ACCELERATING CHILDREN’S HIV/AIDS TREATMENT

PROMISING PRACTICES AND LESSONS LEARNED FROM IMPLEMENTATION OF THE ACT INITIATIVE

APRIL 2017
This report shares ACT’s legacy – an unparalleled wealth of experiences, lessons and insights.
ACCELERATING CHILDREN’S HIV/AIDS TREATMENT

FOREWORD

Children living with HIV are far more than statistics. They are young lives, hopes and prospects. Each is an important part of a family, a community, a country.

We know that, with antiretroviral therapy (ART), people living with HIV can have full and productive lives. Yet, back in 2014, children’s access to these life-saving drugs was limited. Only 44% of those in need were receiving treatment worldwide.

This situation reflected major challenges in pediatric HIV. These included how to find children who had been exposed to HIV, how to give them access to a test and how to support them to start and keep taking effective treatment. There were also particular challenges for children as they got older—in terms of juggling their HIV-positive status and treatment needs with the pressures of adolescence.

The ‘treatment gap’ for children was unacceptable. Something had to be done. Something that would go beyond business as usual and bring a new sense of urgency, focus and determination.

In response, PEPFAR and CIFF came together to launch the Accelerating Children’s HIV/AIDS Treatment (ACT) Initiative. This public-private partnership represented an unprecedented investment of resources, expertise and energy. It was designed to, in just two years, achieve a shift in the landscape for pediatric HIV. Working in nine priority African countries, it aimed to initiate an additional 300,000 children living with HIV on ART.

ACT was not just about saving lives in the present. It was also about strengthening the health systems and platforms needed to achieve lasting change, continuing to save lives in the future. Investing in children is not only the right thing to do, it is the smart thing.

ACT engaged a diversity of implementing partners who used creative strategies to reach and retain children living with HIV. These were informed by national policies and common challenges along the HIV care and treatment cascade, while being tailor-made to the specific needs of children and adolescents. By September 2016, 561,610 children were accessing treatment in the nine countries.

ACT did not function in isolation. It was conceived within “The Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive”, which saw a 60% reduction in new HIV infections among children in 21 sub-Saharan African priority countries. Now, the Initiative’s results are key to Start Free, Stay Free, AIDS Free—a super fast-track approach to ending AIDS among children, adolescents and young women, with goals for 2018 and 2020. The framework is based on the fundamental principle that everyone living with HIV should have access to ART.

PEPFAR and CIFF are committed to controlling and ultimately ending the AIDS epidemic. ACT was a major step in that direction. However, the work must continue.

This report shares ACT’s legacy—an unparalleled wealth of experiences, lessons and insights. It shows how obstacles can be overcome, innovations developed and progress made. It is a testimony to the remarkable people, organizations and institutions involved, who refuse to give up on children living with HIV.

This report shows how, by working together, we can and will change the future of pediatric HIV.

Ambassador Deborah Birx, U.S. Global AIDS Coordinator and Special Representative for Global Health Diplomacy

Kate Hampton, Chief Executive Officer, CIFF
PARTICULAR THANKS ARE GIVEN TO:

- The governments and ministries of health in ACT countries – namely, Cameroon, Democratic Republic of Congo, Kenya, Lesotho, Malawi, Mozambique, Tanzania, Zambia, and Zimbabwe.

- The implementing partners in ACT countries, including those that responded to the call for inputs to inform this report. (See Annex 1 for a full list of ACT implementing partners.)

- All individuals, organizations, and stakeholder groups involved in the initiative within facilities and communities in the ACT countries – health care workers, community health workers, peer educators, community-based organizations, community leaders, and parents and caregivers.

- U.S. government agencies (the U.S. Centers for Disease Control and Prevention, U.S. Department of Defense, Peace Corps, and United States Agency for International Development) and PEPFAR country teams in the ACT countries.
ACRONYMS

ACT: Accelerating Children’s HIV/AIDS Treatment
AGPAHI: Ariel Glaser Pediatric AIDS Healthcare Initiative
AMPATH Plus: Academic Model Providing Access to Healthcare
AMURT: Ananda Marga Universal Relief Team
ANC: antenatal care
APOC: adolescent package of care
ART: antiretroviral therapy
ARV: antiretroviral
CATS: Community Adolescent Treatment Supporter
CBCHS: Cameroon Baptist Convention Health Services
CCS: Centro de Colaboração em Saúde
CDC: United States Centers for Disease Control and Prevention
CHAK: Christian Health Association of Kenya
CHASS: Clinical and Community HIV/AIDS Services Strengthening
CIFF: Children’s Investment Fund Foundation
COE: Centers of Excellence (University of Nairobi)
DBS: dried blood spot
DRC: Democratic Republic of Congo
EGPAF: Elizabeth Glaser Pediatric AIDS Foundation
EID: early infant HIV diagnosis
FACES: Family AIDS Care and Education Services
FGH: Friends in Global Health
FHI: Family Health International
Global Plan: The Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive
HDA: HIV Diagnostic Assistant
HPP: Health Policy Project
HTC: HIV testing and counseling
ICAP: International Center for AIDS Care and Treatment Programs
KARP: Kenya AIDS Response Program
KCCB: Kenya Conference of Catholic Bishops
MDH: Management and Development for Health
MSH: Management Sciences for Health
NACP: National AIDS Control Program
NASCOP: National AIDS and STI Control Program
OVC: orphans and vulnerable children
PCR: polymerase chain reaction
PEPFAR: United States President’s Emergency Plan for AIDS Relief
PITC: provider-initiated testing and counseling
PMTCT: prevention of mother-to-child transmission of HIV
PTA: Pediatric Technical Advisor
RRI: Rapid Results Initiative
SRHR: sexual and reproductive health and rights
TB: tuberculosis
THPS: Tanzania Health Promotion Support
TICoT: Tanzania Initiative to Accelerate Children on Treatment
UCSF: University of California at San Francisco
UNAIDS: The Joint United Nations Programme on HIV and AIDS
UNICEF: United Nations Children’s Fund
URC: University Research Company
USAID: United States Agency for International Development
WHO: World Health Organization
ZPCT: Zambia Prevention, Care, and Treatment
We can and will change the future of pediatric HIV
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ACT was supporting 561,610 children living with HIV with access to high-quality treatment.
This report shares the promising practices and lessons learned from the Accelerating Children’s HIV/AIDS Treatment (ACT) Initiative. It was informed by a call for inputs, issued to more than 100 implementing partners in nine countries. The report is for local, national, regional, and global stakeholders interested in the design, implementation, funding, and sustainability of HIV care and treatment for children. It can be used in the countries involved in ACT and beyond.

ACT was a concerted, strategic, and ambitious response to the treatment gap among children with HIV. In the absence of antiretroviral therapy (ART), 50% of children living with HIV die before their second birthday, and 80% die before their fifth birthday. Early initiation of treatment is known to significantly lower mortality among children. Yet, as of 2014, of the estimated 1.9 million children living with HIV worldwide, fewer than half (44%) were receiving ART. The majority of those children were in sub-Saharan Africa.

The two-year ACT Initiative was launched at the Africa Leaders Summit in August 2014. It aimed to initiate an additional 300,000 children living with HIV on life-saving treatment in priority countries in Africa. ACT was a $200 million public-private partnership that brought together the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) and the Children’s Investment Fund Foundation (CIFF), which committed $150 million and $50 million, respectively. ACT was implemented in nine PEPFAR-supported countries in Africa: Cameroon, the Democratic Republic of Congo (DRC), Kenya, Lesotho, Malawi, Mozambique, Tanzania, Zambia, and Zimbabwe. CIFF’s focus countries were Kenya, Malawi, Tanzania, and Zimbabwe.

In 2014/15, the first year of ACT, ART coverage for children under 15 years of age rose in all nine countries. Increases of more than 10% were seen in Kenya, Lesotho, Malawi, Tanzania, Zambia, and Zimbabwe. Coverage in Zimbabwe reached 80%, compared with 49% coverage globally.

As of September 2016, the end of its two-year program, ACT was supporting 561,610 children (19 years or under) living with HIV with access to high-quality treatment. Between 2014 and 2016, the number of children under 15 years receiving treatment with support from PEPFAR and CIFF increased by 44% across the nine countries. As of September 2016, the ACT initiative had also enabled 16,431,861 children (19 years or under) to have an HIV test, with 468,149 found HIV-positive.

As a public-private partnership, ACT combined a unique pool of resources and technical expertise to achieve greater efficiencies, leading to these combined results. Each organization brought value and comparative advantages to the partnership. PEPFAR and CIFF shared a focus on transparency, accountability, innovation, and scale, working closely in joint planning and the review of program
results. In many cases, PEPFAR and CIFF funded the same implementing partners. ACT showed the power of public-private partnerships and how increased focus and attention can lead to tremendous impact in just two years.

ACT was designed to contribute to global frameworks for health, development, and HIV – notably, the Sustainable Development Goals\(^3\) and the 90-90-90 HIV treatment targets\(^4\). It was developed within the closing phases of “The Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive” (Global Plan)\(^5\), which saw a 60% reduction in new HIV infections among children in 21 sub-Saharan African priority countries. ACT was also key to the 2016 launch of Start Free, Stay Free, AIDS Free. This new global framework, led by PEPFAR and the Joint United Nations Programme on HIV and AIDS (UNAIDS), represents a super-fast-track approach to the scale-up of HIV prevention, treatment, care, and support for children, adolescents, and young women.
EXECUTIVE SUMMARY

ACT’s PROMISING PRACTICES

ACT was designed around seven programmatic pillars that represent the components of a comprehensive, sustainable response to pediatric HIV care and treatment. The pillars are informed by bottlenecks along the care and treatment cascade. This report uses ACT’s seven pillars to illustrate the initiative’s promising practices:

PILLAR 1: POLICY FOR PEDIATRIC HIV SERVICES

Supported countries in strengthening the national strategies, plans, and standards needed to provide a strong framework and leadership for an effective response to pediatric HIV. ACT’s promising practices addressed the following:

a. Strengthening national strategies and policies for children’s HIV care and treatment
b. Ensuring well-coordinated and multisectoral national responses to pediatric HIV
c. Adapting national human resource policies to support pediatric HIV
d. Developing national standards of care and treatment for children living with HIV

PILLAR 2: COMMUNITY ENGAGEMENT

Ensured that community stakeholders were meaningfully involved, deployed, and respected within all relevant aspects of ACT’s work—from the design of programs to the delivery of services and the monitoring of results. This included stakeholders such as children and adolescents living with HIV; parents, caregivers, and family members; community health workers; peer educators; community-based organizations; and community leaders. ACT’s promising practices addressed the following:

a. Raising awareness and mobilizing communities about HIV care and treatment for children
b. Engaging community leaders and local gatekeepers on pediatric HIV
c. Deploying community health workers to provide HIV care and treatment for children
d. Maximizing peer-based approaches for children’s HIV care and treatment
e. Engaging communities in quality improvement for pediatric HIV

PILLAR 3: HIV CASE IDENTIFICATION

Devised and implemented the strategies needed to systematically identify and target children exposed to HIV, provide them with high-quality HIV testing, and confirm their HIV status. ACT’s promising practices addressed the following:

a. Using systematic strategies to find and test children exposed to HIV
b. Strengthening human resource cadres for HIV case finding among children
c. Strengthening laboratory/commodities support for HIV testing and treatment for children
d. Improving the quality and efficiency of HIV case finding among children
EXECUTIVE SUMMARY

PILLAR 4: LINKAGE TO HIV CARE AND TREATMENT SERVICES

Ensured that, once their status was known, children living with HIV were efficiently and effectively connected to the HIV care and treatment services needed. This required strong links between HIV testing and counseling and ART services, as well as coordination with wider support services for children’s and adolescents’ health and well-being, such as nutrition, social welfare, and sexual and reproductive health and rights (SRHR). ACT’s promising practices addressed the following:

a. Strengthening referral systems for HIV care and treatment for children
b. Involving volunteers and peers in linking children testing HIV-positive with care and treatment
c. Deploying specialized human resources to link children to HIV care and treatment

PILLAR 5: HIV TREATMENT INITIATION, MONITORING, ADHERENCE, AND RETENTION

Ensured that, once identified as HIV-positive and linked to care and treatment, children received the comprehensive, high-quality services needed to successfully start and adhere to ART. This, in turn, helped them achieve and maintain viral suppression. It involved a continuum of support and services provided within facilities and communities. ACT’s promising practices addressed the following:

a. Implementing tailored models of care and treatment for children living with HIV
b. Strengthening human resources to support children accessing HIV care and treatment
c. Ensuring community-based support for children living with HIV
d. Strengthening case management for children living with HIV
e. Addressing gaps in the pediatric HIV care and treatment cascade

PILLAR 6: STRATEGIC INFORMATION FOR PEDIATRIC HIV SERVICES

Ensured that the tools, processes, and systems were in place to collect accurate, useful strategic information about pediatric HIV care and treatment and to apply it to the setting and monitoring of targets and standards. This, in turn, improved the effectiveness and efficiency of interventions. ACT’s promising practices addressed the following:

a. Developing tools to collect and use data on HIV care and treatment for children
b. Improving the quality of strategic information about pediatric HIV

PILLAR 7: DOMESTIC RESOURCE COMMITMENTS FOR PEDIATRIC HIV SERVICES

Supported countries in strengthening the sustainability of ACT’s work and results by increasing the investment of domestic resources in pediatric HIV care and treatment. ACT’s promising practices addressed the following:

a. Analyzing the resource needs for reaching pediatric HIV care and treatment targets
b. Developing innovative financing for pediatric HIV
c. Evaluating the sustainability of investments in children’s HIV care and treatment
ROADMAP FOR FUTURE ACTION

The report concludes that ACT was a concerted and intensive effort to accelerate children’s HIV treatment as never before. During its two years, the initiative produced an unprecedented bank of strategies and experiences, which are essential for building on and sustaining ACT’s results in the countries where it operated and beyond. In combination, ACT’s lessons learned represent a wealth of ideas about success factors, as well as gaps and challenges. The following presents a road map of what works for accelerating pediatric HIV care and treatment, based on the lessons learned.

Roadmap of ‘what works’ for accelerating children’s HIV treatment
EXECUTIVE SUMMARY

1. Partner with government:
Work in partnership with the government and health authorities at all levels to ensure an enabling policy and strategy environment for pediatric HIV care and treatment; the application of high-quality national guidelines and standards; and the implementation of a well-coordinated, multisectoral, sustainable national response.

2. Engage communities:
Ensure the meaningful involvement of parents, caregivers, children, and adolescents living with HIV, from the very start and throughout programs, as essential leaders, implementers, and evaluators of responses to pediatric HIV care and treatment.

3. Collaborate with leaders:
Collaborate with community leaders and local stakeholders (including community health workers), from the very start and throughout programs, as partners in the design, delivery, and monitoring of HIV care and treatment for children.

4. Reach children in need of HIV testing:
Invest in and continually improve systematic ways to identify children exposed to HIV and enable them to have an HIV test. Examples include index/family testing models and provider-initiated testing and counseling (PITC) in priority pediatric services, such as tuberculosis (TB) and malnutrition clinics and inpatient departments.

5. Strengthen the cascade:
Work across facilities and stakeholders to identify and address breaks in the cascade of pediatric HIV care and treatment. This includes ensuring rapid linkage of children testing HIV-positive to care, community-based follow-up of children defaulting on ART appointments, viral load testing, peer-based support for adherence to ART, and intensive counseling on disclosure for adolescents.

6. Tailor packages:
Provide tailored packages of care and treatment for children and adolescents living with HIV, responding to their specific needs. These should address the whole person, combining clinical services with peer and psychosocial support.

7. Support health care workers:
Maximize the role of lay and professional health care workers in pediatric HIV and enable them to build relevant skills and knowledge, combining attention to clinical issues with child/adolescent-friendly ways of working. Support their role through a combination of training and ongoing capacity building, such as through on-the-job mentoring.

8. Strengthen laboratories/commodities:
Collaborate with laboratory and commodity-related personnel and institutions to strengthen the relevant infrastructure and management systems and to avoid delays or breaks in the supply chain for pediatric HIV care and treatment.

9. Use strategic information:
Develop effective tools and systems to collect strategic information on pediatric HIV care and treatment, including data disaggregated by age. Use such information to conduct real-time analyses of results, to identify what is or is not working, and to make prompt changes to programs and resource allocations.

10. Build sustainability:
Apply a holistic approach to sustainability for pediatric HIV care and treatment and work across stakeholder groups to not only mobilize the financial resources required but also maintain strong standards, policies, systems, and services.
ACT was a concerted, strategic, and ambitious response
ACCELERATING CHILDREN’S HIV/AIDS TREATMENT

INTRODUCTION

WHO IS THIS REPORT FOR?

This report shares the promising practices and lessons learned from the ACT Initiative. It was informed by a call for inputs, inviting the over 100 ACT implementing partners in nine countries to contribute their experiences, success factors and challenges.

This report is for local, national, regional, and global stakeholders interested in the design, implementation, funding, and sustainability of HIV care and treatment for children. It can be used in the countries involved in ACT and beyond.

WHAT WAS ACT, AND WHY WAS IT NEEDED?

ACT was a two-year initiative launched at the Africa Leaders Summit in August 2014. It aimed to initiate an additional 300,000 children† living with HIV on life-saving ART in nine priority countries in Africa. The initiative was a $200 million public-private partnership that brought together PEPFAR and CIFF, which committed $150 million and $50 million, respectively.

In the lead-up to 2014, there had been major progress in the global response to HIV. For adults, there was significantly better access to HIV testing and counseling (HTC), antiretroviral drugs (ARVs), and effective prevention for those at risk of exposure to HIV or living with HIV. There had also been unprecedented progress in the prevention of mother-to-child transmission (PMTCT of HIV), reflecting actions by PEPFAR and other key partners under the Global Plan. By the end of 2015, new HIV infections among infants had decreased by 60% in 21 of the most affected countries in Africa.

Although progress was also being seen for children living with HIV, it remained unacceptably slow. Without ART, 50% of children die before their second birthday, and 80% die before their fifth birthday. Early initiation of treatment is known to significantly lower mortality among children living with HIV. Yet, as of 2014, of the estimated 1.9 million such children worldwide, the majority of whom live in sub-Saharan Africa, fewer than half (44%) were receiving ART. In some regions, such as West and Central Africa, access to treatment was substantially lower for children living with HIV than for adults.

Many factors were contributing to this treatment gap for children. The challenges varied from country to country, but often included those listed in Box 1.

ACT was a concerted, strategic, and ambitious response to these challenges.

† Children refers to people age 19 years or under, as defined by the World Health Organization. This includes adolescents (10–19 years).
INTRODUCTION

Box 1: Factors affecting the treatment gap for children living with HIV

- Barriers to identifying children exposed to HIV
- Low availability of appropriate HTC services for children and their families
- Lack of supportive national policies, such as on the age of consent to have an HIV test
- Limited HIV drug options for children
- High loss to follow-up among children living with HIV – for example, due to their poor linkage to care and poor retention on ART
- Limited youth-friendly support for adolescents living with HIV, with them “falling between the gaps” of children’s and adults’ services
- Ongoing stigma related to HIV within families, communities, and health facilities
- Cultural and economic barriers to early care seeking, affecting children’s health outcomes
- Limited guidelines and protocols specific to children living with HIV
- Poor task distribution among health personnel, such as with nurses not able to prescribe ART to children
- Limited capacity, expertise, and confidence among health care workers to support children living with HIV
- Limited availability, ownership, and use of strategic information about children living with HIV, such as data disaggregated by different age groups

WHAT WERE ACT’S RATIONALE AND OBJECTIVES?

The ACT Initiative was designed to catalyze global partners to respond to the challenges in pediatric HIV care and treatment in low-resource settings by targeting technical and financial resources to selected high-burden countries.

Box 2: The rationale for ACT

“Saving the lives of children with HIV is not only the right thing to do; it is the smart thing. By treating children early in their HIV infection, they can stay healthy and thrive. Healthy children who can pursue their dreams will grow economies, create jobs and strengthen their communities for decades to come.” - PEPFAR Annual Report to Congress 2017
INTRODUCTION

ACT aimed to improve access to better treatment formulations and increase domestic investment for pediatric HIV. It would also maximize established ART programs for adults (built on good practices, lessons learned, and strong partnerships) to rapidly and sustainably close the treatment gap for children. This would improve child survival and family health by significantly reducing HIV-related morbidity and mortality.

ACT’s main objective was to initiate an additional 300,000 children living with HIV on high-quality treatment by the end of September 2016. The subobjectives were as follows:

• Increase pediatric HIV case finding by scaling up routine, systematic, and targeted HIV testing for children and adolescents in high-priority settings; expanding the coverage of HIV DNA polymerase chain reaction (PCR) testing; and determining the final HIV status for all HIV-exposed infants, with effective linkage to and initiation of ART.

• Build a health care workforce trained to provide pediatric HIV care and treatment services.

• Provide World Health Organization (WHO)-recommended ART regimens.

• Achieve long-term retention in HIV care and treatment and viral suppression for children, using family- and adolescent-friendly service-delivery models at all levels of the health care system and improving linkages with community systems of support.

• Create an enabling environment for HIV testing, care, and treatment services for infants, children, and adolescents by updating policies and mobilizing and educating communities.

• Plan for continued expansion of pediatric ART services after 2016 using a sustainable planning approach.
INTRODUCTION

**WHAT WERE ACT’S PROGRAMMATIC PILLARS?**

ACT was designed around seven programmatic pillars that represent the components of a comprehensive, sustainable response to pediatric HIV care and treatment (see Figure 1).

*Figure 1: The ACT programmatic pillars*

### ACT’S PROGRAMMATIC PILLARS

<table>
<thead>
<tr>
<th>PILLAR 1: Policy for pediatric HIV services</th>
<th>PILLAR 2: Community engagement</th>
<th>PILLAR 3: HIV case identification</th>
<th>PILLAR 4: Linkage to HIV care and treatment services</th>
<th>PILLAR 5: HIV treatment initiation, monitoring, adherence, and retention</th>
<th>PILLAR 6: Strategic information for pediatric HIV</th>
<th>PILLAR 7: Domestic resource commitment for pediatric HIV services</th>
</tr>
</thead>
</table>

ACT’s pillars were informed by bottlenecks experienced along the pediatric HIV care and treatment cascade (see Figure 2). They served as a common framework across all countries, guiding each program on how to improve and accelerate its action. The pillars were used to structure assessments of gaps and opportunities, identify priorities for ACT country strategies, assess programmatic progress, and identify the changes needed to meet targets. The pillars were not to be considered separate from the integrated health systems already operating within each country.

In its ACT strategy guidance, PEPFAR set out standards, technical activities, and measurable outcomes for each pillar.

The larger context of the programmatic pillars and ACT’s work was as follows:

- To improve integrated platforms of primary care and social services for maternal, newborn, and child populations
- To address the comprehensive needs of vulnerable adolescent populations
- To leverage increased domestic commitments to the health of children and families
Look in the right places for children exposed to HIV
(ACT Pillar 3)

Engage communities to increase interest in and acceptability of HIV testing for children
(ACT Pillar 2)

Track every child living with HIV and link them to treatment
(ACT Pillar 4)

Ensure national ART policies address the specific needs of children and support the early initiation of treatment
(ACT Pillar 1)

Address the specific challenges of retaining adolescents living with HIV in treatment
(ACT Pillar 5)

Actively track program progress and rapidly address gaps
(ACT Pillar 6)

Assess and mobilize domestic resources to sustain progress on pediatric HIV care and treatment
(ACT Pillar 7)

Figure 2: Applying ACT’s pillars to bottlenecks in the pediatric HIV care and treatment cascade
WHERE AND HOW DID ACT OPERATE?

ACT was implemented in nine PEPFAR-supported countries in Africa: Cameroon, DRC, Kenya, Lesotho, Malawi, Mozambique, Tanzania, Zambia, and Zimbabwe. CIFF’s focus countries were Kenya, Malawi, Tanzania and Zimbabwe. Countries were selected based on the following criteria:

• **Lowest coverage of treatment for children in need** – Inadequate coverage leads to high mortality among children living with HIV.

• **Highest burden of pediatric HIV** – Targeting large populations of children living with HIV has the greatest impact on global pediatric treatment coverage.

• **Highest difference between adult and pediatric treatment coverage** – Countries with high adult coverage have shown that they can scale up treatment.

At the global level, the ACT partnership was managed by a joint steering committee, with management and technical staff and consultants from PEPFAR and CIFF. The committee and the implementation of ACT were further supported by technical and program personnel at PEPFAR headquarters in Washington, D.C.

In each country, the PEPFAR country team, working in close collaboration with the national government’s ministry of health, guided the strategy and management of ACT. The work was operationalized by implementing partners – local and international organizations already receiving funding from PEPFAR to provide HIV services. Each country had up to 35 implementing partners, totaling more than 100 across the initiative. All implementing partners reported directly to PEPFAR. The CIFF-supported implementing partners also reported to the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) Lead Implementing Partner Project, contracted by CIFF to support administration and management.
INTRODUCTION

**WHAT DID ACT ACHIEVE?**

In 2014/15, the first year of ACT, ART coverage for children under 15 years of age rose in all nine countries (see Table 1). Increases of more than 10% were seen in Kenya, Lesotho, Malawi, Tanzania, Zambia, and Zimbabwe. Coverage in Zimbabwe reached 80%, compared with 49% coverage globally.

Table 1. ART coverage for children under 15 years in ACT countries (2010-2015)

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
</tr>
</thead>
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<tr>
<td>Cameroon</td>
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<td>10</td>
<td>12</td>
<td>13</td>
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</tr>
</tbody>
</table>

As of September 2016, the end of its two-year program, ACT was supporting 561,610 children living with HIV with access to high-quality treatment in the nine priority countries (see Table 2). Between 2014 and 2016, the number of children under 15 years receiving treatment with support from PEPFAR and CIFF increased by 44% across the nine ACT-supported countries. The initiative also achieved important results in relation to HIV testing for children and the identification of children living with HIV.
INTRODUCTION

Table 2: Key results from the ACT Initiative in nine priority countries in Africa (as of September 2016)

<table>
<thead>
<tr>
<th>INDICATOR</th>
<th>AGE OF CHILDREN</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Under 15 years</td>
</tr>
<tr>
<td>Children living with HIV receiving treatment</td>
<td>352,076</td>
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<tr>
<td>Children testing for HIV</td>
<td>10,067,199</td>
</tr>
<tr>
<td>Children testing for HIV found HIV-positive</td>
<td>241,443</td>
</tr>
</tbody>
</table>

Designed as a public-private partnership, ACT combined a unique pool of resources and technical expertise to achieve greater efficiencies, leading to these combined results. Each organization brought value and comparative advantages to the partnership. PEPFAR and CIFF shared a focus on transparency, accountability, innovation, and scale, working closely in joint planning and review of program results. In many cases, PEPFAR and CIFF funded the same implementing partners. ACT showed the power of public-private partnerships and how increased focus and attention can lead to tremendous impact in just two years.

ACT’s results made a critical contribution to the global frameworks and targets that guide responses to health, HIV, and pediatric care and treatment. These include the 90-90-90 treatment targets and the Start Free, Stay Free, AIDS Free framework.
INTRODUCTION

Box 3: ACT’s contribution to global frameworks, including Start Free, Stay Free, AIDS Free

ACT was conceptualized within the global frameworks for health and development—notably, the Millennium Development Goals and the Sustainable Development Goals. It was also designed to make a strategic contribution to the frameworks for the international response to HIV, including 90-90-90, which is an initiative led by UNAIDS and partners to accelerate the achievement of treatment targets. The aim of 90-90-90 is that, by 2020, 90% of all people living with HIV know their HIV status, 90% of all people with diagnosed HIV infection receive sustained ART, and 90% of all people receiving ART have viral suppression. ACT was developed within the closing phases of the Global Plan. In 2016, it was key to the launch of Start Free, Stay Free, AIDS Free, which represents a global super-fast-track approach to the scale-up of HIV prevention, treatment, care, and support for children, adolescents, and young women. This new program aims to mobilize global momentum around an ambitious agenda, building on existing initiatives, such as ACT. Start Free, Stay Free, AIDS Free is a coalition led by UNAIDS and PEPFAR. Its three core components are supported by agreed goals. For AIDS Free, these include “provide 1.6 million children (0–14 years) and 1.2 million adolescents (15–19) living with HIV with ART by 2018.”

ACT supported nine countries in Africa to make important progress toward the AIDS Free goal—as of September 2016, the end of the ACT Initiative, 561,610 children living with HIV in the nine priority countries were receiving ART.
Figure 3: ACT countries, implementing partners and key results (as of September 2016)

**CAMEROON**
- 7 ACT implementing partners
- 9,548 children receiving ART:
  - 6,043 under 15 years
  - 3,505 aged 15-19 years
- 385,208 children had an HIV test, with 7,277 testing HIV-positive

**DEMOCRATIC REPUBLIC OF CONGO**
- 9 ACT implementing partners
- 5,028 children receiving ART:
  - 3,526 under 15 years
  - 1,502 aged 15-19 years
- 387,817 children had an HIV test, with 5,684 testing HIV-positive

**KENYA**

**TANZANIA**

**MALAWI**

**ZAMBIA**

**ZIMBABWE**

**MOZAMBIQUE**

**LESOTHO**
- 7 ACT implementing partners
- 9,548 children receiving ART:
  - 6,043 under 15 years
  - 3,505 aged 15-19 years
- 385,208 children had an HIV test, with 7,277 testing HIV-positive

**INTRODUCTION**
ZIMBABWE:
- 80,836 children receiving ART:
  - 48,767 under 15 years
  - 32,069 aged 15-19 years
- 278,751 children had an HIV test, with 7,898 testing HIV-positive

MOZAMBIQUE:
- 8 ACT implementing partners
- 75,265 children receiving ART:
  - 55,711 under 15 years
  - 19,554 aged 15-19 years
- 1,099,190 children had an HIV test, with 30,315 testing HIV-positive

KENYA:
- 35 ACT implementing partners
- 115,292 children receiving ART:
  - 81,149 under 15 years
  - 34,143 age 15-19 years
- 6,023,175 children had an HIV test, with 133,330 testing HIV-positive

TANZANIA:
- 8 ACT implementing partners
- 71,736 children receiving ART:
  - 50,891 under 15 years
  - 20,845 aged 15-19 years
- 3,945,614 children had an HIV test, with 83,996 testing HIV-positive

MALAWI:
- 6 ACT implementing partners
- 77,193 children receiving ART:
  - 53,507 under 15 years
  - 23,686 aged 15-19 years
- 1,705,365 children had an HIV test, with 84,343 testing HIV-positive

ZAMBIA:
- 20 ACT implementing partners
- 118,326 children receiving ART:
  - 46,477 under 15 years
  - 71,849 aged 15-19 years
- 1,749,547 children had an HIV test, with 73,017 testing HIV-positive

CAMEROON:
- 8 ACT implementing partners
- 8,386 children receiving ART:
  - 6,005 under 15 years
  - 2,381 aged 15-19 years
- 278,751 children had an HIV test, with 7,898 testing HIV-positive
ACT’S PROMISING PRACTICES AND LESSONS LEARNED

PILLAR ONE: POLICY FOR PEDIATRIC HIV SERVICES

1.1. INTRODUCTION TO PILLAR 1

This pillar focused on supporting countries to strengthen the national strategies, plans, and standards needed to provide a strong framework and leadership for an effective response to pediatric HIV.

ACT’S PROGRAMMATIC PILLARS

| PILLAR 1: Policy for pediatric HIV services | PILLAR 2: Community engagement | PILLAR 3: HIV case identification | PILLAR 4: Linkage to HIV care and treatment services | PILLAR 5: HIV treatment initiation, monitoring, adherence, and retention | PILLAR 6: Strategic information for pediatric HIV | PILLAR 7: Domestic resource commitment for pediatric HIV services |

1.2. PROMISING PRACTICES UNDER PILLAR 1

A. STRENGTHENING NATIONAL STRATEGIES AND POLICIES FOR CHILDREN’S HIV CARE AND TREATMENT

Across the nine priority countries, ACT’s stakeholders played a key role in supporting the review and development of national strategies and policies related to pediatric HIV care and treatment. These were based on international guidance. Examples include WHO’s “Guideline on When to Start Antiretroviral Therapy” (2015) and “Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection” (2016), which recommended the initiation of ART in all people living with HIV, including children, regardless of their CD4 count.

As an example, Tanzania was one of the first countries to, in May 2015, adopt a test-and-start approach, whereby people who test HIV-positive are immediately initiated on ART. This reflected commitment by the Ministry of Health and National AIDS Control Program (NACP) to accelerate HIV treatment for children. The adoption of ACT, known as the Tanzania Initiative to Accelerate Children on Treatment (TICoT), was complemented by the development of regional strategies and plans specifically on pediatric treatment. The work was driven by the NACP’s Pediatric Technical Working Group that included PEPFAR, implementing partners and UN agencies, notably WHO and the United Nations Children’s Fund (UNICEF).
ACT’S PROMISING PRACTICES AND LESSONS LEARNED

In Kenya, the PEPFAR country team and ACT implementing partners supported the government and National AIDS and STIs Control Programme (NASCOP) to specifically focus on children within implementation of the National Plan for Accelerating HIV Care and Treatment 2015-2017. This plan was based on a test-and-start approach.

In Cameroon, the Cameroon Baptist Convention Health Services (CBCHS) supported the government’s development of the National Pediatric HIV/AIDS Acceleration Plan. Similarly, in Lesotho, the University Research Co. (URC) collaborated with the Ministry of Health to review the national test-and-treat guidelines (based on WHO’s 2015 and 2016 guidance and the 90-90-90 treatment targets) and to ensure attention to children. The revised guidelines are now being implemented countrywide.

Implementing partners also made important contributions to rolling out national strategies to subnational levels. For example, CARE Kenya held meetings with district and local stakeholders, including schools and religious organizations, to disseminate the National Pediatric ART Policy.

In some contexts, the PEPFAR country teams and ACT implementing partners worked with governments to facilitate national responses to pediatric HIV through the removal of policy or commodity barriers. Examples from Kenya include lowering the age of consent for HIV testing (from 18 to 15 years) and introducing pellet formulations of lopinavir/ritonavir. The latter makes it easier for infants and children to take this ARV drug, which is preferred by WHO as the best way to treat pediatric HIV infection.

B. ENSURING WELL-COORDINATED AND MULTISECTORAL NATIONAL RESPONSES TO PEDIATRIC HIV

ACT’s implementing partners engaged in national and subnational mechanisms to ensure effective coordination of their own work, as well as the wider response to pediatric HIV. For example, in Lesotho, URC found that an ACT technical working group provided a vital platform for stakeholders to present their progress, avoid duplication, leverage resources, and improve the quality of services.

Tanzania Health Promotion Support (THPS) seconded staff to the NACP who supported a National Pediatric Technical Working Group. In Kenya, African Medical and Research Foundation (Amref) participated in similar technical working groups, but at the county level. These groups, which included representatives of health facilities, county health management teams, and subcounty health management teams, enabled the sharing of strategic information. Meanwhile, some implementing partners coordinated nationwide campaigns on pediatric HIV, such as the Rapid Results Initiative (RRI) in Kenya (see Case Study 1).
CASE STUDY 1: SUPPORTING A NATIONAL RAPID RESULTS INITIATIVE – EGPAF, KENYA

In Kenya, NASCOP and its partners had made efforts to improve the finding of children living with HIV. However, the country was still falling behind on its targets. In response, a national RRI was carried out during 11 April to 12 July 2016, reaching all 47 of the country’s counties. The aim was to optimize a set of services for children and adolescents, comprised of HTC (including the use of rapid test kits), enrollment into care, ART initiation, viral load testing, isoniazid preventive therapy uptake and retention in care.

As its contribution to the RRI, EGPAF supported the development of RRI tools, conducted county-level sensitization on the initiative and participated in county performance review meetings as part of a National Technical Advisors Team. With a focus on the 21 high-burden counties supported by ACT, EGPAF provided supportive supervision to the counties to ensure their full engagement and implementation of the RRI strategies. The RRI taskforce implemented a robust monitoring system, involving daily reporting to the subcounty level, weekly reporting to the county level and fortnightly reporting to the national level (using a well-structured reporting tool called ‘hot reports’). The county-level Technical Assistance Teams used WhatsApp technology to share and discuss their ‘hot reports’. To avoid stock-outs during the RRI, supply levels (of rapid test kits, ARVs, dried blood spot (DBS) tests and viral load tests) were routinely monitored, with prompt procurement. Also, all of the EGPAF-supported counties conducted monthly county performance review meetings, with analysis of ACT’s data against the RRI’s objectives. EGPAF supported an RRI stocktaking meeting to evaluate the achievements, challenges and lessons learned during the initiative.

Overall, the RRI made a significant contribution to the success of the ACT Initiative in Kenya, with over 3 million HIV tests conducted among children and adults. A total of 5,905 children were found to be HIV-positive, with 4,840 of them in the 21 high-burden counties.
ACCELERATING CHILDREN’S HIV/AIDS TREATMENT

ACT’S PROMISING PRACTICES AND LESSONS LEARNED

C. ADAPTING NATIONAL HUMAN RESOURCE POLICIES TO SUPPORT PEDIATRIC HIV

Many ACT stakeholders found that, in addition to having strong national strategies, it was vital to address human resource policies related to pediatric HIV. This was important to ensure not only that there were enough health care personnel to accelerate relevant programs, but also that they were fit for purpose—that is, having the right skills and knowledge and being deployed in an effective, cost-efficient way, including through task shifting or task sharing. This was especially critical in contexts with shortages in health care staff or where personnel had intensive workloads.

As an example, in DRC, the PEPFAR country team and implementing partners supported the development of a task sharing policy to accompany the National Pediatric Operational Plan, both of which were based on a test-and-treat approach for all children 0-14 years. They contributed to pediatric treatment being recognized as a national priority. Similarly, in Kenya, the PEPFAR country team and implementing partners supported the government to develop and implement a national task sharing policy.

In Lesotho, the PEPFAR country team and ACT implementing partners worked with the government to roll out nurse-initiated management of ART. This important strategy enabled nurses to take on ART-related responsibilities that were previously only allowed for doctors and medical officers. It not only saved the health system’s time and money but also improved access for children living with HIV and their families who, for example, no longer had to travel to national or district hospitals for treatment. In Kenya, progress was seen in task sharing for HTC. Lay personnel, including community health workers, were allowed to conduct HIV testing—something previously only permitted for doctors and nurses.

This national-level work on human resource policies complemented the extensive efforts of ACT’s implementing partners at the subnational and facility levels to build the capacity of health care workers in pediatric HIV care and treatment. This work included training and mentorship, as described in other sections of this report, such as under Pillar 5.

D. DEVELOPING NATIONAL STANDARDS OF CARE AND TREATMENT FOR CHILDREN LIVING WITH HIV

A further ACT contribution to national responses to pediatric HIV was the development of standards, packages, and models specific to children and adolescents. An example was seen in Kenya, where multiple implementing partners supported the roll-out of a national adolescent package of care (APOC), one of the first of its type in Africa (see Case Study 2).
CASE STUDY 2:
IMPLEMENTING THE NATIONAL ADOLESCENT PACKAGE OF CARE – KENYA

Kenya’s APOC was endorsed by the government’s Ministry of Health and NASCOP, with the aim of it being used in more than 500 facilities. The APOC provided national guidance on effective services and support for adolescents living with HIV. The roll-out of the APOC was supported by the PEPFAR country team and a number of ACT implementing partners. For example, Amref trained 80 nurses and clinical officers, contributing to a total of 1,789 health care workers being trained as of 2016. The Kenya Conference of Catholic Bishops (KCCB)-Kenya AIDS Response Program (KARP) used the APOC to tailor minimum services for adolescents across all of their facilities.

ICAP found that training and mentoring health care workers in the APOC led to facilities scaling up and improving their services for adolescents. The work included introducing specific measures for the age group, such as separate clinic sessions, increased psychosocial support groups, and gender- and age-specific services. ICAP also used a standardized curriculum to train 110 adolescent mentors in the package, giving them the knowledge and skills needed to offer one-to-one psychosocial support. This improved the meaningful involvement of adolescents living with HIV, enabling them to take charge of their own care while also supporting their peers. Newly diagnosed adolescents, as well as those with adherence issues or high viral loads, were paired with a trained mentor to ensure personalized support.

ICAP’s use of the APOC complemented its wider contribution to Kenya’s test-and-start strategy, which was based on a “check-flag-act” line listing approach to identify missed opportunities, ensure timely initiation on ART, and improve the uptake of viral load testing. This approach led to all eligible adolescents registered with HIV care services being recalled and counseled to initiate ART. By the end of ACT, 116 of ICAP’s 170 supported health facilities were implementing adolescent-friendly clinics. In total, 3,442 (99%) of 15-19 year olds registered in care were receiving ART, with 12-month retention levels of 85%-90%.
1.3. LESSONS LEARNED ABOUT PILLAR 1

Across ACT, many lessons were learned about ‘what works’ for implementation of the programmatic pillars, including Pillar 1. It should be noted that, while the lessons often applied to many different contexts, they did not necessarily apply to all of the ACT countries or implementing partners.

Box 4: Lessons learned from implementation of ACT Pillar 1

For pediatric HIV policy, it is important to:

• Collaborate nationally to ensure that there is a set of supportive policies on pediatric HIV care and treatment that provides a framework for effective action at all levels and to maintain a focus on children within wider national strategies for “test and treat.”

• Advocate for not only strong national frameworks for pediatric HIV but also the measures needed to make them happen, such as human resource policies that facilitate task sharing or task shifting.

• Have formal, multistakeholder national and subnational platforms for sharing pediatric HIV care and treatment results and challenges and for identifying necessary changes to policies and strategies.

• Develop standard packages on pediatric and adolescent HIV that are based on good practice and that shorten the learning curve, ensuring a strong and consistent technical approach across a country.
PILLAR TWO: COMMUNITY ENGAGEMENT

2.1. INTRODUCTION TO PILLAR 2

This pillar focused on ensuring that community stakeholders were meaningfully involved, deployed, and respected within all relevant aspects of ACT’s work – from the design of programs to the delivery of services and the monitoring of results. This included stakeholders such as children and adolescents living with HIV; parents, caregivers, and family members; community health workers; peer educators; community-based organizations; and community leaders.

ACT’S PROGRAMMATIC PILLARS

| PILLAR 1: Policy for pediatric HIV services | PILLAR 2: Community engagement | PILLAR 3: HIV case identification | PILLAR 4: Linkage to HIV care and treatment services | PILLAR 5: HIV treatment initiation, monitoring, adherence, and retention | PILLAR 6: Strategic information for pediatric HIV | PILLAR 7: Domestic resource commitment for pediatric HIV services |

2.2. PROMISING PRACTICES UNDER PILLAR 2

A. RAISING AWARENESS AND MOBILIZING COMMUNITIES ABOUT HIV CARE AND TREATMENT FOR CHILDREN

Many of ACT’s implementing partners found that it was vital to combine their technical interventions with raising awareness among communities. This awareness raising focused on positive messages about the benefits of children knowing their HIV status and accessing care and treatment.

For some implementing partners, this work took the form of national campaigns, as with Centro de Colaboração em Saúde (CCS) and the Saber é Viver campaign in Mozambique (see Case Study 3). In Malawi, EGPAF complemented national and community radio campaigns with community sensitization meetings, reaching 109,500 community members and 180 community leaders in 12 traditional authorities. All of the activities combined positive messages about pediatric HIV services with highlighting risks, such as of children living with HIV defaulting on treatment. In Malawi, Jhpiego found that providing health talks in communities and facilities was an effective way to build local knowledge about pediatric HIV, in turn increasing the uptake of HTC services among children and caregivers. This contributed to Jhpiego enabling 97,116 children under 15 years to have an HIV test.
In some contexts, implementing partners adapted their awareness-raising methods to specific communities. For example, in Kenya, the University of Manitoba found that, within their work with sex workers and street families, it was vital to use peers to deliver messages about pediatric HIV. This approach built the trust needed for the technical activities, such as Family Testing Days, that were central to the program’s success.

**CASE STUDY 3:**
**CONDUCTING A NATIONAL CAMPAIGN ON PEDIATRIC HIV – CCS, MOZAMBIQUE**

Figure 4: A Saber é Viver campaign message on the importance of HIV treatment for children

In Mozambique, CCS was a lead organization in a national campaign called Saber é Viver (“To Know Is to Live”). The campaign aimed to raise awareness about pediatric HIV, address HIV stigma, and encourage young people to know their HIV status. The seven-week initiative, which started in June 2016, was implemented in partnership with the government’s Ministry of Health and Ministry of Education and coordinated by the Clarisse Machanguana Foundation, a youth organization led by a famous female basketball player. The campaign focused on the use of information tools to reach young people in schools and communities. Its activities included programs on national television, radio broadcasts, art murals, theater performances, films, community health fairs (including HTC services), and an awareness-raising walk involving provincial governors and community leaders.
Saber é Viver involved seven ACT implementing partners, working in 30 districts in seven provinces. Overall, it mobilized more than 100 local and national leaders and reached 112,874 participants (33,317 in schools; 79,557 in communities) and 700,000 through social media. The campaign made an important contribution to ACT’s overall results in Mozambique, including a 17% rise in the number of children living with HIV newly initiated on ART and treatment coverage of 93% and 100% among infants under 12 months and children under 5 years, respectively.

B. ENGAGING COMMUNITY LEADERS AND LOCAL GATEKEEPERS ON PEDIATRIC HIV

Implementing partners also found it important to engage with local leaders as gatekeepers to communities’ commitment to pediatric HIV care and treatment. As an example, in Tanzania, THPS mobilized community leaders on the value of pediatric HIV testing and treatment and provided information about national targets and priority interventions. THPS also participated in meetings of council multisectoral AIDS committees and ward development committees as important mechanisms to influence local decision making.

In Kenya, Ananda Marga Universal Relief Team (AMURT) learned that it was essential to engage with community leaders and conduct community sensitization before starting HTC among orphans and vulnerable children (OVC). It was also important to involve community leaders in human resource issues, such as ensuring that HTC counselors came from the local community and that community mobilizers came from OVC caregivers. This approach contributed to the program being able to test 98% of its target number of OVC and to link 100% of those testing HIV-positive to care and treatment.

C. DEPLOYING COMMUNITY HEALTH WORKERS TO PROVIDE HIV CARE AND TREATMENT FOR CHILDREN

An essential success factor for ACT was the engagement of community health workers, who often served in a voluntary capacity. This was central to improving the effectiveness and time/cost efficiency of interventions, such as by shifting tasks away from clinicians and toward people based in, and knowledgeable about, local communities. Examples across ACT’s countries and pillars included community health workers performing the following tasks:

- Identifying children who were exposed to HIV and eligible for HIV testing
- Referring HIV-exposed or ill children to health facilities to have an HIV test
- Providing pre- and post-test counseling to children having an HIV test
- Conducting HIV testing for children
- Accompanying children testing HIV-positive to care and treatment services
- Tracing children living with HIV who miss appointments or default on treatment
- Supporting children living with HIV to adhere to ART
- Serving as a link between communities and health facilities for children living with HIV
- Participating in program forums to review pediatric HIV data and identify challenges
Such roles made an important contribution to ACT’s results. For example, in Kenya, Lifeskills Promoters deployed community health workers and HTC providers to conduct targeted, door-to-door HIV testing for OVC (children who, if they have lost a parent to HIV, are at higher risk of HIV exposure). The volunteers led on sensitizing the caregivers and OVC on the need and availability of HTC. After testing, they linked those children found to be HIV-positive to convenient health facilities for care and treatment. Afterwards, they conducted monthly follow-up visits to provide ongoing support. The strategy increased local ownership of ACT’s activities and the uptake of HIV testing. Overall, 13,854 OVC received HTC, with 99.8% of those testing positive for HIV being linked to care and treatment.

Some implementing partners emphasized engagement with traditional health care structures in communities. For example, in Mozambique, Family Health International (FHI) 360 worked with traditional midwives to refer infants exposed to HIV (who they identified in their routine work in communities) to health facilities for early infant HIV diagnosis (EID) services.

D. MAXIMIZING PEER-BASED APPROACHES FOR CHILDREN’S HIV CARE AND TREATMENT

A further core practice in ACT was the engagement of community members living with HIV to support others in pediatric HIV care and treatment. Examples of such peers include the following:

• **Adolescents living with HIV.**
  In Kenya, the University of California at San Francisco (UCSF) Family AIDS Care and Education Services (FACES) supported adolescents living with HIV to lead peer-to-peer psychosocial support and to help with adherence to ART.

• **Mothers living with HIV.**
  In Tanzania, URC supported mother-to-mother programs, with women living with HIV encouraging others to access HIV testing (both for themselves and their children) and to link to care and treatment services.

• **People living with HIV.**
  In Zimbabwe, ACT deployed case workers living with HIV to use their own experiences to support parents and caregivers in overcoming fear and denial related to HIV and, in turn, supporting their children to access HIV services.

E. ENGAGING COMMUNITIES IN QUALITY IMPROVEMENT FOR PEDIATRIC HIV

Implementing partners used various strategies to engage community members and leaders in guiding ACT’s interventions. The strategies were particularly important for identifying program bottlenecks and ways to overcome them. As an example, in Cameroon, CBCHS held monthly forums for the parents and guardians of children living with HIV. These forums had a dual benefit-enabling the implementing partner to provide updates on pediatric HIV and enabling community members to provide feedback on services.

In Tanzania, URC rolled out a community-based quality improvement model designed to strengthen the pediatric HIV care and treatment cascade. Community
quality improvement teams identified the most vulnerable children in the local area and linked them to services. The approach complemented other program strategies, such as the capacity building of county health management teams and most vulnerable children committees to collect and use data to improve the program’s performance.

2.3. LESSONS LEARNED ABOUT PILLAR 2

Box 5: Lessons learned from implementation of ACT Pillar 2

For community engagement in pediatric HIV care and treatment, it is important to:

- Mobilize and engage local communities at the earliest possible stages of programs and continue to engage or re-engage them as the work progresses.

- Combine the provision of pediatric HIV services with the reinforcement of positive messages for communities, such as about the benefits of HIV testing for children.

- Address ongoing HIV-related stigma among communities and families that limits the willingness of parents or caregivers and children to engage with HIV services.

- Engage with a full range of community gatekeepers of relevance to children and HIV, including local, traditional, and religious leaders.

- Build community ownership of ACT interventions involving local people as partners, rather than targets, and engaging them in all stages of the design and monitoring of interventions.

- Identify engaging ways, such as radio broadcasts, to communicate messages about pediatric HIV to communities with low literacy or poor health care seeking behaviors.
ACT’S PROMISING PRACTICES AND LESSONS LEARNED

PILLAR THREE: HIV CASE IDENTIFICATION

3.1. INTRODUCTION TO PILLAR 3

This pillar focused on devising and implementing the strategies needed to systematically identify and target children exposed to HIV, provide them with high-quality HIV testing, and confirm their HIV status.

ACT’S PROGRAMMATIC PILLARS

PILLAR 1: Policy for pediatric HIV services
PILLAR 2: Community engagement
PILLAR 3: HIV case identification
PILLAR 4: Linkage to HIV care and treatment services
PILLAR 5: HIV treatment initiation, monitoring, adherence, and retention
PILLAR 6: Strategic information for pediatric HIV
PILLAR 7: Domestic resource commitment for pediatric HIV services

3.2. PROMISING PRACTICES UNDER PILLAR 3

A. USING SYSTEMATIC STRATEGIES TO FIND AND TEST CHILDREN EXPOSED TO HIV

Central to achieving ACT’s objectives in a two-year time frame was the development and scale-up of effective and efficient strategies for identifying children exposed to HIV and ensuring their access to HIV testing. Many implementing partners started this work by mapping who the children most likely to be exposed to HIV were and where to find them. As an example, in Kenya, KCCB-KARP mapped out all of the OVC centers in their catchment area.

Across ACT’s countries, priority strategies, as guided by PEPFAR (see Box 6), were used for pediatric HIV case finding. These are described in the following pages, with examples of promising practices.
Box 6: PEPFAR strategies for HIV case finding among infants, children, and adolescents

1. Strengthen EID for HIV-exposed infants.

2. Test all children of adults receiving any HIV services (PMTCT, care, ART) through facility- or home-based index case testing.

3. Test all children and adolescents attending TB clinics or malnutrition services and those admitted to the pediatric ward.

4. Screen all OVC for HIV risk and provide testing as appropriate.

5. In high-prevalence settings (5%), test mothers or infants attending immunization or under-5 clinics to identify HIV-exposed infants.

Strategy 1: Strengthen EID for HIV-exposed infants

Strengthening EID, which was fundamental to the ACT Initiative, involved the systematic follow-up of HIV-exposed infants until 18 months or the end of the breastfeeding period. The strategy included providing access to DNA PCR testing and, for those found HIV-positive, linkage to pediatric care and treatment.

EGPAF – Mozambique was one of several implementing partners that used mentor mothers to increase the uptake of HIV testing within antenatal care (ANC) services and to facilitate EID (see Case Study 4). As another strategy, in Kenya, the Program for Appropriate Technology in Health (PATH) sensitized health care workers on EID to ensure the testing of infants exposed to HIV within 2 months of age, as well as those between 2 and 12 months. This approach benefited from the use of an EID website, combined with facility-level HIV early intervention registers to identify eligible clients.
CASE STUDY 4:
USING MENTOR MOTHERS TO IMPROVE EARLY INFANT DIAGNOSIS – EGPAF, MOZAMBIQUE

In Gaza Province, Mozambique, EGPAF deployed mentor mothers to increase the retention of women living with HIV in ANC services, as well as the provision of EID for infants at two months. The implementing partner recruited and trained 350 mentor mothers (women living with HIV) in seven priority districts. The mothers conducted monthly home visits to new PMTCT and pediatric clients. They also traced patients who were lost to follow-up and conducted TB and malnutrition screening among mothers and children.

EGPAF found that this strategy improved the health-seeking behaviors and outcomes for pregnant women living with HIV. For example, 73% of women attended four ANC sessions at facilities that had mentor mothers, compared to 55% at facilities without. The strategy also improved the health outcomes for infants, with increased levels of EID achieved. The challenges of the approach included that it had limited male partner involvement, and there was a lower uptake of visits by mentor mothers among women in urban areas. However, overall, it provided a cost-effective, volunteer-based model that can be replicated and sustained at other health facilities.

Strategy 2: Test all children of adults receiving any HIV services (PMTCT, care, ART) through facility- or home-based index case testing

Index or family testing, a widely used strategy across ACT, involves health service providers actively offering HIV testing for the children of clients receiving HIV services (known as index clients) and for the siblings of children living with HIV. This testing was critical to improving the effectiveness of pediatric HIV case finding, as it provided a means to systematically identify and target those children most likely to have been exposed to HIV. It also helped improve the acceptability of HIV testing for children. For example, in Cameroon, an implementing partner reported that parents welcomed family testing, expressing that they had been looking for such an opportunity to know their children’s HIV status.

As shown in Case Study 5 from Lesotho, models of index/family testing were used in facility- and community-based interventions. Across ACT, adaptations were made to local contexts to ensure that the approach was as strategic as possible. For example, in Kenya, EGPAF focused on the family members of people newly diagnosed as HIV-positive, while AMURT, which worked in high-burden rural communities, focused on door-to-door family testing.
In Tanzania, Management and Development for Health (MDH) made specific efforts to ensure that all siblings of registered children living with HIV were tested. The work involved collaboration with Dar es Salaam Regional Health Management Team, council health management teams, mentoring nurses and doctors. It involved a number of steps, starting with informing parents/guardians about the importance of sibling testing, then using care and treatment cards to record all siblings and, during clinic days, interviewing parents/guardians to confirm the number of siblings and mobilize them to access HCT. Subsequently, the day before testing services, an SMS reminder was sent to the parents/caregivers. There was also the option of home testing, conducted by community health workers. Parents/carergivers not attending appointments were followed up by phone, in facilities and/or the community. Any siblings found to be HIV-positive were initiated on ART on the same day. In January 2015 - April 2016, MDH scaled up a pilot program to 48 health facilities. This led to 18,820 siblings being offered HIV testing for the first time. Of these, 5% were found to be HIV-positive (compared to a level of 1% for routine HCT in the facilities), with 98% of them enrolled in treatment. MDH found that an important success factor for this approach was providing HIV testing in a non-judgemental, child friendly and age appropriate manner.

Many implementing partners used an index or family testing approach within specific events. In Malawi, EGPAF implemented a Know Your Child’s Status campaign (see Case Study 6), while Management Sciences for Health (MSH) ran Family Testing Days in 76 facilities. In Kenya, an evaluation of the pediatric cascade enabled ICAP to increase the efficiency of its index testing through the use of family registers and reporting templates. These tools improved the documentation of client details and minimized repeat testers. Overall, during the course of ACT, index testing helped ICAP test 658,696 children 0-14 years old for HIV, with 4,409 found HIV-positive and 93% of them initiated on ART.
CASE STUDY 5:
PILOTING MODELS OF INDEX TESTING TO IDENTIFY CHILDREN EXPOSED TO HIV – LESOTHO

In Lesotho, national guidelines called for the partners and children of clients living with HIV (index clients) to be actively approached for testing. Yet, in most sites in 2016, the coverage of HIV testing for the children of such clients was less than 40%. Know Your Child’s Status campaigns had produced a low yield, with less than 1% of the children in the general population testing HIV-positive. In response, ACT implementing partners developed a two-prong approach to more systematically reach the children of adults living with HIV:

1. Facility-based approach: A new index testing form was rolled out in 120 PEPFAR-supported health facilities. The form aimed to more systematically identify the sexual partners and children of adults living with HIV who were enrolled in care services. Adults were first counseled on the importance of knowing the HIV status of partners and children. They were then given the form to take home, with instructions to bring their family members to the next visit. When the latter came to the facilities, they were fast-tracked for HIV testing. The form was then updated and inserted into the index client’s file. During the pilot, 3,523 adult index clients were counseled, resulting in 429 children having an HIV testing.

Figure 4. The new index testing form developed in Lesotho

<table>
<thead>
<tr>
<th>Partner</th>
<th>Male</th>
<th>Female</th>
<th>ART Clinic</th>
<th>Date ART Start</th>
<th>Date noted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test 1</td>
<td>P</td>
<td>N</td>
<td>Ind</td>
<td><em><strong>/</strong></em>/___</td>
<td><em><strong>/</strong></em>/___</td>
</tr>
<tr>
<td>Test 2</td>
<td>P</td>
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<tr>
<td>Test 3</td>
<td>P</td>
<td>N</td>
<td>Ind</td>
<td><em><strong>/</strong></em>/___</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Index Patient</th>
<th>Name</th>
<th>Unique Number</th>
<th>Date of Birth</th>
<th>Date ART Start</th>
<th>Unique Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test 1</td>
<td>P</td>
<td>N</td>
<td>Ind</td>
<td><em><strong>/</strong></em>/___</td>
<td><em><strong>/</strong></em>/___</td>
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<tr>
<td>Test 2</td>
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<tr>
<td>Test 3</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Child 1</th>
<th>Male</th>
<th>Female</th>
<th>Date of Birth</th>
<th><em><strong>/</strong></em>/___</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test 1</td>
<td>P</td>
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<tr>
<td>Test 2</td>
<td>P</td>
<td>N</td>
<td>Ind</td>
<td><em><strong>/</strong></em>/___</td>
</tr>
</tbody>
</table>

Instructions:
- Complete family tree for all sexual partners and children of the index HIV patient. If the index patient has more than one sexual partner, complete a form for each partner. If the index patient has more than 4 children, complete additional forms as needed so that all children are recorded.
- If the index HIV patient is a child, complete the form for all the child’s siblings and biological parents.
- HIV-negative sexual partners of index HIV patients should be tested for HIV every 3 months if having unprotected intercourse. If index patient is not on ART, or if index patient has a non-suppressed viral load (>1,000 copies per ml).
- Children of index male HIV patients need HIV testing if their biological mother is HIV-positive or her HIV status is unknown/not documented.
- Index testing/family tree form should be reviewed and updated at every clinical visit.
2. **Community-based approach:** A model to track index clients (see Figure 5) was introduced through district health management teams in Maseru and Berea. The districts had health centers and hospitals that had been identified as recruitment points for index clients. In April 2015, counselors were placed in the facilities’ maternal and child health clinics, ART corners, and TB clinics to identify index clients for family testing in their communities. In late May, the model was rolled out, with the households of index clients clustered together and HTC teams deployed to communities. The results included the following:

- 67.6% of index clients who were approached about family testing accepted.
- Through visits to 992 households of index clients, 2,604 family members underwent HIV testing. Of these, 71.1% were children, and 8.8% were adolescents.
- Overall, 2% of children and 3% of adolescents tested HIV-positive. Higher levels of HIV-positivity were seen among those identified through male index clients and clients newly diagnosed with HIV.
- 90% and 83% of the children and adolescents, respectively, newly diagnosed with HIV were linked to treatment.

*Figure 5: Model of community-based index testing*
CASE STUDY 6:
IMPLEMENTING KNOW YOUR CHILD’S STATUS CAMPAIGNS – EGPAF-MALAWI

In November 2015, EGPAF launched Know Your Child’s Status campaigns in 45 facilities in 6 districts of Malawi. During ART clinics, adults receiving treatment were invited to bring their children for HIV testing on Saturdays (when children would not be in school and parents not at work). The adults were motivated by expert clients (people living with HIV) and received refunds for their transport costs. Meanwhile, at each facility, a multidisciplinary team was convened, including HIV Diagnostic Assistants (HDAs) to provide HTC; clinical and nursing staff to enroll children into care and treatment; and data clerks to record the information. Same-day ART initiation was provided for children under the age of five who were newly diagnosed with HIV, while older children were managed according to the relevant national guidelines.

The Know Your Child’s Status campaigns resulted in 101,684 children having an HIV test. Of those, 1,815 were found to be HIV-positive, with 90% of them initiated on ART. A cost analysis study was conducted for January-September 2016, focusing on three districts (Mzimba North, Mzimba South, and Rumphi). This analysis estimated that the cost per pediatric client tested was $6.11, and the cost per new pediatric HIV diagnosis was $347. While there is limited published data on the costs for pediatric HIV testing, these estimates are in line with available benchmarks for adult testing and for PEPFAR expenditure analysis in Malawi. The study suggests that Know Your Child’s Status campaigns may be a cost-effective strategy for pediatric testing, case identification, and linkage to ART.

Figure 6. Children participating in a Know Your Child’s Status event at Ntcheu District Hospital

Isabel Garcia/EGPAF, 2016
Loness Kadaya and Victoria Bliati are living with HIV. Both live in Ntcheu, central Malawi, 15 kilometers from town. They walk the one-and-a-half hours to Ntcheu District Hospital multiple times a week to volunteer as expert clients. As Loness explains: “Our main task is to encourage fellow clients … to bring their children for testing and help get them initiated on ART if they are reactive.”

Today, the women are working at the final Know Your Child’s Status event, which has taken place at the hospital one Saturday a month. After 10 months of these events, the children of every client have now been tested. At today’s final event, five of the 250 children undergoing HTC test positive. All are started on treatment and asked to return two weeks later to check their progress and refill their prescriptions. Because the children will take ART for the rest of their lives, their parents will need motivation to ensure they adhere to the regimen. That is where expert clients like Loness and Victoria come in. They have been trained to assist with drug adherence, and, as mothers themselves, they understand the dedication it takes to keep children healthy as they grow. Loness and Victoria demonstrate how they are prioritizing their children’s lives, a lesson they will dedicate themselves to as they continue serving their communities.

*Figure 7. Loness Kadaya, an expert client, shares her health passport with other parents and children living with HIV to show how she has adhered to treatment*
ACT’s PROMISING PRACTICES AND LESSONS LEARNED

Strategy 3: Test all children and adolescents attending TB clinics or malnutrition services and those admitted to the pediatric ward

Within ACT, index/family testing strategies were routinely combined with PITC at health facility services most commonly used by HIV-exposed children. As examples, in Mozambique, Friends in Global Health (FGH) targeted its work at TB clinics (see Case Study 7), while FHI 360’s Community HIV/AIDS Services Strengthening (CHASS) improved HIV testing for children admitted to Beira Central Hospital. The latter responded to a scenario in which fewer than 20% of pediatric admissions were being tested, despite government guidelines making HTC mandatory for all hospital inpatients. The implementing partner developed a strategy that included allocating a lay HTC counselor to every child admitted to the pediatric ward; training 30 hospital technicians in PITC, with a focus on EID; prioritizing the processing of PCR samples in the laboratory; and systematizing HTC record books to minimize stock-outs of commodities. The strategy contributed to a major increase in the proportion of children admitted to the hospital’s pediatric ward knowing their HIV status, from 24% in June 2016 to 72% in November 2016.

In Malawi, Jhpiego scaled up PITC by deploying 106 HDAs in its 52 ACT-supported sites in four districts. They were placed at high-yield entry points, such as nutrition rehabilitation units, supplementary feeding programs, and outpatient departments. This contributed to a significant increase in Jhpiego’s HIV testing rates among children younger than 15 years, with a total of 97,116 receiving HTC.

Many implementing partners took specific steps to ensure that their testing services were not only available but also as accessible as possible to children and their families. For example, in Kenya, the University of Nairobi’s Centers of Excellence in HIV Medicine (University of Nairobi-COE) provided 24-hour HTC services in pediatric emergency units, while KCCB-KARP extended their HTC services to nights and weekends.
CASE STUDY 7:
IMPROVING CASE FINDING FOR HIV/TB CO-INFECTED CHILDREN – FGH, MOZAMBIQUE

In Mozambique, HIV testing at TB facilities is mandatory for all patients and a one-stop TB/ HIV model had been implemented for several years. However, in practice, there remained a number of challenges related to children. These included difficulties in diagnosing TB in children and a lack of experience in HIV management among pediatric TB clinicians. The barriers also included pill burden and clients being lost to follow-up. In response, FGH carried out a multipronged intervention that included providing HIV health care workers with training in pediatric TB, followed by mentoring within facilities to support effective TB diagnosis. It also included training TB clinical officers in HIV pediatric care, allocating a lay counselor in TB services to conduct PITC, and implementing a standard operating procedure to conduct preventative home visits to children.

The intervention helped FGH achieve important progress—notably, in the number of TB pediatric patients with known HIV status (93%) and the number of those testing HIV-positive being initiated on ART (84%).

Figure 8. HIV testing and linkage to ART for children at TB services
Strategy 4: Screen all OVC for HIV risk and provide testing as appropriate

Some ACT implementing partners developed specific strategies to locate OVC within communities, screen them for HIV risk, and provide them with HIV testing as needed. This was found to be more effective than an earlier approach that involved testing all OVC, which, in countries such as Malawi and Mozambique, had produced low numbers of children testing HIV-positive.

In DRC, implementing partners supported collaboration between clinical personnel and OVC organizations to identify how best to reach OVC and, as appropriate, provide HIV testing. Similarly, in Zimbabwe, ACT bridged the health and social sectors, bringing together HIV and OVC initiatives. The strategy included deliberately recruiting health volunteers into the OVC workforce and increasing HIV literacy among OVC volunteers. The latter enabled volunteers to better integrate attention to HIV testing and treatment within their ongoing work with OVC, such as relating to child protection. Meanwhile, in Mozambique, CCS integrated HTC into wider health screening for OVC conducted at orphanages and boarding schools in two provinces. During ACT, the implementing partner enabled 735 OVC in Inhambane and 2,849 in Maputo City to have an HIV test and to be screened for TB and nutrition. In both provinces, 3% of the children tested HIV-positive.

Strategy 5: In high-prevalence settings (5%), test mothers or infants attending immunization or under-5 clinics to identify HIV-exposed infants

Many implementing partners combined some or all of the above strategies with providing HIV testing for both mothers and infants within maternal, newborn, and child health services—notably, those for immunization and under-5 clinics. This approach not only reached a large number of children potentially exposed to HIV, but also helped reduce the stigma associated with HIV testing by integrating it into mainstream child health services that appeal to parents.

As an example, in Kenya, the Coptic Hospital Hope Centre offered HIV testing to mothers bringing their children for immunization; if the mother tested positive, testing was also offered to her children. Also in Kenya, ICAP prioritized the screening of mothers and children at immunization clinics to ensure that all eligible lactating mothers were tested. In addition, multiple implementing partners supported the government policy of 100% screening and testing in postnatal, immunization, and under-5 services.

B. STRENGTHENING HUMAN RESOURCE CADRES FOR HIV CASE FINDING AMONG CHILDREN

To implement strategies for case finding and HIV testing among children, ACT implementing partners needed to increase and strengthen human resources. This
often combined recruiting new cadres of personnel with building the capacity of existing ones. As an example, in Malawi, cadres with specific responsibilities related to pediatric HIV case finding included the following:

• **HIV Diagnostic Assistants.**
  This lay cadre supported pediatric HIV case finding, linkage to care, and defaulter tracing. It also served as a connection between facility and community-based support. For example, the Malawi AIDS Counseling and Resource Organization and Lighthouse trained 171 HDAs and deployed them to 62 priority health facilities in four districts (Dedza, Lilongwe, Mchinji, and Ntcheu). Their role included conducting PITC in priority service delivery points for pregnant women and children. An example of the results could be seen in Ekwendeni Community Hospital, a high-burden facility in Mzimba North District where, in a one-year period, HDAs increased the uptake of HIV testing by 184% among women at ANC clinics, with scale-up also seen among children.

• **HIV Testing Services Counselors.**
  This lay cadre provided specific support for HIV case finding and PITC across different service delivery points of health facilities. For example, the Baylor College of Medicine Children’s Foundation recruited, trained, and deployed nearly 200 HIV testing services counselors at facilities throughout the South East Zone and the Lilongwe/Salima Districts of the Central Zone. These personnel contributed to 221,255 children receiving HTC during 2014–2016.

• **Pediatric Technical Advisors (PTAs).**
  This cadre provided additional technical support to lay and clinical health workers in relation to pediatric HIV case finding and case management. For example, MSH deployed PTAs to provide one-on-one support to staff and clinical mentors to build their capacity. The PTAs, combined with the use of HDAs, contributed to an increase in the number of children undergoing HIV testing, from 39,536 at September 2015 to 76,589 at September 2016. Of those children, 3,140 were identified as HIV-positive and were started on ART.

As noted, the introduction of these specific cadres was complemented by training and tools for existing health care personnel. In combination, these approaches made an important contribution to ACT’s programmatic Pillar 7 in terms of providing sustainable capacity and expertise on pediatric HIV that can benefit communities and health facilities beyond ACT.

In some contexts, implementing partners also improved the physical space in which HIV testing was provided. As an example, in Kenya, the Christian Health Association of Kenya (CHAK) engaged health service administrators in rearranging child welfare clinics and triage points to accommodate HTC counselors. Also in Kenya, an evaluation of the work of UCSF FACES found that one of the most effective approaches for increasing levels of HIV testing was a one-time investment in improving the space in which services were delivered. This involved setting up 40 tents, each with 100 tables and chairs, at clinics to improve the availability and privacy of HTC.
The clinics also made their spaces more welcoming and nurturing of children, such as by providing sports equipment, books, and art supplies.

C. STRENGTHENING LABORATORY/COMMODITIES SUPPORT FOR HIV TESTING AND TREATMENT FOR CHILDREN

Pillar 3 required attention to the laboratory and commodity systems needed to accelerate pediatric HIV case finding. This included identifying bottlenecks to the testing process, such as long turnaround times for EID results and stock-outs of test kits, and finding ways to address them. In Lesotho, URC Laboratory Project established a molecular laboratory (see Case Study 8), while, in Mozambique, FHI 360 CHASS improved the supply of HIV test kits in all of its sites in order to avoid stock-outs. In DRC, the government’s laboratory in Lubumbashi was renovated to make it functional for EID and viral load testing. Also, a memorandum of understanding was developed with private laboratories to provide additional EID and viral load services.

As seen in Case Study 10, in some countries, ACT implementing partners used communication technologies, such as WhatsApp, to improve coordination between laboratories and other stakeholders involved in HIV case finding, care, and treatment.

CASE STUDY 8:
STRENGTHENING LABORATORY SUPPORT FOR CASE FINDING – URC-LABORATORY PROJECT, LESOTHO

To accelerate pediatric HIV testing, as well as follow-on care and treatment, the URC Laboratory Project in Lesotho took steps to improve the infrastructure and systems for laboratory and commodities support. These improvements included establishing a molecular laboratory at Mafeteng, with the required equipment and human resources to improve access to EID and viral load testing. They established cold rooms at Mafeteng and the National Reference Laboratory for storing EID and viral load reagents. The implementing partner also procured 15,000 EID tests and 100,000 viral load tests. These efforts were complemented by the development of a Laboratory Information System Dashboard to capture relevant data and disaggregate it according to age, sex, district, facility, and viral suppression. This dashboard enabled the identification of any problems and necessary actions, such as in the case of commodities at risk of stock-out.

One of the major challenges faced by the URC Laboratory Project was a large backlog in laboratory processes. This challenge was addressed through a number of strategies to increase capacity, such as adding human resources (e.g. data clerks), providing extra computers, and implementing a 16-hour-a-day/6-day-a-week laboratory shift system.
D. IMPROVING THE QUALITY AND EFFICIENCY OF HIV CASE FINDING AMONG CHILDREN

Within ACT, pediatric case identification was improved through the routine analysis of strategic information, combined with specific efforts for quality improvement and assurance. Implementing partners collected and used data to assess their results and, where necessary, introduce changes.

As an example, in Malawi, data for Baylor College of Medicine Children’s Foundation indicated that even though providing pediatric HTC across their services on weekends raised the number of tests performed, it did not significantly increase the number of HIV cases identified. The resources being used in smaller facilities were exceeding the benefits. In response, the implementing partner decided to target weekend services more specifically by offering testing at inpatient and maternity services and for high-risk individuals, such as the family members of ART clients.

In Tanzania, URC appointed a pediatric quality improvement focal point at each facility. The focal points were accountable for each facility’s targets for HTC (and other areas of pediatric HIV) and the navigation of children across different HIV testing, care, and treatment service points. Also in Tanzania, a PITC Quality Improvement Collaborative brought ACT implementing partners (Ariel Glaser Pediatric AIDS Healthcare Initiative (AGPAHI), CSSC and ICAP) together with the Ministry of Health, NACP and regional health management teams. The intervention focused on 25 health facilities in two regions (Geita and Simiyu) and targeted children under 15 years admitted to pediatric/adult wards or attending TB clinics. It involved quality improvement teams at each site developing and testing “change ideas” (to improve systems and processes). The teams were supported by site-level coaching and learning sessions (to share ideas and analyze results). Overall, the process identified 27 successful “change ideas”, such as conducting daily monitoring of pediatric PITC during clinical rounds, including pediatric PITC in handover reports between shifts and operating a “no child discharged without knowing HIV status” campaign. The collaborative saw rapid and important results during its 11-month intervention period (May 2015–March 2016). For example, 16,569 children (66% of the total of 25,282 admitted) received PITC. Of those children, 263 (1.6%) tested HIV-positive and 255 (97%) were enrolled in care. A further result was that the number of days with stock outs of test kits reduced from 8.8 per month to 1.5.

In Kenya, data used in an evaluation of the UCSF FACES family model for HTC helped demonstrate the strategy’s benefits compared to programwide inpatient and outpatient testing (see Case Study 9). In Malawi, Jhpiego found that an HIV testing services quality assurance system that combined regular quality-control samples and proficiency tests of HDAs with strong supervision improved the quality of their HTC interventions.
**ACT’S PROMISING PRACTICES AND LESSONS LEARNED**

Such measures were supported by a range of tools to strengthen the gathering and use of data. Many of these tools aided the screening of clients in order to improve the effectiveness of facilities’ targeting. For example, in Kenya, CHAK used a tally sheet in its outpatient and inpatient departments that listed HIV status as a mandatory field for information-collection about clients. This helped identify children eligible for testing. Similarly, in Malawi, EQUIP/Partners in Hope used a pediatric HTC screening tool that involved asking seven screening questions of 1,870 pediatric inpatients admitted to wards and provided with HTC. A study of the tool found that the children with specific answers to the screening questions were four times more likely to test HIV-positive.

**CASE STUDY 9: EVALUATING A FAMILY MODEL FOR PEDIATRIC HIV CASE FINDING UCSF-FACES, KENYA**

In Kenya, ACT operated in a context where fewer than half of all children 18 months to 14 years old with a parent living with HIV had ever been tested for HIV. The situation was particularly critical in the Nyanza Region, where, at 15.1%, HIV prevalence was nearly three times the national average. Here, UCSF FACES became a leader in the family model of care for finding and following up with HIV cases among children. The ACT implementing partner developed a step-by-step approach that went from enrolling index patients and supporting their disclosure to testing all of their family members and initiating those found HIV-positive in care and treatment. The process was supported by a comprehensive set of family services, such as family-centered counseling and clinic appointments.

*Figure 9: The family model of care approach used by UCSF FACES*

- Enroll index patients
- Assist disclosure
- Test all family members
- Enroll all family members who are HIV-positive

**Family-centered counseling and education**

- Family-centered clinic appointments and follow up
- HIV prevention services
- Comprehensive HIV care and treatment
- Counseling and support groups (eg. family planning, psychosocial)
- Caregiver, adolescent, and children’s clubs

**CONTINUOUS FAMILY TESTING REVIEW AND FOLLOW UP**
3.3. LESSONS LEARNED ABOUT PILLAR 3

Box 7: Lessons learned from implementation of ACT Pillar 3

To support pediatric HIV case identification, it is important to:

• Prioritize proactive and systematic HIV case-finding strategies, including the use of index/family testing and the provision of testing in high-yield services (such as TB and malnutrition clinics).

• Ensure that the infrastructure for HIV testing, such as laboratories and supply chains, is prepared to cope with scaled-up demand.

• Take quality improvement measures to ensure a balance between increasing the quantity of HTC services and maintaining their appropriateness and effectiveness for children.

• Collaborate with all relevant stakeholders to identify and address specific bottlenecks in the HTC cascade, such as long turnaround times for EID results.

• Integrate HTC within other routine pediatric health services (such as vaccination) that appeal to parents and help address HIV-related stigma.

• Ensure that the spaces in which HIV testing is conducted are appropriate, confidential, and comfortable for children.

• Provide ongoing support for parents to disclose their own HIV status to their families, as a step that makes it more likely for their children to access HTC.

• Develop national information systems that disaggregate HTC data (such as by different ages), enabling active analysis of the testing rates and results for different groups.
ACT’S PROMISING PRACTICES AND LESSONS LEARNED

PILLAR FOUR: LINKAGE TO HIV CARE AND TREATMENT SERVICES

4.1. INTRODUCTION TO PILLAR 4

This pillar focused on ensuring that, once their status was known, children living with HIV were efficiently and effectively connected to the HIV care and treatment services needed. This required strong links between HTC and ART services, as well as coordination with wider support services for children’s and adolescents’ health and well-being, such as nutrition, social welfare, and SRHR.

ACT’S PROGRAMMATIC PILLARS

PILLAR 1: Policy for pediatric HIV services
PILLAR 2: Community engagement
PILLAR 3: HIV case identification
PILLAR 4: Linkage to HIV care and treatment services
PILLAR 5: HIV treatment initiation, monitoring, adherence, and retention
PILLAR 6: Strategic information for pediatric HIV
PILLAR 7: Domestic resource commitment for pediatric HIV services

4.2. PROMISING PRACTICES UNDER PILLAR 4

A. STRENGTHENING REFERRAL SYSTEMS FOR HIV CARE AND TREATMENT FOR CHILDREN

Many of ACT’s implementing partners standardized and strengthened referral systems to ensure that, for children testing HIV-positive, care and treatment services were both available and accessible. This included improving mechanisms and information systems to streamline clients’ journey between HIV testing points and other services – those focused on HIV and those for children’s wider needs. Technical assistance was provided to improve the functionality of referral systems, such as in terms of their coverage and efficiency.

As an example, in Kenya, the University of Nairobi-COE collaborated with Nairobi County to develop a county-level linkage directory, which contributed to the organization achieving a 97% increase in the number of newly diagnosed children being linked to and enrolled in HIV care. Meanwhile, some implementing partners, such as MDH in Tanzania (see Case Study 10), made innovative use of communication technology to strengthen their referrals.
In Tanzania, MDH used WhatsApp to strengthen communication between different people and institutions involved in pediatric HIV, including those responsible for the linkage and referral of children testing HIV-positive. The stakeholders included clinicians, county health management teams, nurses, drivers, and laboratory technicians. The approach centered around a core Pediatric WhatsApp Group that, in turn, was linked to smaller groups, such as of mentors or data management staff.

The use of WhatsApp helped the implementing partner reduce misunderstandings among the cadres (both within the same facility and across different facilities), build shared ownership of the work, and speed up processes. Specific results included that it contributed to MDH improving the efficiency of its referral systems and achieving an 89% linkage rate of children living with HIV to care. In addition, WhatsApp helped MDH reduce the turnaround time for DBS results (from 3 weeks to 4 days) and to increase the proportion of DBS results being delivered to mothers (to 79%).
B. INVOLVING VOLUNTEERS AND PEERS IN LINKING CHILDREN TESTING HIV-POSITIVE WITH CARE AND TREATMENT

Peer- and volunteer-based interventions were particularly vital for strengthening the success rate and cost efficiency of linking children living with HIV to care and treatment services. The following are examples of the type of peers and volunteers involved:

- **Expert clients.**
  In Malawi, Jhpiego trained people living with HIV to serve as expert clients to link children living with HIV to treatment services and to trace children who missed appointments, including through the use of cell phones.

- **Community health workers.**
  In Zambia, implementing partners brought community health workers and facilities together in a “track, trace, and link” strategy to target every child known to have tested HIV-positive but not yet on ART (see Case Study 11).

- **Peer educators.**
  In Kenya, KCCB-KARP combined the use of linkage registers and peer educators to accompany all children identified as HIV-positive to care and treatment services. This contributed to a 97% linkage rate between different facilities.

- **Support groups.**
  In DRC, implementing partners used adolescent and mentor mother support groups to help children who tested HIV-positive and their families by linking them to care and treatment services.

- **Parent/guardian forums.**
  In Cameroon, CBCHS used parent/guardian forums to educate families about how, with treatment, children living with HIV could lead productive lives. These forums contributed to increased levels of linkage as part of CBCHS’s family model, leading to more than 98% of children identified as living with HIV being initiated on ART.

A feature across many of these interventions was the physical accompaniment of children between testing sites and care and treatment services, whether in the same or different health facilities. The rationale was to ensure that children not only physically reached the required services, but did so in a friendly, supportive way. This approach helped address HIV-related stigma (often a particular challenge for adolescents) and increased their likely uptake of and retention in services. Often, accompaniment was supported by actions within care and treatment facilities, such as with patient flows reorganized to ensure that children newly diagnosed as HIV-positive were fast-tracked.
CASE STUDY 11: USING VOLUNTEERS TO ‘TRACK, TRACE AND LINK’ CHILDREN – FHI 360, ZAMBIA

In Zambia, fewer than half of children identified as HIV-positive were being initiated on ART. In 2016, during a seven-month extension to its program, Zambia Prevention, Care and Treatment (ZPCT) II Bridge – an initiative led by FHI 360 in collaboration with the government and the Ministries of Health and Community Development and Mother and Child Health–set a target of initiating 11,000 children on treatment. To achieve this, ZPCT II Bridge developed a two-pronged strategy:

1. Clearing the backlog of children known to be HIV-positive but not initiated on treatment. This step started with a mapping of community groups working in the catchment areas of facilities supported by ZPCT II Bridge. Subsequently, the groups, such as neighborhood health committees, faith-based organizations, and support groups for people living with HIV, were engaged to follow up with children known to be HIV-positive but not yet on treatment. The groups were given orientation to the work, including agreed procedures and milestones. Progress reviews were carried out every two weeks.

2. Initiating all newly diagnosed children on treatment and linking them to care, with intensive monitoring.

This involved strategies at the following levels:

a. Facility level: An additional 110 lay counselors were deployed to provide HTC in all inpatient wards for children in 16 major hospitals with high patient volumes. To ensure the availability of treatment, additional clinicians were placed in 16 high-volume facilities to support children’s initiation on ART immediately after their diagnosis or referral.

b. Community level: The Zambian Network of People Living with HIV located member households and, with consent, conducted HIV testing for their children. Those children found HIV-positive were referred for care and ART.

The ZPCT II Bridge strategies led to increases in children living with HIV (both backlog cases and newly diagnosed) being initiated on ART, achieving progress towards Zambia’s 90-90-90 national treatment targets.
C. DEPLOYING SPECIALIZED HUMAN RESOURCES TO LINK CHILDREN TO HIV CARE AND TREATMENT

Similar to Pillar 3, ACT’s ongoing use of volunteers and peers was complemented by the deployment of specific cadres of human resources to improve the quantity and quality of linkage to HIV care and treatment. These personnel played broadly similar roles but with different levels of technical expertise and responsibility. Examples in different countries include the following:

• **Linkage agents.**
  In Cameroon, EGPAF used these agents to physically link children testing HIV-positive to care and treatment services. As of September 2016, this contributed to an average 91% of children testing HIV-positive being linked to ART.

• **Linkage care navigators.**
  In Kenya, the University of Nairobi-COE provided physical and psychosocial accompaniment for children who tested HIV-positive, ensuring their same-day enrollment in the National Hospital Comprehensive Care Centre or referral to another site. This contributed to a 97% increase in the number of children newly enrolled in HIV care.

  - **Linkage nurses.**
    In Malawi, EGPAF used linkage nurses in health facilities to ensure that EID was integrated into all maternal, newborn, and child health services; PITC was routinely conducted in key locations (nutrition rehabilitation units, pediatric wards, and under-5 clinics); infants and children testing HIV-positive were linked to care and treatment; and missed appointments for ART were identified and addressed. Their work was complemented by linkage data being reviewed in quarterly program review meetings and discussed by the district health management team. The presence of linkage nurses in district hospitals and Mzuzu Central Hospital contributed to the
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number of children discharged with known HIV status rising to 81% in April-June 2016. It also contributed to 97% of children testing HIV-positive through Know Your Child’s Status days being linked to care and treatment.

• **Linkage officers.**
  In Kenya, ICAP deployed these officers with a linkage register to locate children newly diagnosed with HIV and identify those not yet enrolled in care and treatment. The officers provided phone and text appointment reminders to caregivers and, where necessary, physically traced missing clients. The register enabled them to conduct a real-time assessment of each client, identifying any specific reasons for nonlinkage, such as in the case of a child dying or declining treatment. This information enabled the program to develop solutions, such as strengthening post-test counseling or increasing support for disclosure. The strategy contributed to 92.8% of the 4,409 children found HIV-positive being enrolled in care.

• **Linkage experts.**
  In Malawi, Baylor College of Medicine Children’s Foundation deployed linkage experts, using an approach that included identifying a linkage focal person, improving postdiagnosis counseling, using a linkage register, and having expert clients and community health workers track patients who missed appointments. The approach contributed to increases in both the linkage between HTC and care services and the initiation of treatment.

• **HTC linkage trackers.**
  In Kenya, linkage trackers were recruited, trained, and deployed by UCSF FACES to work alongside HTC counselors and HTC leads. They were complemented by wider teams, including nurses, laboratory staff, adolescent peer educators, and data technologists. The benefits of this scaled-up workforce included that 100% and 79% of children and adolescents (respectively) who were tested for HIV and found HIV-positive were linked to and enrolled in HIV care. In addition, 95% and 56% (respectively) were initiated on ART.

The ACT Initiative often involved strengthening the performance of personnel, including efforts to encourage and mobilize health care workers. In Kenya, CARE instituted a system whereby those staff members conducting HTC were expected to take personal responsibility (with the support of adolescent and parent peers) for linking every child testing HIV-positive to care and treatment. This was backed up by the sharing of data, on a weekly basis, within the program and with the government, as well as monthly meetings to review staff performance. This system contributed to CARE seeing a rise in the level of linkage of children to care and treatment from 82% in the first quarter of its project to 88% in the fourth quarter.

In Zimbabwe, ACT introduced two new results-based financing indicators to incentivize personnel and facilities to provide HIV testing and initiate children on treatment. Similarly, in Kenya, PATH used a performance-based incentive practice to encourage health care
workers to reach high levels of children’s enrollment in care and treatment. This practice contributed to an increase in PATH’s linkage rates in both high- and low-burden counties, from 86% in 2015 to 94.3% in 2016.

Many implementing partners used strategic information tools and processes to strengthen the quality of staff and volunteers’ linkage work in order to meet their ambitious targets and address any underperformance. In Cameroon, CBCHS instituted HIV task teams at every point of entry to improve the identification, testing, and linkage of all HIV-positive cases to the ART clinic. Members were required to bring their entry point reports to a monthly task team meeting so they could be reviewed and validated before being included in the program’s formal reporting.

In Maputo City, Mozambique, CCS conducted weekly monitoring of PCR test results for children under one year of age to ensure timely delivery of test results to mothers and, in the case of children testing HIV-positive, rapid linkage to care and treatment. This weekly EID monitoring was supported by a monthly evaluation, using all available data and reporting tools, of the program’s linkage rates and ART coverage. A comparison between data for October 2014-June 2015 and July-September 2016 showed an increase in ART coverage for infants living with HIV from 53% to 83%.

### 4.3. LESSONS LEARNED ABOUT PILLAR 4

**Box 8: Lessons learned from implementation of ACT Pillar 4**

To ensure linkage to HIV care and treatment services, it is important to:

- Use diverse strategies (such as accompaniment, texts, and phone calls) to prevent any delay in children’s linkage to HIV care and treatment.

- Address bottlenecks to effective linkage, for example by providing treatment services on weekends or reorganizing patient flows in facilities to fast-track children who test HIV-positive.

- Use strategies that emphasize the rapid linkage of children living with HIV from HTC services to treatment, aiming for same-day enrollment.

- Address age-specific challenges to effective linkage, such as HIV-related stigma and fear of disclosure among adolescents living with HIV.

- Use peer support to improve the comfort level and acceptability – among parents, caregivers, and children – of children living with HIV being linked to care and starting treatment.

- Invest in partnership and shared standards with other facilities to facilitate effective referrals from HIV testing to care and treatment services.
PILLAR FIVE: HIV TREATMENT INITIATION, MONITORING, ADHERENCE, AND RETENTION

5.1. INTRODUCTION TO PILLAR 5

This pillar focused on ensuring that, once identified as HIV-positive and linked to care and treatment, children received the comprehensive, high-quality services needed to successfully start and adhere to ART. This, in turn, helped them achieve and maintain viral suppression. It involved a continuum of support and services provided within facilities and communities.

5.2. PROMISING PRACTICES UNDER PILLAR 5

A. IMPLEMENTING TAILORED MODELS OF CARE AND TREATMENT FOR CHILDREN LIVING WITH HIV

An essential feature of the ACT Initiative was the development and implementation of tailored (or “differentiated”) models of care and treatment for children and adolescents living with HIV. These models were based on national policies and aimed to ensure high levels of initiation, monitoring, adherence, and retention within services. The models were specific to the clinical and social needs of children and adolescents and were informed by the lessons of adult treatment programs.

Many of ACT’s implementing partners provided tailored services for specific target groups. For example, in Mozambique, Fundação Ariel Glaser Contra o SIDA Pediátrico provided family clinics (see Case Study 12). In Malawi, Jhpiego established mother/infant pair clinics at all 52 of its ACT-supported sites. These clinics functioned as a one-stop shop for mothers and their HIV-exposed infants, serving to both reinforce PMTCT messages and ensure access to infant testing. The clinics made an important contribution to Jhpiego’s overall results, with 3,552 EID DNA PCR tests being performed. As a result, 86 infants (2.4%) were found HIV-positive, and all of them were initiated on treatment.
Population-specific services appealed to clients, because they combined a safe space with tailored support. They also helped health care workers by providing an opportunity (away from other duties) to focus on the specific needs of mothers, children, and adolescents living with HIV. In Kenya, Amref found that, by separating children’s and adults’ services in high-volume health facilities, as well as by scheduling such clinics on specific days (such as Saturdays), there was increased uptake of services and reduced absenteeism among children.

CASE STUDY 12:
PROVIDING FAMILY CLINICS TO SUPPORT CHILDREN LIVING WITH HIV - FUNDAÇÃO ARIEL GLASER CONTRA O SIDA PEDIÁTRICO, MOZAMBIQUE

Figure 12: Retention of children living with HIV in care and treatment services in sites with or without a family approach
Fundação Ariel Glaser Contra o SIDA Pediátrico used a family approach in 11 health facilities in Cabo Delgado and Maputo Provinces, Mozambique. The model originated in Machava General Hospital and was adapted to ACT, with emphasis on the retention of pediatric clients. It involved all family members being seen at the same time at the same HIV clinic and receiving a package of family services, including testing. Family members living with HIV had their clinical appointments (such as to address adherence and disclosure issues) together, provided by the same doctor. ARV prescriptions and laboratory samples were also carried out for all family members.

Although the implementing partner had used the family approach since 2011, the resources for ACT enabled it to scale up the work in the two provinces. It found that, compared to other (control) health facilities, the approach led to significantly better rates of retention in care and treatment for children living with HIV.

Implementing partners found that it was especially important to provide tailor-made care and treatment for adolescents living with HIV. As illustrated in Case Study 13, this involved using a range of creative, innovative strategies, including attention to communication materials and service-delivery methods.

One popular approach was Adolescent Clubs (also known as Teen Clubs). These clubs commonly combined psychosocial support (such as discussions about positive living) with access to health information (such as on SRHR) and treatment services (such as viral load testing). They were tailor-made to the specific needs of young people living with HIV. For example, in Kenya, Teen Clubs provided by the University of Nairobi-COE supported adolescents in transitioning from child to adult ART services, thus improving their retention in care and viral load suppression.

Adolescent Clubs took place in an adolescent-friendly environment that was confidential, nonjudgmental, and enjoyable (for example, with social and sports activities). The clubs were often led by adolescents trained as peer mentors and supported by counseling and clinical personnel. This approach brought concrete benefits. For example, EQUIP, which provided seven Teen Clubs for more than 900 adolescents in Malawi, saw increased rates of adolescents accessing ART and viral load testing. Similarly, in Tanzania, Deloitte Consulting Limited found that combining clubs with psychosocial support led to increased levels of adolescents initiating, adhering to, and being retained in ART.

As an alternative or complement to these clubs, some implementing partners provided psychosocial support groups. As examples, in Mozambique, CCS provided pediatric and adolescent support groups, while in Kenya, University of Maryland linked all children enrolled in care to a psychosocial support group for them and their parents/caregivers.
In addition to population-specific approaches, implementing partners also established differentiated models of care for children and adolescents at different stages of living with HIV. For example, in Kenya, UCSF FACES used a model for adolescents with stable viral suppression that enabled them to refill their prescription for ARVs at home or at school.

CASE STUDY 13:
ACT INSIGHTS INTO PROVIDING SPECIFIC SUPPORT FOR ADOLESCENTS LIVING WITH HIV

ACT produced valuable lessons on supporting adolescents along the HIV care and treatment cascade. Even though they share common issues with children and adults living with HIV, adolescents can face additional or heightened needs. They are going through a specific time in their lives – one characterized by physical, social, and emotional change. Typical adolescent challenges, such as about relationships, social anxiety, and becoming sexually active, can be compounded by HIV – and vice versa. For example, adolescents living with HIV might experience intense social stigma, lack relevant sexual health information, need to change their HIV medications, or face logistical difficulties (such as with ART clinics only open during school hours). These factors can lead to situations in which, for example, adolescents stop taking ART. At this crucial time, they may find themselves “falling between the gap” of HIV services, fitting neither those designed for children nor those for adults. ACT’s implementing partners used a range of strategies to understand the specific needs of adolescents living with HIV and to provide appropriate care and treatment.

Figure 13: A page from Binti and Mwas—a comic book for adolescents living with HIV in Kenya
**ACT’S PROMISING PRACTICES AND LESSONS LEARNED**

- **Listening to adolescents.**
  In Kenya, UCSF FACES used focus group discussions with adolescents living with HIV to better understand and address their barriers to improving viral load suppression rates.

- **Acknowledging adolescents’ specific needs.**
  In Tanzania, AGPAHI found that talking about sensitive issues, such as unprotected sex, was difficult in support groups involving a mixed age range of children. In response, AGPAHI separated out the older participants and introduced peer education, enabling the adolescents to discuss their issues freely.

- **Using peer educators.**
  In Kenya, ICAP trained more than 60 adolescent peer educators to provide support groups and one-on-one support for other young people living with HIV.

- **Providing adolescent clubs.**
  In Tanzania, AGPAHI used adolescent clubs, which combine psychosocial support with care and treatment services, to provide a safe space for those living with HIV.

- **Providing adolescent-only clinics.**
  In Mozambique, CCS implemented Servico Amigo do Adolescente e Jovem – one-stop-clinics for adolescents living with HIV that combined SRHR services with HIV care and treatment, plus peer education for behavior change.

- **Training health care workers in adolescent-friendly approaches.**
  As seen in Case study 17, a model was used in Zimbabwe that combined facility-and-community-based support for adolescents and trained health care workers in HIV care, treatment, and psychosocial support for young people.

- **Using adolescent-friendly communication.**
  As seen in Case Study 3, in Mozambique, implementing partners used social media, such as Facebook, within the Saber é Viver awareness-raising campaign for adolescents.

- **Addressing policy barriers for adolescents.**
  In Kenya, ACT’s implementing partners increased opportunities for HTC by using the country’s reduction in the legal age of consent for HIV testing (from 18 to 15 years).

- **Producing tailor-made resources for and about adolescents.**
  As seen in Case Study 16, in Kenya, the University of Maryland School of Medicine collaborated with the Ministry of Health and NASCOP to produce a guide for health care workers on caring for adolescents living with HIV, as well as a comic for use by adolescents themselves (see Figure 13).

- **Providing adolescent-specific initiatives.**
  In Kenya, implementing partners supported Operation Triple Zero, which focused on improving viral suppression rates among adolescents living with HIV through attention to “zero missed appointments, zero missed drugs, and zero viral load.” It was based on voluntary enrollment, with the ultimate aim that those participating would be transitioned to a model of care for HIV-stable adolescents.

- **Using strategic information about adolescents.**
  As seen in Case Study 19, in Kenya, EGPAF developed an ACT dashboard that, in 2017, will include age-disaggregated data to enable the tracking of specific indicators.
B. STRENGTHENING HUMAN RESOURCES TO SUPPORT CHILDREN ACCESSING HIV CARE AND TREATMENT

Many of ACT’s implementing partners took steps to strengthen the capacity of human resources related to pediatric HIV care and treatment. These approaches aimed to ensure that health care personnel had the knowledge, skills, and attitudes needed to provide high-quality support based on national policies and international guidelines. The work often combined a focus on clinical expertise (such as in pediatric ART regimens) with attention to child-friendly approaches. It included the following practices:

• **Formal training.**
  For example, in Mozambique, ICAP set up pediatric training centers to train 76 health care workers in FY 2016. In Tanzania, Deloitte Consulting Limited trained health care workers through a national curriculum on initiating and monitoring pediatric HIV treatment.

• **Centers of Excellence.**
  In Cameroon, EGPAF/United States Centers for Disease Control and Prevention (CDC) supported the establishment of four Pediatric Training Centers of Excellence and a National Pediatric HIV Management curriculum to train personnel and decentralize capacity and services (see Case Study 14).

• **On-site mentorship.**
  In Tanzania, AGPAHI and other ACT implementing partners developed a sit-in approach, with mentors attached to each facility to support health care workers (see Case Study 15). Also in Tanzania, Baylor College of Medicine Children’s Foundation followed up capacity building of training-of-trainers and clinical mentors with on-site coaching. This approach helped people translate their new knowledge into practical skills and solve the day-to-day challenges of patient care.

• **National Warm Line.**
  In Tanzania, EGPAF supported a Warm Line (similar to a hotline, but run by peers) to ensure ongoing technical support to mentors and health care workers involved in pediatric HIV care and treatment. The line had a mobile application to enable communication through text messages, calls, and group discussions, including between district and master mentors. It also had a web-based forum to facilitate the discussion of complicated pediatric cases among mentors, health care workers, and policymakers at different levels. The Warm Line was supported by the Ministry of Health and Community Development, Gender, Elderly and Children, which instructed regional and district-level health management teams to use it as a national tool.

As described under Pillar 1, these efforts were often enhanced by national policy changes related to human resources. An important example was nurse-initiated ART, which was a critical task-shifting step that helped increase the efficiency and effectiveness of the care and treatment cascade.
In many contexts, these efforts were also backed up by the production of tools and guides. As seen in Case Study 16, in Kenya, the University of Maryland School of Medicine produced user-friendly, practical toolkits for health care personnel, including a Guide for Caring for Children and Adolescents Living with HIV\(^{17}\). The implementing partner also produced resources for use by infants, children, and adolescents that were focused on practical and positive messages about living with HIV.

**CASE STUDY 14:**
**ESTABLISHING PEDIATRIC TRAINING CENTERS OF EXCELLENCE – EGPAF, CAMEROON**

In Cameroon, the government adopted task shifting for pediatric HIV in 2013, but it was not systematically practiced. Also, there was no national technical working group on pediatric care and treatment, and clinical work was dominated by a few specialists in tertiary hospitals. In 2015, at the start of ACT, this scenario was resulting in low uptake (~5\%) of ART among children living with HIV, as well as poor-quality services. Two of the gaps were related to the training and mentoring of nonspecialist health care workers (notably, general practitioners and nurses) on high-quality case management of children living with HIV and the decentralization of pediatric care and treatment.

In response, EGPAF – Cameroon supported the establishment of four Pediatric Training Centers of Excellence to serve as training and mentoring sites for health care workers, as well as hubs for expertise in high-quality clinical pediatric care and treatment. The centers are based in each of the PEPFAR-supported regions of the country (Centre, Littoral, North West, and South West). All of the staff involved (including the managing directors, nurses, and social workers) underwent training and mentoring on the management of pediatric HIV, based on an EGPAF-supported National Pediatric HIV Management curriculum. In turn, training and mentoring were provided to high-volume HIV facilities around the centers. The latter led to pediatric services being decentralized to such facilities and patient flows being reorganized. In total, during the timeframe of ACT, 517 health care workers received training.
Caring for children living with HIV can be complex. Calculating the right dosage of medication for young, growing bodies is difficult, and children’s nutrition must be regularly monitored. Diagnosing complicated HIV-related infections for any patient is hard enough, but it is even harder when children are too young to answer a clinician’s probing questions. It is no wonder that nurses inexperienced in pediatric HIV care are uncomfortable treating children, for fear they may do more harm than good.

Enter the mentor. Hands-on coaching of clinicians is rare, especially for the treatment of children with HIV. Yet, since mid-2015, mentors have swarmed 24 health centers supported by ACT in Shinyanga, Tanzania, to increase nurses’ skills and confidence in treating children living with HIV. A team of six mentors from AGPAHI have tripled the coaching time they normally spend with nurses to as many as three or four days per quarter. Between visits, the mentors check in by phone to consult on difficult cases and update progress against action plans. Their name for this — the sit-in approach — is fitting. Mentors attach themselves to each facility, advising on every aspect of pediatric care.
They ease the congestion in crowded clinics, make sure drugs are in stock, document records, offer strategies to deal with stigma and disclosure, and, of course, examine patients. The AGPAHI mentors were augmented by a team of 18 government mentors from local district facilities. Trained by the ACT-supported Baylor International Pediatric AIDS Initiative, the district coaches work with nurses in lower-level clinics. They also provide mentoring capacity within the government system to help sustain the gains of ACT.

One challenge common to lower-level nurses is calculating the proper drug dosage for a child’s changing weight and age. Underdosing can be dangerous, leading to complications like pneumonia, but busy nurses often fail to adjust prescriptions on time. “After mentoring, everything changes,” said Flora Silutongwe, a district mentor. “They learn to prescribe and document the cases properly, and health outcomes improve dramatically.”

One result is that ACT-supported facilities have seen a significant drop in the number of deaths among pediatric HIV patients. Coupled with a change in the national policy in December 2015, which allowed more children to be initiated on HIV treatment, the mentoring triggered a 58% drop in deaths from 2015 to 2016.

Figure 15: HIV-related deaths among children under 15 years at four ACT-supported facilities
The value of the sit-in approach is most apparent with complicated cases. One morning, Fidelis Temba, a clinical program officer, examined Stephano Daudi, a four-year-old boy who had been on HIV treatment for two years. Josephine Masesa, an HIV nurse at Ushetu Health Centre, observed closely. Temba questioned Stephano’s mother and discovered that the child is three months late for a blood test to monitor the effectiveness of his treatment. Temba noted the boy’s pale complexion and off-and-on fever. His distended belly suggested a case of parasitic worms, since his quarterly deworming treatment was also three months late. Thus far, it was a run-of-the-mill case. However, Temba then explored the family’s medical history and grew anxious. Stephano’s father, also living with HIV and on treatment, had been diagnosed and given treatment for TB, and it’s not clear if he had fully recovered. Stephano’s mother, also living with HIV, had not yet started treatment, which could have meant trouble for Stephano should she become ill and unable to care for him.

The exposure to TB, plus the potential for anemia and malnutrition that could result from the case of worms, could be severe. Temba prescribed immediate deworming treatment and an antibiotic to quell Stephano’s fever. He also ordered a test to ensure that Stephano’s treatment was fully suppressing the HIV virus. Temba made an appointment for his mother to start treatment the following week.

The risks in Stephano’s case could have been easily missed, and the lesson was not lost – even on an experienced HIV nurse like Masesa. Sometimes with long queues of patients, she says, nurses forget or don’t take the time to fully complete patient examinations, like reviewing the family’s health history. After the session with Temba, Masesa said, “We will fill [the health history] out, and we will know why.”
CASE STUDY 16:
PRODUCING TAILOR-MADE RESOURCES FOR PEDIATRIC HIV CARE AND TREATMENT – MARYLAND UNIVERSITY SCHOOL OF MEDICINE, KENYA

In Kenya, the University of Maryland School of Medicine collaborated with the Ministry of Health and NASCOP to produce a series of resources to support pediatric HIV care and treatment. These resources included the following specifically designed for use by children and adolescents living with HIV:

- *Binti Mzuri* – a story book about a five-year-old girl living with HIV (see Figure 17)
- *Binti and Nurse Anna* – a picture book for 10-12 years olds living with HIV
- *Binti and Mwas* – a comic book for adolescents living with HIV, addressing issues such as peer pressure, adherence, psychosocial support, viral load and disclosure (see example page in Case Study 13)

Figure 17: A page from Binti Mzuri – a story book about a five-year-old girl living with HIV

Mama Binti asks Nurse Anna what they should do to keep Binti healthy.

Nurse Anna tells Mama Binti not to worry. She will give Binti medicines called A-R-Vs, which will keep Binti healthy and strong.
The resources also included technical materials to support health care workers, such as a Guide for Caring for Children and Adolescents Living with HIV. The guide provides a comprehensive toolkit, with sections on minimum package of care, pediatric HTC tool, clinical assessment, opportunistic infections, nutrition care and support, psychosocial support, adolescent wellness, legal considerations, and caregiver support. The guide sets out clear, user-friendly information and algorithms based on national policies and guidelines, such as on recommended ARV regimens for children.
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C. ENSURING COMMUNITY-BASED SUPPORT FOR CHILDREN LIVING WITH HIV

Of critical importance throughout ACT, the work of facility-based personnel was complemented by peer, volunteer, and community support for the initiation, monitoring, adherence, and retention in HIV treatment of children and adolescents. A strong example of this was mentor mothers, whose other roles were described in Case Study 4. In countries such as Mozambique, where EGPAF supported a communications platform to exchange information and support among women, the mentor mother approach reinforced facility-based services—in particular, by increasing the retention of mothers and infants in care and treatment. A similarly strong community-based model, which also worked in close collaboration with facilities, was Community Adolescent Treatment Supporters (CATS), as used in Zimbabwe (see Case Study 17).

Jonathan B. Levine, 2016
CASE STUDY 17: DEPLOYING COMMUNITY ADOLESCENT TREATMENT SUPPORTERS – ZIMBABWE

In Zimbabwe, ACT implementing partners used CATS, a youth-led model, to provide a continuum of care and treatment for adolescents living with HIV. The model combines services at health clinics (such as counseling, youth corners, and referrals to other services) and communities (such as home visits, support groups, and the tracing of clients lost to follow-up). The model was found to bring benefits to adolescents’ HIV care and treatment, such as with higher levels of adherence to ART and increased retention in treatment.

Figure 19: CATS model providing a continuum of care for children and adolescents living with HIV

The CATS model also improved adolescents’ overall health – for example, with increased psychosocial well-being and better access to wider services, such as for SRHR. Overall, CATS made an important contribution to the national Accelerated Action Plan for Pediatric HIV Treatment, which provided a framework for ART coverage among children living with HIV to reach 80%.
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D. STRENGTHENING CASE MANAGEMENT FOR CHILDREN LIVING WITH HIV

A further promising practice was the improved management of pediatric HIV cases, including those that were complex. In Kenya, the University of Nairobi-COE instituted a system of individual case management involving a multidisciplinary team and collaboration with the Ministry of Health for children failing first- or second-line ART. Such systems were backstopped by implementing partners’ ongoing processes of coordination and information exchange among relevant stakeholders. For example, in Mozambique, CCS instituted pediatric teams that involved pediatric advisors, pediatric provincial managers, and pediatric officers, alongside personnel involved in HTC, psychosocial support, monitoring and evaluation, and communications. The teams worked together to review their ACT-related progress and take strategic decisions. In some countries, such efforts were sometimes further enhanced by efforts to gain feedback from children and their parents/guardians on the services they received and suggestions for changes. For example, in Kenya, UCSF FACES conducted focus-group discussions among children and adolescents to hear their perspectives on how to improve support for viral suppression.

E. ADDRESSING GAPS IN THE PEDIATRIC HIV CARE AND TREATMENT CASCADE

A vital lesson from ACT was the need to identify quick, systematic ways to address breaks in the pediatric HIV care and treatment cascade. An example of such a break was children who were lost to follow-up. Typically, such children were identified as HIV-positive and initiated in treatment services, but then missed appointments at ART clinics. Implementing partners responded to this challenge in various ways. In Tanzania, AGPAHI and EGPAF used lay counselors and children/adolescent clubs to find and support children who missed clinic appointments. This approach contributed to an improved retention rate in ART services, from 78% in 2015 to 87% in 2016. In Zimbabwe, implementing partners deployed mother/infant pair trackers in communities.

In Tanzania, MDH used a “Promise to Come” register to encourage patients to take responsibility for and keep their regular appointments. Patients were asked to identify a convenient date for their next appointment and to sign up to it in the clinic’s diary. The day before the appointment, the clinic called the patient to confirm or reschedule the time. Through this system, MDH saw an increase in patients’ attendance rate at regular appointments, from 54% to 86%.

Another common break in the cascade was disclosure of HIV status. This was seen in different forms, such as with parents/guardians not disclosing a child’s HIV status to the child or adolescents not disclosing their status to others. In Kenya, ICAP provided intensive training and mentoring to health care workers in child-centered counseling to sensitively support parents to disclose their child’s HIV-positive status.
(see Case Study 18). Meanwhile, a further challenge to the cascade was adherence to ART, which was addressed by multiple implementing partners. For example, in Kenya, KCCB-KARP provided booster counseling sessions for adolescents and parents/guardians to specifically address adherence.

A notable feature of ACT was attention to viral load monitoring and suppression for children living with HIV. It typically involved a multilevel, multi-stakeholder approach. For example, some implementing partners integrated attention to viral load into the training of health care workers, the messages of peer educators, the sessions of adolescent clubs, and the strengthening of laboratory support. Many implementing partners reported promising results from this approach. For example, in Kenya, CHS achieved universal coverage of viral load testing for eligible patients at its clinics, with 73% viral suppression among children under 10 years old. It complemented its facility-based work with community-based initiatives, such as home visits to adolescents who were failing to achieve viral suppression, in order to identify and address the social factors affecting their adherence. Also in Kenya, KCCB-KARP scaled up the uptake of viral load testing among children across all of its facilities. It combined a line-listing process, supported by electronic medical records; improved laboratory networks (to speed up testing); and case discussions by multidisciplinary teams (to focus on children found with a detectable viral load, identify the reasons for their treatment failure, and develop an individual action plan).

**CASE STUDY 18:**
**SUPPORTING DISCLOSURE OF HIV STATUS FOR CHILDREN AND ADOLESCENTS – ICAP, KENYA**

A father in Nyanza Province, Kenya, had been apprehensive about informing his seven-year-old daughter that she was living with HIV. Like many parents, he had been putting off a difficult, yet essential, conversation. “Before today, he told her that the doctor visits and pill regimen would help ward off another bout of malaria,” said Kevina Simiyu, pediatric clinical officer. “It’s common for parents to tell children something else is wrong.” During a recent visit to a local hospital, the father received counseling from health care workers and gained the information and confidence needed to inform his daughter of her HIV status.

Despite the challenges of HIV disclosure involving children, it is becoming more frequent in Kenya. It is also increasing among adolescents, aided by changes in the country’s guidelines, which shifted the age of consent for HIV testing from 18 to 15 years. This change broke down one of the major barriers to reaching elusive adolescents. Young people once estranged from health care were, for the first time, entrusted to make decisions about their own health. Adolescents once reluctant to be open about their HIV status and seek treatment for fear of stigma from family and community members now had a place to go, while maintaining anonymity.
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Modeled on an adolescent HIV package of care developed by ICAP, NASCOP developed a structured approach to improve communication and counseling skills, adolescent mental health evaluations, and SRHR programming. Central to those changes was the start of adolescent-friendly services. ICAP restructured services at facilities to have designated days when only adolescents are seen. It also trained more than 60 adolescent peer educators who provide one-on-one support and lead support groups of other young people living with HIV. These peer workers interact with health care staff, giving them unique perspectives not often found in training sessions. Health care workers, once nervous about working with adolescents, now rely on the peers to improve their strategies and communication, such as related to disclosure. “We are working together as a team,” says Jackson Onsarre, clinical pediatric officer in Siaya County. “I have a greater sense of the challenges of growing up with HIV, and I think that makes me a better health care provider.” Since the project began, HIV services for adolescents have been launched at more than 125 ICAP-supported health facilities in Eastern South and Nyanza provinces.

Kevina Simiyu’s supervision of the father’s HIV disclosure to the young girl is a metaphor for Kenya’s new approach to pediatric HIV. Everyone has a seat at the table – especially children. Children and their families, an integrated and well-connected health care system, plus exceptionally trained health care workers all come together to share information and devise a way forward.

Everyone has some responsibility. The results of this multifaceted approach are evident. A year before the ACT Initiative, just over 8,500 children were tested for HIV in Kenya and 150 children living with HIV were identified per month at ICAP-supported facilities. After ACT, that number rose to more than 40,400 children and adolescents tested and more than 330 HIV cases per month. Over 91% of those found HIV-positive were linked to care. According to Dr. Elaine Abrams, ICAP’s Senior Research Director, these numbers are only part of the picture: “HIV services for children and adolescents are more holistic and everything is connected. We’ve established a strong platform to provide the essential services that children and families with HIV deserve.”
5.3. LESSONS LEARNED ABOUT PILLAR 5

Box 9: Lessons learned from implementation of ACT Pillar 5

For HIV treatment initiation, monitoring, adherence and retention, it is important to:

• Combine formal training of health care workers with on-the-job mentoring to translate new learning about pediatric HIV care and treatment into their daily responsibilities.

• Maximize lower levels of human resource cadres, such as lay adherence counselors and peer educators, to improve both the cost-effectiveness and quality of client care and follow-up.

• Emphasize the psychosocial component of care for children living with HIV, such as providing opportunities for them to socialize and access counseling.

• Ensure that national policies (such as on the age of consent) match the real lives and needs of adolescents, such as for HIV testing and treatment and for SRHR services.

• Use multiple methods, such as phone calls, texts, and visits by community health workers, to persistently follow up with children who default on treatment.

• Establish systems and build capacity to promptly and systematically address any breaks in the HIV care and treatment cascade, such as a child missing an ART appointment.

• Acknowledge and identify ways to address the specific, intensified challenges faced by adolescents living with HIV, such as becoming sexually active or fearing disclosure of their HIV status.

• Ensure that HIV care and treatment services are not only available but also logistically accessible to children, such as providing them at appropriate locations and times.
**ACT’S PROMISING PRACTICES AND LESSONS LEARNED**

**PILLAR SIX: STRATEGIC INFORMATION FOR PEDIATRIC HIV SERVICES**

6.1. INTRODUCTION TO PILLAR 6

This pillar focused on ensuring that the tools, processes, and systems were in place to collect accurate, useful strategic information about pediatric HIV care and treatment and to apply it to the setting and monitoring of targets and standards. This, in turn, would improve the effectiveness and efficiency of interventions.

**ACT’S PROGRAMMATIC PILLARS**

| PILLAR 1: Policy for pediatric HIV services | PILLAR 2: Community engagement | PILLAR 3: HIV case identification | PILLAR 4: Linkage to HIV care and treatment services | PILLAR 5: HIV treatment initiation, monitoring, adherence, and retention | PILLAR 6: Strategic information for pediatric HIV services | PILLAR 7: Domestic resource commitment for pediatric HIV services |

6.2. PROMISING PRACTICES UNDER PILLAR 6

A. DEVELOPING TOOLS TO COLLECT AND USE DATA ON HIV CARE AND TREATMENT FOR CHILDREN

ACT’s implementing partners developed a large number of tools to collect, analyze, and use data. Examples included a tally sheet for use at all entry points to capture facilities’ daily and weekly data on HTC and linkage to care and treatment (EGPAF – Cameroon); an Access Database for use in the reception of facilities to identify index clients not yet offered family testing (Coptic Hospital Hope Centre, Kenya); and a whiteboard for use at entry points to high-yield health facilities to capture real-time data and monitor the pediatric care and treatment cascade (Deloitte Consulting Limited, Tanzania).

In some countries, implementing partners developed dashboards to collect ACT data across different indicators and consolidate it in user-friendly formats, such as graphs. An example was provided by EGPAF in Kenya (see Case Study 19). Meanwhile, in Tanzania, EGPAF set up a specific national database to support the acceleration and systematization of EID. This EID database enabled facilities to communicate with laboratories about the status of DBS samples. After the samples were processed, the results were stored in an online system that, through a dashboard, allowed all districts and facilities to follow up test results online. In addition, 120 health facilities were capacitated to use a mobile application
CASE STUDY 19: DEVELOPING A NATIONAL ACT DASHBOARD – EGPAF, KENYA

In Kenya, to achieve the national 90-90-90 targets, a robust monitoring and evaluation system was vital. There was a need for improved data sharing and use at all levels - national, county, sub-county and facility. Initially, as a stopgap measure and using 2013 HIV estimates, EGPAF developed a Microsoft Excel-based, auto-updating ACT dashboard. This aimed to assist NASCOP, county governments and relevant stakeholders to: monitor progress towards the 90-90-90 targets in real time; identify the gaps across the HIV care and treatment cascade; and quickly identify data quality issues for follow-up with counties for prompt action. The dashboard was housed within the NASCOP website. However, as its use and importance grew, and as the limitations of Microsoft Excel became challenging, there was a need to develop a web-based dashboard. This will improve on versatility and flexibility and have the capacity to monitor progress down to the lowest levels.

Based on the Ministry of Health’s existing HIV data collection and reporting tools, the ACT dashboard only featured data on children and adults. However, in 2017, the Ministry will roll-out revised tools to capture data for children and adolescents, disaggregated by age and sex. The web-based dashboard will capture Kenya’s 2015 revised HIV estimates, plus age-disaggregated data for children and adolescents, for accurate performance monitoring across the 90-90-90 cascade.

Figure 20: Monitoring the 90-90-90 cascade through the national ACT dashboard
ACT’S PROMISING PRACTICES AND LESSONS LEARNED

B. IMPROVING THE QUALITY OF STRATEGIC INFORMATION ABOUT PEDIATRIC HIV

Quality improvement and assurance was a key principle and practice for ACT. As described across the pillars, many implementing partners took steps to institutionalize attention to issues of quality. As an example, in Tanzania, EGPAF conducted quality improvement projects to monitor selected pediatric HIV indicators by facility-based quality improvement teams, which were supervised by county health management teams.

A further principle was the collaborative review of strategic information, which aimed to build ownership and shared responsibility for ACT’s work by identifying not only results but also gaps and weaknesses. For example, in Kenya, Amref assessed data through facility-level reviews, as well as through county and subcounty technical working groups. In Malawi, Jhpiego continuously engaged in data and performance review with facility-level Ministry of Health staff, leading to the development of action plans to address bottlenecks. In some contexts, steps were taken to engage local leaders and communities in the collection and analysis of strategic information. In Mozambique, N’Weti used a community scorecard tool to monitor the quality of HIV treatment services and facilitate feedback on harmful policies and practices (see Case Study 20). In Kenya, Academic Model Providing Access to (AMPATH Plus) found that regular reviews of data with local stakeholders, such as community health workers, helped strengthen their motivation and build shared ownership of the program’s results.

CASE STUDY 20:
USING A COMMUNITY SCORE CARD – N’WETI, MOZAMBIQUE

In Mozambique, a number of factors were affecting the quality of services for pediatric HIV. Examples included breaches in confidentiality, low awareness of child rights, long waiting times at services, illicit charges, and stock-outs of medicines. In combination, these negatively affected the health-seeking behavior and retention in care and treatment of children living with HIV. Within ACT, one response (led by N’Weti, an implementing partner) was a community scorecard, which enabled local communities to monitor the quality of services provided by government health facilities and give feedback on areas for improvement. N’Weti targeted service users, people living with HIV, and their families in four provinces, engaging them in a multistep cycle from mobilization to information collection, meetings, and advocacy.
The community scorecard process contributed to important improvements in pediatric HIV care and treatment services, such as reduced waiting times, strengthened quality of care, better availability of ARVs, and reduced illicit charges. The process also helped improve ownership of the health facility, awareness of the right to health, and relationships between clients and service providers. The card provided service users with a voice to hold health facilities accountable for the quality of their services. It also provided them with a means to influence the planning and policies for services at all levels, including a method for taking priorities that lacked a local solution to higher levels, including through national advocacy.

Figure 21. N’Weti’s community score card cycle and links to different levels of advocacy on pediatric HIV
ACT’S PROMISING PRACTICES AND LESSONS LEARNED

6.3. LESSONS LEARNED ABOUT PILLAR 6

*Box 10: Lessons learned from implementation of ACT Pillar 6*

For strategic information for pediatric HIV services, it is important to:

- Have ambitious targets that encourage all relevant personnel to focus on priority pediatric HIV interventions and the quality of their work.

- Implement systems to create shared ownership of pediatric HIV data, not just within facilities but also across different facilities and stakeholders.

- Use collaborative reviews of data (involving all relevant stakeholders, such as local leaders and communities) to devise joint action plans to address areas of underperformance.

- At all levels, build a culture of not just collecting, but also interrogating, program data in order to identify gaps and necessary changes.

- Build national data systems that disaggregate HIV data not just for “children” and “adults” but also for specific age groups of concern to ACT, such as adolescents.

*Eric Bond/EGPAF, 2016*
ACT’S PROMISING PRACTICES AND LESSONS LEARNED

PILLAR SEVEN: DOMESTIC RESOURCE COMMITMENTS FOR PEDIATRIC HIV SERVICES

7.1. INTRODUCTION TO PILLAR 7

This pillar focused on supporting countries in strengthening the sustainability of ACT’s work and results by increasing the investment of domestic resources in pediatric HIV care and treatment.

ACT’S PROGRAMMATIC PILLARS

PILLAR 1: Policy for pediatric HIV services
PILLAR 2: Community engagement
PILLAR 3: HIV case identification
PILLAR 4: Linkage to HIV care and treatment services
PILLAR 5: HIV treatment initiation, monitoring, adherence, and retention
PILLAR 6: Strategic information for pediatric HIV
PILLAR 7: Domestic resource commitment for pediatric HIV services

7.2. PROMISING PRACTICES UNDER PILLAR 7

A. ANALYZING THE RESOURCE NEEDS FOR REACHING PEDIATRIC HIV CARE AND TREATMENT TARGETS

In some countries, detailed analyses were conducted on the resource needs for sustaining ACT's gains into the future and for meeting national treatment targets. In Tanzania, a comprehensive study by the Health Policy Project (HPP) combined such a financial analysis with a qualitative assessment of the major programmatic barriers to accelerating and sustaining action on pediatric HIV (see Case Study 21).
CASE STUDY 21: QUANTIFYING THE RESOURCE NEEDS TO MEET PEDIATRIC ART TARGETS – HPP, TANZANIA

In Tanzania, ACT provided $30 million in 2015 and 2016 to support the procurement of pediatric ART commodities, service delivery, and health systems strengthening (including national-level databases, guidelines, and tools). To inform resource mobilization and sustainability planning, HPP conducted research on the actions and resources needed to build on ACT’s results and achieve the national targets for pediatric ART21.

Figure 22. Number of children (0-14 years) living with HIV and national targets for pediatric ART

Note: NACP targets are for December of each year, whereas the ACT target is for September 2016. The number on ART in 2014 is the actual number reported. Source: MOHSW, Unpublished.

HPP’s research, which was published in April 2016, was based on a qualitative assessment that involved interviews with the NACP and ACT implementing partners about the challenges experienced along the pediatric HIV care and treatment cascade (see Figure 23).

HPP combined this assessment with a quantitative analysis of the costs for meeting the country’s pediatric treatment targets, plus a comparison between those costs and the available funding from ACT. This identified that, in 2015–2020, an estimated $159 million would be needed to cover the costs involved.
ACCELERATING CHILDREN’S HIV/AIDS TREATMENT

ACT’S PROMISING PRACTICES AND LESSONS LEARNED

Figure 23. Challenges along the pediatric care and treatment cascade

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<thead>
<tr>
<th>CASE IDENTIFICATION</th>
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<tbody>
<tr>
<td><strong>Ages 0-18 months:</strong></td>
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<tr>
<td>Lack of follow-up testing 6 weeks after birth and testing through child health service delivery points.</td>
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<tr>
<td>Delayed or misplaced results.</td>
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<tr>
<td>HIV EID and reagent stockouts.</td>
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<tr>
<td>Dysfunctional dried blood spots transportation zones.</td>
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<tr>
<td><strong>Older than 18 months:</strong></td>
</tr>
<tr>
<td>Lack of health worker initiative to test.</td>
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<tr>
<td>Test kit stock outs.</td>
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<tr>
<td>Age of consent for adolescents.</td>
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</tbody>
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<thead>
<tr>
<th>LINKAGE TO CARE AND ART INITIATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of patients when referred to other facilities.</td>
</tr>
<tr>
<td>Parents difficulty accepting a child’s HIV-positive status.</td>
</tr>
<tr>
<td>Weak patient tracking and monitoring (including inability to monitor by age).</td>
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<tr>
<td>Lack of coordination with other services.</td>
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<table>
<thead>
<tr>
<th>RETENTION AND VIRAL LOAD SUPPRESSION</th>
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</thead>
<tbody>
<tr>
<td>Unavailability of viral load testing.</td>
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<tr>
<td>Stock outs and irrational use of ARVs.</td>
</tr>
<tr>
<td>Lack of provider knowledge, skills, and comfort working with children.</td>
</tr>
<tr>
<td>Lack of effective patient tracking mechanisms.</td>
</tr>
<tr>
<td>Insufficient patient knowledge and support groups.</td>
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</tbody>
</table>

HPP’s study concluded that scaling up pediatric ART is crucial for Tanzania to meet its 90-90-90 targets. Under ACT, the country aimed to accelerate pediatric ART coverage over a two-year period. Meanwhile, the NACP aimed to double the number of children aged 0–14 years on ART during 2014–2016 and to achieve 100% coverage by 2018. Meeting these ambitious targets will require significant investments in strengthening the pediatric care and treatment cascade. In 2016/17, ACT funding was supporting 45% of the country’s pediatric ART commodity procurement requirements. After the completion of ACT, these costs would need to be met by the government of Tanzania; the Global Fund to Fight AIDS, Tuberculosis and Malaria; or other funding sources. Additional investments might be needed after 2017 to address recurring or new challenges along the cascade, such as identifying children who are hard to reach.

Based on this research, HPP recommended that a sustainability plan should be developed to ensure that pediatric ART gains were maintained past 2016 and that challenges along the ART cascade were adequately addressed. It emphasized that Tanzania would likely need to mobilize additional financial resources and consider more efficient pediatric ART service-delivery models to achieve cost savings.
**B. DEVELOPING INNOVATIVE FINANCING FOR PEDIATRIC HIV**

In some countries, the ACT Initiative mobilized or supported attention to innovative sources of financing for pediatric HIV care and treatment. For example, in Lesotho, Mobilizing HIV Identification and Treatment was launched by Vodafone, working in partnership with the Ministry of Health, the United States Agency for International Development (USAID), and other stakeholders. This public-private partnership aimed to double the number of children living with HIV accessing ART in three years. It combined private-sector financial support with the use of mobile technology. The latter included “Text to Treatment”, which is a mobile payment system to address transport costs for children living with HIV attending health clinics.

In Tanzania, an AIDS Trust Fund was launched in March 2015, aiming to mobilize, manage, and disburse domestic funds to support the national response to HIV. Alongside mobilizing resources, the government of Tanzania committed approximately $2.42 million to the fund for fiscal year 2016/17. Although the fund does not specifically address children, there is ongoing advocacy for a proportion of its resources to target pediatric HIV.

**C. EVALUATING THE SUSTAINABILITY OF INVESTMENTS IN CHILDREN’S HIV CARE AND TREATMENT**

To inform national planning on how to maintain and build on ACT’s progress, CIFF has commissioned an external evaluation of the sustainability of the initiative’s work in four countries (see Case Study 22).
This evaluation will result in a detailed report describing the prospects and pathways for the long-term sustainability of ACT’s investments, equipping stakeholders with the data and recommendations needed to inform future sustainable resource allocations and programming.

**CASE STUDY 22:**
**CONDUCTING AN EXTERNAL EVALUATION OF THE SUSTAINABILITY OF ACT INVESTMENTS**

An evaluation is being implemented to assess the sustainability of investments in accelerating pediatric HIV treatment within CIFF’s four focus countries for ACT. The evaluation, conducted by Rabin Martin, is designed to provide CIFF, the pediatric HIV community, and a broader audience interested in sustainability with recommended pathways for continued pediatric HIV treatment in the context of national health systems. The evaluation team is using CIFF’s definition of sustainability: “the continuation of a program’s social, economic, or environmental impact after CIFF leaves.” The evaluators will focus on three domains of sustainability: governance, leadership, and accountability; financing; and program capacity. The process will answer the following questions:

1. Are the essential domains of CIFF-funded ACT programming sustainable in Kenya, Malawi, Tanzania, and Zimbabwe at six and 12 months after CIFF’s main ACT funding has concluded?

2. What is needed to ensure that CIFF-funded ACT programming is maintained 12 months beyond main program funding?

The approach will combine the following:

- **Qualitative methodology.** This will include key informant interviews with CIFF staff, selected PEPFAR stakeholders, implementing partners, relevant United Nations agencies, and selected government stakeholders in each of the four countries.

- **Quantitative methodology.** This will use selected quantitative indicators, based on available data from CIFF, PEPFAR, public databases, and implementing partners. The indicators will be based on existing metrics collected by implementing partners.

The evaluation started in 2017 and will involve assessments at six and 12 month periods after the end of CIFF’s main funding. It will highlight areas in which program activities are being sustained in partnership with the local government, nongovernmental organizations, HIV stakeholders, and other funders. The evaluation is designed to complement PEPFAR’s existing sustainability efforts, including the Sustainability Index and Dashboard Tool. The new data collected and recommendations produced will be made available to ACT partners and other stakeholders to inform the creation, scale-up, and sustainability of future programs.
7.3. LESSONS LEARNED ABOUT PILLAR 7

Box 11: Lessons learned from implementation of ACT Pillar 7

For domestic resource commitments for pediatric HIV services, it is important to:

- Combine analysis of the financial investment needed to achieve national pediatric targets with a qualitative assessment of the practical obstacles to the care and treatment cascade.

- Support the production of both comprehensive financial data and disaggregated program data to enable an accurate estimate of the cost to address the treatment gap for children.

- Use a holistic definition of sustainability that addresses social, economic, and environmental impacts and that allows the evaluation of different sustainability domains.

- Recognize the critical role of diverse stakeholders — not only national governments, but also others, such as civil society organizations — in sustaining cost-effective action on pediatric HIV.
The initiative produced an unprecedented bank of strategies and experiences.
ACT was a concerted and intensive effort to accelerate children’s HIV treatment as never before. This report shows how, during its two years, the initiative produced an unprecedented bank of strategies and experiences. These learnings are essential for building on and sustaining ACT’s results, in the nine countries where it operated and beyond. Examples of ACT’s lessons learned are shared under each of the pillars addressed in this report. In combination, they represent a wealth of ideas about success factors, as well as gaps and challenges. Informed by these lessons, the following presents a road map of what works for accelerating pediatric HIV care and treatment.

Figure 25. Road map of what works for accelerating children’s HIV treatment
**ROADMAP FOR FUTURE ACTION**

1. **Partner with government:**
   Work in partnership with the government and health authorities at all levels to ensure an enabling policy and strategy environment for pediatric HIV care and treatment; the application of high-quality national guidelines and standards; and the implementation of a well-coordinated, multisectoral, sustainable national response.

2. **Engage communities:**
   Ensure the meaningful involvement of parents, caregivers, children, and adolescents living with HIV, from the very start and throughout programs, as essential leaders, implementers, and evaluators of responses to pediatric HIV care and treatment.

3. **Collaborate with leaders:**
   Collaborate with community leaders and local stakeholders (including community health workers), from the very start and throughout programs, as partners in the design, delivery, and monitoring of HIV care and treatment for children.

4. **Reach children in need of HIV testing:**
   Invest in and continually improve systematic ways to identify children exposed to HIV and enable them to have an HIV test. Examples include index/family testing models and PITC in priority pediatric services, such as TB and malnutrition clinics and inpatient departments.

5. **Strengthen the cascade:**
   Work across facilities and stakeholders to identify and address breaks in the cascade of pediatric HIV care and treatment. This includes ensuring rapid linkage of children testing HIV-positive to care, community-based follow-up of children defaulting on ART appointments, viral load testing, peer-based support for adherence to ART, and intensive counseling on disclosure for adolescents.

6. **Tailor packages:**
   Provide tailored packages of care and treatment for children and adolescents living with HIV, responding to their specific needs. These should address the whole person, combining clinical services with peer and psychosocial support.

7. **Support health care workers:**
   Maximize the role of lay and professional health care workers in pediatric HIV and enable them to build relevant skills and knowledge, combining attention to clinical issues with child/adolescent-friendly ways of working. Support their role through a combination of training and ongoing capacity building, such as through on-the-job mentoring.

8. **Strengthen laboratories/commodities:**
   Collaborate with laboratory and commodity-related personnel and institutions to strengthen the relevant infrastructure and management systems and to avoid delays or breaks in the supply chain for pediatric HIV care and treatment.

9. **Use strategic information:**
   Develop effective tools and systems to collect strategic information on pediatric HIV care and treatment, including data disaggregated by age. Use such information to conduct real-time analyses of results, to identify what is or is not working, and to make prompt changes to programs and resource allocations.

10. **Build sustainability:**
    Apply a holistic approach to sustainability for pediatric HIV care and treatment and work across stakeholder groups to not only mobilize the financial resources required but also maintain strong standards, policies, systems, and services.
### ANNEX 1: ACT IMPLEMENTING PARTNERS

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>ACT implementing partners</th>
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</table>
| **Cameroon** | 1. Cameroon Baptist Convention Health Services (CBCHS)  
2. CARE  
3. Catholic Relief Services (CRS)  
4. Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)  
5. ICAP  
6. Metabioata  
7. Supply Chain Management System (SCMS)  
8. World Health Organization (WHO) |
| **DRC** | 1. 4Children  
2. American Society for Microbiology (ASM)  
3. Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)  
4. ICAP  
5. Management Sciences for Health (MSH)  
6. Population Services International (PSI)  
7. Provic  
8. Rural Health Program (Projet Santé Rurale; SANRU)  
9. Supply Chain Management System (SCMS) |
| **Kenya** | 1. Academic Model Providing Access to Healthcare / People-centered, Leadership, Universal Access, Sustainability (AMPATH Plus) / Moi Teaching and Referral Hospital  
2. African Medical and Research Foundation (Amref)  
3. Ananda Marga Universal Relief Team (AMURT)  
4. CARE International  
5. Catholic Relief Services (CRS)  
6. Centre for Health Solutions  
7. Children of God Relief Institute (COGRI)  
8. Christian Health Associate of Kenya (CHAK)  
9. Eastern Deanery AIDS Relief Program (EDARP)  
10. Elizabeth Glaser Pediatric Foundation (EGPAF)  
11. FHI 360  
12. Health Strat Kenya / Kenya Prisons HIV Prevention Care and Treatment  
13. Henry M. Jackson Foundation (HJF)  
14. Hope Worldwide Kenya  
15. ICAP  
16. Integrated Marginal Arid Regions Innovative Socialized Health Approach (IMARISHA) Consortium  
17. Impact Research and Development Organization (IRDO)  
18. International Rescue Committee  
19. Jhpiego  
22. Kenya Medical Research Institute  
23. Kisumu West |
## Annex I: ACT Implementing Partners

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<th>ACT Implementing Partners</th>
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<td>Lesotho</td>
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<td>2. Columbia University</td>
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<td>3. Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)</td>
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<td></td>
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<td>6. Population Services International (PSI)</td>
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<td>3. EQUIP/ Partners in Hope</td>
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<td>4. Jhpiego</td>
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<td>6. Management Sciences for Health (MSH)</td>
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<td>Mozambique</td>
<td>1. Centro de Colaboração em Saúde (CCS)</td>
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<td>2. Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)</td>
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<td>3. FHI 360 – Community HIV/AIDS Services Strengthening (CHASS)</td>
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<td>4. Friends in Global Health (FGH)</td>
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<td>5. Fundação Ariel Glaser Contra o Sida Pediatrico</td>
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<td>6. ICAP</td>
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<td>Tanzania</td>
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<thead>
<tr>
<th>COUNTRY</th>
<th>ACT implementing partners</th>
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</table>
| Zambia  | 1. American International Health Alliance (AIHA)  
2. Broadreach  
3. Catholic Relief Services (CRS)  
4. Centre for Infectious Disease Research in Zambia (CIDRZ)  
5. DISCOVER  
6. Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)  
7. FHI 360  
8. Jhpiego  
9. Project Concern International (PCI)  
10. Provincial Health Offices for Lusaka, Southern, Western, and Eastern Provinces  
11. Systems for Better Health (SBH)  
12. SMH 360  
13. Supply Chain Management System (SCMS) / Global Health Service Partnership (GHSP)  
15. University of Maryland  
16. University Teaching Hospital HIV/AIDS Program  
17. The University of Zambia (UNZA)  
18. Zambia Family (ZAMFAM)  
19. Zambia Prevention, Care and Treatment (ZPCT) II Bridge  
20. Zambia Rising |
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The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) was the technical lead on the research, production and dissemination of this report. This built on EGPAF’s role as the Lead Implementing Partner supporting programmatic and financial grants management for all recipients of CIFF-ACT funding. Sarah Middleton-Lee was the lead technical writer.