<td>“PMTCT and Paediatric ART Services Project”</td>
</tr>
<tr>
<td>Birchenough Bridge Hospital and Rujeko Home Based Care Programme</td>
<td>“RHODE (Reducing Home Deliveries)”</td>
</tr>
</tbody>
</table>
For more information:

Paediatric – Adolescent Treatment Africa
Building 20, Suite 205-5A, Waverley Business Park
Wyecroft Road, Mowbray, Cape Town 7705
Telephone: +27 21 447 9566
Email: info@teampata.org
Website: www.teampata.org
Twitter: @teampata
Facebook: Paediatric – Adolescent Treatment Africa

The PATA – C³ Summit was kindly supported by:

[Logos for supporting organizations]