

Bringing Kids to Care Project

Zambia, Malawi, Tanzania and
Indonesia/West Papua -
Baseline Assessment Report

July 2024



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With gratitude,

Tawina Jane Kopa-Kamanga

Team Leader, TAWINA Consultancy Team (TCT)

Executive Summary

Overview

The fight against HIV has seen tremendous progress over the past few decades, especially with the development of **Antiretroviral Therapy (ART)**, which has revolutionized care for people living with HIV. Through consistent ART use, people are living longer and healthier lives, and many of the devastating outcomes of HIV have been mitigated. Nevertheless, UNAIDS, 2023¹ acknowledges continuing challenges in timely and consistent access to ART for a wide section of gender groups such as pregnant and breastfeeding women and children in other regions of the world. For example, children are lost in care due to cracks in the health system particularly in low-income countries. Addressing these gaps requires not only a medical approach but also a robust, community-centered strategy that involves all stakeholders in the fight against HIV (Aidsfonds 2020)².

The **Kids to Care (KtC)** model was developed to fill these gaps by creating a comprehensive approach of care to **Find, Test, Treat, and Retain** children living with HIV and to ensure that pregnant and breastfeeding women are also supported to prevent mother-to-child transmission. The model was built on the recognition that children, as well as pregnant and breastfeeding women living with HIV, are still not accessing health services either because they are not known to the health system or because they have been lost to care (Aidsfonds, 2020)². By fostering stronger connections between communities and health services, the **KtC** model aims to empower individuals and communities to take active roles in finding, testing, treating, and retaining children and pregnant and breastfeeding women in care. The model has been introduced in several countries, and in 2024 expanded to **Zambia, Malawi, Tanzania, and Indonesia/West Papua**, where it has been adapted to local contexts and needs.

Global Context and Challenges

Approximately 1.2 million children under 15 were living with HIV in 2022. While there has been progress in scaling up antiretroviral therapy (ART), access remains inconsistent for many children, particularly in rural areas. There is an ongoing concern about new infections among adolescents, particularly girls, due to various socio-economic and cultural factors³. Furthermore, it is sad that every minute of 2022 someone died from AIDS. It is also worrisome that despite efforts towards 95-95-95 targets millions of people miss out on treatment and this includes 43% of children living with HIV. The World Health Organization (WHO) estimates that around 150,000 adolescents were newly infected with HIV in 2022. Efforts to improve testing and treatment for children continue, with initiatives aimed at increasing awareness among health providers to ensure that children born to HIV-positive mothers are tested promptly and linked to care.

The Global Fund and PEPFAR are actively working to address these gaps. Barriers such as stigma, discrimination, poverty, and lack of transportation persist. Recent studies emphasize the importance of creating community-based programs that provide mobile testing and integrated care to reach underserved populations. There is a growing recognition of the need for integrated health services that encompass HIV treatment alongside maternal and child health initiatives. This holistic approach aims to ensure that children and adolescents receive comprehensive care rather than isolated treatment. The COVID-19 pandemic has highlighted and exacerbated existing disparities in health care access in low-income countries. Resources shifted towards managing the

¹ The path that ends AIDS: UNAIDS Global AIDS Update 2023. Geneva: Joint United Nations Programme on HIV/AIDS; 2023

² Aidsfonds. (2020). *Kids to care model: A comprehensive community-based approach to pediatric HIV*

pandemic, which affected routine healthcare services, including for HIV. Recovery efforts are focusing on revitalizing these essential services.

Furthermore, the **Prevention of Mother-to-Child Transmission (PMTCT)** programs have been successful in reducing the number of new infections, but gaps remain in reaching all pregnant and breastfeeding women (Aidsfonds, 2020)². In a 2021 report UNAIDS observed that many women discovered their HIV status only during pregnancy, which limited the time available for effective interventions. Today, there has been remarkable progress in testing of pregnant and breastfeeding women such that up to 93% of pregnant and breastfeeding women in east and southern Africa are enrolled in ART (UNAIDS, 2023)¹. Still, the challenges that remain concern consistency and may result from socio-economic and structural barriers that prevent individuals from accessing care. One such strategy is found in the Kids to Care Model developed by Aidsfonds.

The Kids to Care Model: A Community-Centered Approach

The **Kids to Care (KtC)** model represents a shift from purely clinical approaches to HIV care to one that places communities at the center of the response. By focusing on the four pillars of **Find, Test, Treat, and Retain**, the KtC model addresses the key points at which individuals—particularly children and pregnant women—are lost to care. The model recognizes that healthcare systems must actively engage communities if they are to end pediatric HIV (Aidsfonds, 2020)². Through this model, community health workers, health partners, and stakeholders are engaged in the process of identifying and supporting individuals living with HIV, ensuring that they are tested, receive treatment, and remain in care.

The Baseline Assessment: A Comprehensive Approach

The baseline assessment for the **Bringing Kids to Care (BKTC)** project was conducted to establish a reference point against which the progress of the project would be monitored and evaluated (Aidsfonds, 2023)⁴. The assessment sought to understand the current state of HIV care for children and pregnant and breastfeeding women in **Zambia, Malawi, Tanzania, and Indonesia/West Papua**, with a focus on identifying gaps in the healthcare system and community responses. The assessment employed a **mixed-methods approach**, combining quantitative data from surveys with qualitative data from key informant interviews and focus group discussions. This comprehensive approach ensured that the assessment captured both the statistical realities of HIV care in the project countries and the lived experiences of individuals affected by HIV.

The **quantitative component** of the assessment involved surveys with **635 caregivers** and pregnant and breastfeeding women across the four project countries. These surveys collected data on access to healthcare, ART adherence, and the challenges faced by caregivers in ensuring their children receive regular care. The **qualitative component** involved **92 key informant interviews** with healthcare workers, community health workers, HIV/AIDS support groups, and development partners, as well as **31 focus group discussions** with caregivers, pregnant and breastfeeding women, and adolescents living with HIV aged 10-14 years. These interviews and discussions provided critical insights into the barriers to accessing care and the socio-economic and cultural factors that influence adherence to ART.

Key Findings and Insights

One of the key findings from the baseline assessment is that almost all women attending antenatal clinics are tested for HIV as part of PMTCT programs. This is a significant achievement, as early testing is critical for preventing mother-to-child transmission (UNAIDS, 2023). However, despite this progress, some children are still being born with HIV, particularly in cases where adherence to ART was inconsistent during pregnancy and breastfeeding.

⁴ Aidsfonds. (2023). *Terms of Reference: Baseline assessment "Bringing Kids to Care"*. Aidsfonds – Soa Aids Nederland

This highlights a concerning gap in the continuum of care, as it indicates that while testing is available and utilized, there are systemic barriers that prevent women from receiving and adhering to the necessary treatment protocols. For instance, some women may not begin ART until after they discover their HIV status during pregnancy, thus limiting its effectiveness in preventing transmission to child. The study also revealed that in regions with limited healthcare access, pregnant and breastfeeding women face challenges such as long travel distances to health facilities, lack of transportation, and financial constraints that hinder their ability to initiate or maintain ART.

Additionally, the assessment identified that while healthcare providers are trained to deliver PMTCT services, there is a need for more robust support systems for mothers to navigate their treatment journey. Caregivers reported feelings of isolation and anxiety regarding their children's health, which can be exacerbated by social stigma associated with HIV. Such emotional and psychological challenges can further complicate adherence to ART, as mothers may fear disclosure of their status and its implications for their family dynamics.

Another key insight from the assessment is the critical role of **community health workers** in bridging gaps in care. These workers have proven to be effective in reaching out to mothers and children in underserved areas, providing health education, social support, and follow-up care. However, the assessment noted that the current capacity of community health workers is often insufficient to meet the demand for services. There is a pressing need for more personnel at both community level and project implementing partner levels to support outreach activities. Furthermore, the voices of children and caregivers were pivotal in shaping the assessment's findings. Many children living with HIV expressed concerns about their treatment regimens and the stigma they face in their communities. Their feedback indicated a strong desire for more inclusive healthcare practices that involve them in discussions about their health. Caregivers echoed these sentiments, stressing the need for healthcare providers to communicate effectively and empathetically with both children and their families. This should create an environment for openly addressing questions and concerns.

The assessment also revealed the need to enhance educational efforts surrounding HIV prevention and treatment, particularly in rural areas where misinformation often prevails. Caregivers reported often lacking access to accurate information regarding ART, PMTCT, and the rights of children living with HIV. Increased educational campaigns that target not only those directly affected but also the broader community could help reduce stigma and foster a more supportive environment for individuals living with HIV.

In summary, while the baseline assessment highlights significant achievements in finding, and testing of pregnant and breastfeeding women and children for HIV, it also underscores the persistent challenges faced by mothers and children in effectively accessing treatment and care. This is more pronounced in children beyond five years of age as their mothers or caregivers no longer bring them for monthly growth monitoring, which is an expected health facility visit unlike ART clinic for children. Due to stigmas and due to livelihood commitments and socio-economic challenges they sometimes skip ART clinics unless their caregiver/mother is steadfast. Addressing these challenges will require more self-awareness among the mothers and caregivers and economic support to bring out their children for ART Clinics. There is also a need to enhance community support through provision of transport aids to ease mobility among community health workers. Lastly, for adolescent children there is a need to pay attention to socio-institutional hindrances to friendliness of healthcare service delivery.

Abbreviations and Acronyms

1

ACC	Action for Community Care
AIDS	Acquired Immuno-Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
BTKC	Bringing Kids to Care
CD4	Clusters of Differentiation 4
CHAI	Clinton Health Access Initiative
CHW	Community Health Workers
CIDRZ	Centre for Infectious Disease Research in Zambia
CLHIV	Children Living with HIV
COWLHA	Coalition for Women Living with HIV and AIDS
DREAMS	Determined, Resilient, Empowered, AIDS-free, Mentored and Safe
EGPAF	Elizabeth Glaser Paediatric AIDS Foundation
EID	Early Infant HIV Diagnosis
EMTCT	Elimination of Mother To Child Transmission
ENA	Extractable Nuclear Antigen
FDG	Focus Group Discussion
HIV	Human Immunodeficiency Virus
IAC	Indonesia AIDS Coalition
KII	Key Informant Interview
NACOPHA	National Council of People Living with HIV in Tanzania
NGO	Non-Governmental Organisation
PATA	Paediatric Adolescent Treatment Africa
PEPFAR	United States President's Emergency Plan AIDS Relief
PLHIV	People Living With HIV
PMTCT	Prevention of Mother to Child Transmission
PrEP	Pre-exposure Prophylaxis
PRICHO	Primrose Community Health Organization
SPSS	Statistical Package for Social Scientists
STI	Sexually Transmitted Infection
TAFU	Towards an AIDS-Free Generation in Uganda
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV/AIDS
UNICEF	United Nations International Children's Emergency Fund
VL	Viral Load
VSL	Village Saving and Loans
WHO	World Health Organisation
ZAMHIA	Zambia Population-based HIV Impact Assessment
ZENITH	Zambia Education Network for Implementation Science Training in Health

1 Introduction

1.1 Background of the Bringing Kids to Care Projects

Aidsfonds, in collaboration with community partners, co-created the **Kids to Care (KtC)** model, which is rooted in the successful **TAFU (Towards an AIDS-Free Generation in Uganda)** program and the **FTT (Find, Test, Treat)** programs implemented in Uganda and Zimbabwe, respectively. The KtC model aligns with UNICEF's **Service Delivery Framework**, aiming to provide comprehensive care to children and families affected by HIV. Based on valuable lessons from these initiatives, the model was contextualized and rolled out in several high-burden countries in Africa, including Nigeria (Lafiyar Yara project), Mozambique (Kusingata project), and South Africa (KidzAlive@home project). These projects led to successful identification of children, as well as pregnant and breastfeeding women living with HIV, who remained in care following enrolling in treatment (Aidsfonds, 2020).

Following the successful implementation of the KtC model in these countries, Aidsfonds has expanded the model to **Zambia, Malawi, Tanzania, and Indonesia/West Papua** through the **Bringing Kids to Care** projects, launched at the beginning of 2024. In this report, the initiatives in the four countries are collectively referred to as the **Bringing Kids to Care Project**. These countries often lose from care children and breastfeeding women living with HIV due to among other reasons: lack of follow ups on new mothers after leaving hospital care, and; lack of a localized system of support and care (Aidsfonds, 2020). However, through interventions such as the Kids to Care model, children living with HIV can thrive and pregnant women with HIV can give birth to HIV-free babies, provided they receive support throughout all the four stages of HIV care: **Find, Test, Treat, and Retain**.

The KtC model also recognizes that bringing all children's cases into HIV care must extend to adolescents. These may have been born with HIV or acquired it through other routes, including unprotected sex, rape, needle sharing. These are often overlooked in conventional HIV response.

Many children living with HIV are often missed in healthcare, face numerous barriers to access treatment and support. Their unique needs must be addressed, and be supported emotionally as well as ensure that they access to ART, and age-appropriate health care services (Aidsfonds, 2020). Furthermore, although the prevalence rates of HIV among children have dropped between 2010 and 2023, they remain higher than the 2025 targets, with an estimated **1.4 million children under 15 living with HIV globally**, and many of these children are not receiving the necessary treatment (UNAIDS, 2023).

The **Kids to Care model** plays a vital role in identifying children living with HIV, linking them to treatment, and providing ongoing support to ensure adherence to ART. By addressing both MTCT and the broader spectrum of HIV transmission among children, we can work towards a comprehensive approach that ensures all children living with HIV receive the care and support they need to lead healthy lives.

1.2 Objectives of the Kids to Care Model

The **Kids to Care (KtC)** Model is a community-based intervention model designed specifically for pediatric HIV programming, developed collaboratively by Aidsfonds and its partners. This innovative model is founded on the understanding that communities must be empowered with

skills and resources to identify and retain children and pregnant and breastfeeding women in care who are not aware of their HIV status.

It is an integral component of the broader pediatric HIV approach aimed at guaranteeing that children living with HIV can lead healthy and fulfilling lives. It empowers communities to actively seek out and support children and pregnant women affected by HIV while simultaneously strengthening the connections between community members and health facilities. The model is structured around four critical stages of care: **Find, Test, Start, and Stay**.

The **"Bringing Kids to Care"** project aims not only to eliminate vertical transmission of HIV but also to ensure that all children living with HIV can thrive and enjoy healthy, full lives. by leveraging community engagement and collaboration.

1.2.1 Objectives of the Baseline Assessment

Aidsfonds sought a Monitoring, Evaluation and Learning consultant to conduct a baseline assessment in Zambia, Malawi, Tanzania and Indonesia/West-Papua, in order to provide a point of reference against which progress will be monitored and evaluated, and to inform the establishment of realistic and achievable targets.

A baseline assessment aims at providing a point of reference against which progress will be monitored and evaluated, and to guide the establishment of realistic and achievable targets as a project starts. The report from this baseline assessment will be used to inform and adjust the Bringing Kids to Care projects to increase effectiveness and optimize the project approach to finding, testing, treating, and retaining children, pregnant and lactating women living with HIV in care. Further, the results will be used to monitor progress of BKTC projects in Zambia, Malawi, Tanzania and Indonesia/West Papua.

The main objective of this baseline assessment was to establish baseline evaluation through literature review and field work (interviews, focus groups discussions, surveys etc.) in order to;

- (i) Collect benchmark data about children living with HIV based on key indicators determined by Aidsfonds and contextualized indicators established by national implementing partners Primrose Community Health Organization (PRICHO), Coalition of Women Living with HIV and AIDS (COWLHA), Action for Community Care (ACC) and Indonesia AIDS Coalition (IAC).
- (ii) Provide insights into the current state of pediatric HIV care, facilitators, barriers and opportunities for children living with HIV (and their caregivers), pregnant and lactating women living with HIV to demand, access, utilize and retain in care.
- (iii) Develop a country profile to illustrate the pediatric HIV care and treatment situation in Zambia, Malawi, Tanzania and Indonesia/West Papua.

Following the above specific objectives, the baseline assessment will, among others:

- Outline the facilitators and barriers at family, community, and health facility level reflecting on the experiences of pregnant and lactating women, and on the personal experiences of children and adolescents living with HIV (e.g. at clinical services; language used, age-appropriate approach, stigma, privacy, age-appropriate disclosure).
- Provide insight in understanding which children are not reached by and/or drop out of paediatric HIV services at district level and why they are not reached.
- Provide an overview of relevant government policies and guidelines at national level and district level, recent developments and recently published research on pediatric HIV in each country.
- Outline pediatric HIV service provision by the governments, government agencies and selected Non-Governmental Organisations at national and district level.

- Provide insight on any upcoming opportunities such as relevant conferences at national and regional level, review of guidelines, advocacy gaps and opportunities.

The findings from this baseline assessment will guide the refinement of project strategies, ensuring they effectively address the needs of underserved children and pregnant and breastfeeding women living with HIV

2 Schematic Problem Presentation

2.1 The Guiding Problem Analysis

The guiding problem, which the BKTC aims to solve for pediatric HIV response in Tanzania, Zambia, Malawi, and Indonesia/West Papua is schematically presented in Figure 1. This presentation highlights possible barriers in the prevention, diagnosis, treatment, and retention of children living with HIV. Based on local data and global best practices from the World Health Organization (WHO) and UNAIDS, this scheme provides a comprehensive analysis of the pediatric HIV epidemic and the unique challenges potentially hindering positive HIV response in these countries

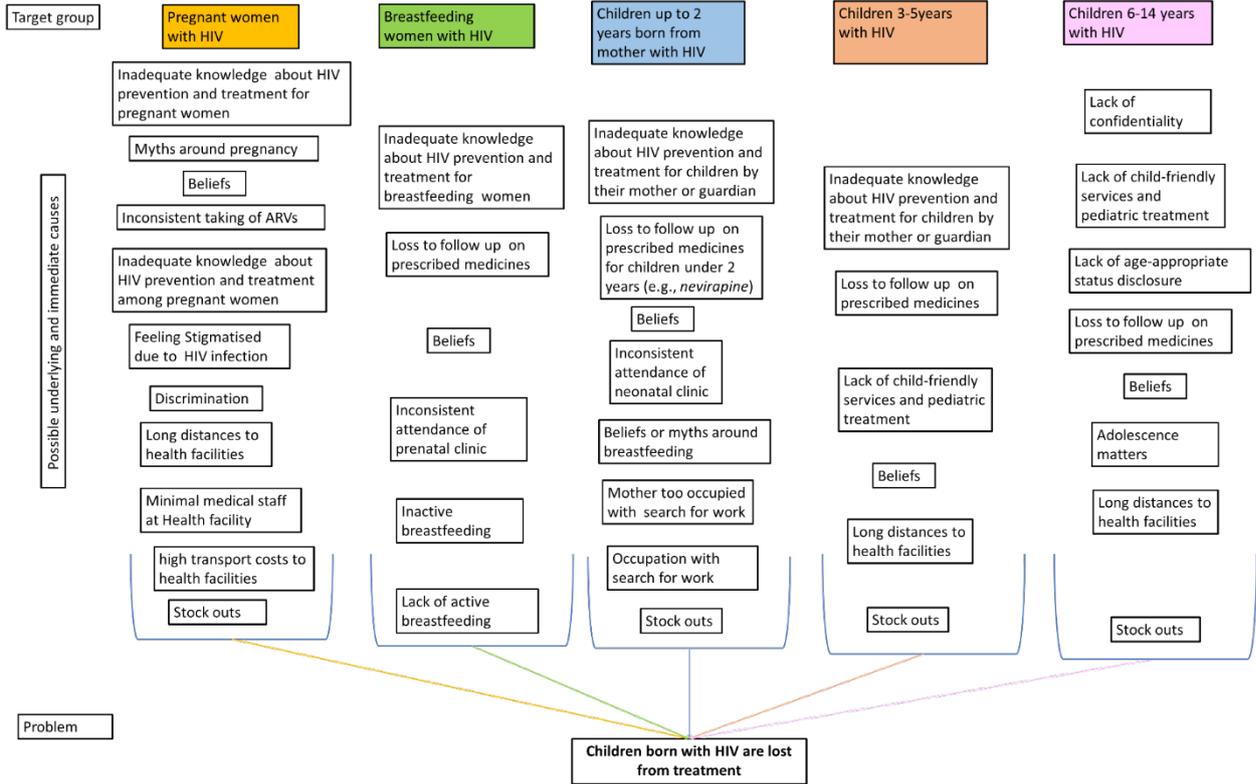


Figure 1: Schematic problem analysis: Children born with HIV are lost from treatment

Note: The possible causes of loss of children from treatment listed under each target group are not in any order.

3 Methodology

3.1 Setting

The baseline assessment for the *Bringing Kids to Care* projects was conducted in the respective districts of the countries where the projects are implemented: Malawi, Tanzania, Zambia, and Indonesia/West Papua. A mixed-method approach, combining quantitative and qualitative data collection, was applied in Malawi, Zambia, and Tanzania. In contrast, only qualitative methods were employed in Indonesia/West Papua. This distinction in data collection methods stemmed from the need to account for the different epidemic profiles across these countries.

In Zambia, Malawi, and Tanzania, quantitative methods were used to gather broad, statistically significant data on HIV prevalence, access to health services and livelihoods, while qualitative methods provided contextual insights into the lived experiences of Pediatric HIV+ and their caregivers as well as pregnant and breastfeeding women. The mixed-method approach ensured a comprehensive understanding of both the scale of the problem and the nuanced barriers to care in these regions.

However, in Indonesia/West Papua, qualitative methods were deemed more appropriate due to the unique characteristics of the epidemic, which differs significantly from the generalized epidemics in the African countries. In Indonesia, the epidemic is more concentrated, and the HIV transmission dynamics require a deeper exploration of social and structural barriers that may not be adequately captured through quantitative surveys. Therefore, a purely qualitative approach was employed to gain in-depth insights into local perceptions, healthcare challenges, and treatment gaps.

3.2 Sampling Method

3.1.1 Sampling for quantitative data collection

Sufficient sample size for the quantitative data collection, was determined to ensure the baseline values are from a representative sample whose results can be generalized with sufficient statistical power. Due to inter-country variation and practical logistical challenges, the sample sizes were determined taking into consideration the number of targeted beneficiary children and women. Thus, both probability and non-probability sampling were employed. Probability sampling was employed only to answer specific research questions, which required a subsample.

To calculate a sample size with sufficient statistical power, the following factors were considered: statistical power of 80%, significance level (0.05) and effect size (the odds ratio) of 1.5, though slightly weaker, would give a sample with sufficient statistical power. Using the G*Power (version 3.1.9.7) software, the required sample estimation was 175 for each of the three countries. The sample size was not uniform across the countries neither intra-country as it relied also on the targeted subject group as per projects proposals. Table 1 shows total sample itemized by countries:

Table 1: Estimated Sample Size

Country	Estimated Sample	Expected attrition (%)	Final estimated sample
Malawi	175	5.6	185

Tanzania	175	9.2	191
Zambia	175	5	184
Total	525	6.6	560

For qualitative data, ideally the number of interviews and discussions were decided after reaching theoretical point of data saturation. However, due to the time constraints of the baseline assessment the participants of the focus group discussions (FGDs) and key informant interviews (KII) were determined beforehand. Burrows and Kendell (1997) suggests three (3) to four (4) FGDs in health-related research. Thus, the minimum number of FGDs in each district was three (3) for each of the review groups (women and the older children). The informants for KIIs were selected purposively through the stakeholder mapping exercise, making sure that a maximum variation of relevant key informants at national and subnational levels was included. Table 2 below gives an outline of KIIs and FGDs that were planned for each country.

Table 2: Number of Key Informant Interviews and Focus Group Discussions per country

Country	Estimated number	
	Key Informant Interviews	Focus Group Discussions
Indonesia	28	6
Malawi	26	9
Tanzania	28	18
Zambia	24	8
Total	106	40

3.3 Data collection methods

The baseline assessment was based on a participatory approach that has triangulated a mix of qualitative and quantitative methods as well as document review.

3.1.2 Document review methods

We reviewed national as well as district level population and general health indicators from official government documents, and more detailed HIV and maternal and child health indicators from the latest official reports, scientific publications, as well as NGO reports at national and local levels from the intervention areas. Other than the documents provided by Aidsfonds's country partners, we employed a scoping review methodology in online general search engine (e.g., google search or duckduckgo) as well as scientific search engine (e.g., pubmed or google scholar) using initial planned keywords similar for all four countries with some country-specific additional keywords as needed.

3.1.3 Qualitative data collection

Qualitative data was gathered through in-depth interviews with key individual informants at national and district levels, and focus groups discussions with pregnant and breastfeeding women, caregivers of Pediatric HIV+ and PLHIV support group. Each country team developed country-specific interview and discussion guides based on a master interview and discussion guides that the team developed together guided by the indicators provided by Aidsfonds and implementing partners.

3.1.4 Quantitative data collection

A short survey using structured questionnaires was carried out to collect quantitative data targeting mothers and care givers of Pediatric HIV+.

3.4 Data management and data analysis

3.1.5 Synthesis of document review

Each country team analyzed the country and local documents, and while between country comparisons have not been made, insights on the current state of HIV case identification and care as well as the facilitators, barriers, and opportunities to accessing HIV care among WLHIV and CLHIV (and their caregivers) have been provided for each country.

3.1.6 Qualitative and quantitative data analysis

Qualitative data was coded separately by each country team using the same deductive coding tree, while allowing for inductively adding nodes that are context specific as needed. This has been triangulated with survey results to provide a complete picture of baseline situation in the countries. Quantitative data was analysed in Stata and SPSS to draw proportions, means, correlations and regressions to explain the likelihood that a child born with HIV will be lost to care.

3.5 Ethical considerations

The baseline study was commissioned as part of an ongoing project to help align its interventions to problems identified by each country communities. Since this was a non-medical intervention, the study obtained approvals from the respective authorities in the BKTC project countries.

The study team further developed an informed consent that was read out to all participants to seek their informed consent before participating in the study (see Appendix 2).

The baseline assessment team adhered strictly to ethical principles to ensure the protection and dignity of all respondents. A core tenet of the process was the principle of no harm, ensuring that no participant experienced physical, emotional, or psychological harm throughout the data collection exercise.

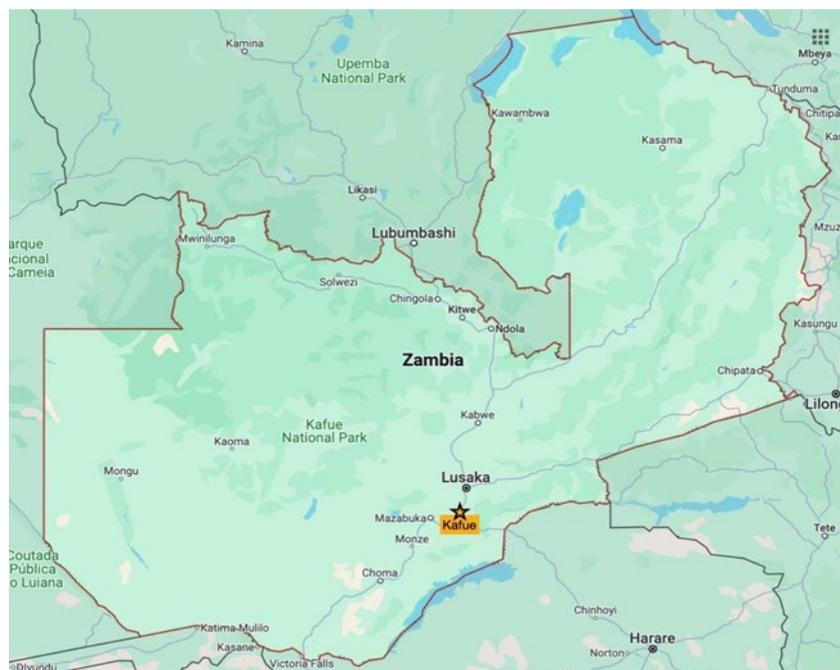
In keeping with the commitment to confidentiality, the team took meticulous care to protect the sensitive and private information of all respondents. Personal data was anonymized and de-identified to ensure privacy, and only such de-identified data was shared with partners or included in reports. Moreover, to underscore the respect for participants' confidentiality, no photographs of respondents were taken, whether in focus groups or individual interviews. This measure further reinforced the ethical standards upheld during the assessment, ensuring that the dignity and privacy of all respondents remained paramount.

4 Country Specific Profiles

4.1 Zambia

Zambia is a landlocked country situated in the heart of Southern Africa, sharing its borders with eight nations: Angola, Botswana, the Democratic Republic of Congo, Malawi, Mozambique, Namibia, Tanzania, and Zimbabwe. In terms of demographics, Zambia is one of the world's youngest countries by median age, with a population estimated at 19.6 million in 2021, exhibiting a growth rate of 2.7% per year (World Bank, 2021)⁵.

Children and adolescents under the age of 15 account for 51.2% of the total population, highlighting the importance of addressing their health needs. In 2021, an estimated 80,000



children aged 0-14 years were living with HIV, representing approximately 0.4% of the total child population in the country. Progress on HIV management among these was slow as only 60% received life-saving HIV treatment (Ministry of Health, 2021). By 2022 children living with HIV registered a viral load suppression of 84.8% (Ministry of Health, 2022)⁶. Among pregnant and breastfeeding women, it was estimated that 83% received treatment to prevent vertical

Figure 2: Map of Zambia showing project district

transmission of HIV to their infants (UNAIDS, 2022)⁷.

One of the barriers to expansion of HIV treatment in low-income countries is gender inequalities in decision making among women over their bodies including seeking health services. Additional obstacles include poverty, long distances to health facilities, and impassable roads during the rainy season.

Moreover, many parents avoid utilizing health services such as growth monitoring and family planning, further complicating efforts to monitor their children's health status. The criminalization and stigmatization of sex work both from the perspective of communities and community health workers limits children of sex workers from accessing adequate HIV services. This is common in towns around cities and urban areas like Kafue lies on the periphery of Lusaka. The WHO notes that these societal issues create an environment where children, especially those from vulnerable populations, are often overlooked and underrepresented in HIV care (World Health Organization,

⁵ World Bank. (2021). *Zambia overview*

⁶ Ministry of Health (2022). *Annual health statistics report 2022*. Lusaka: Government of Zambia.

⁷ UNAIDS. (2022). *Global AIDS update 2022: Confronting inequalities*

2020)⁸.

Viral load suppression rates also reflect the effectiveness of treatment adherence among children living with HIV. In Zambia, approximately 84% of children on ART achieve viral load suppression, which is crucial for improving health outcomes and reducing transmission risks (Ministry of Health, 2022). However, this still leaves a considerable number of children who are not achieving this critical health goal, thereby underscoring the urgent need for targeted interventions.

The project district for the **Bringing Kids to Care (BKTC)** model is located in **Kafue**, situated in **Lusaka Province**. Kafue covers an area of **4,471 km²** and has an estimated population of **219,574** (Zambia Statistics Agency, 2021)⁹. This district has been selected due to its significant need for enhanced pediatric HIV services and community engagement in care (World Bank, 2021)¹⁰.

The Bringing Kids to Care (BKTC) model is implemented as part of a project titled Scale Up and Enhance HIV Pediatric Care with an Integrated Family Care Approach by the Primrose Community Health Organization (PRICHO). PRICHO is dedicated to providing comprehensive, quality, and cost-effective health services, creating welcoming environments where adolescents, young people, men, and women can make informed choices regarding their sexual and reproductive health rights. The organization's approach is grounded in principles of dignity, equality, and social justice.

Primrose Community Health Organization primarily operates within Kafue District, focusing on five thematic areas of health including HIV services, economic empowerment, climate change mitigation and adaptation, education and water sanitation and hygiene. Their engagement in HIV services dates back to 2004, following a governmental commitment to expand access to antiretroviral therapy for HIV-positive individuals. Since then, PRICHO has become a key player in addressing the health needs of vulnerable populations in Zambia.

Scale Up and Enhance HIV Pediatric Care with an Integrated Family Care Approach Project

The Scale Up and Enhance HIV Pediatric Care with an Integrated Family Care Approach Project is implemented in partnership with the Amos Youth Centre, which has successfully identified and oriented eight sports mentors to integrate community-based sports activities into the Kids to Care model. These activities serve as a strong foundation for raising awareness and improving access to pediatric and adolescent HIV care services.

This project is strategically designed to collaborate with various stakeholders at national, district council, and community levels. Key partners include the Ministry of Health (through the District Health Office and Neighborhood Health Committees), the Departments of Social Welfare, Small and Medium Enterprises, Community Development, Agriculture, National Registration, and civic, traditional and religious leaders, the District Chapter of the Network for Zambian People Living with HIV, Development Aid from People to People, the District Education Board, the Parents Teachers Association, and the Kafue District Football Association. At the local level, the project actively engages community health workers, volunteer health workers, religious and traditional leaders, and youth support groups to ensure a broad reach and effective implementation.

The primary goal of the project is to improve ART access and quality of care for infants, children and adolescents. The specific objectives of the project are as follows:

- Strengthen and sustain community systems to enhance early identification, testing, and treatment of 1,200 children who are unaware of their HIV status aged 0-14 years, along

⁸ World Health Organization. (2020). *Global health sector strategy on HIV 2016-2021: On the fast-track to accelerate action for ending the AIDS epidemic by 2030*.

⁹ Zambia Statistics Agency. (2021). *Population and housing census 2021: Preliminary results*

¹⁰ World Bank. (2021). *Zambia overview*.

with pregnant and lactating women. This effort aims to bridge the gaps in the prevention of mother-to-child transmission (PMTCT) and pediatric HIV response, ensuring that these individuals are linked into care before, during, and after delivery.

- Enhance clinic-community collaborations between multidisciplinary pediatric and children's HIV treatment teams, community-based organizations (CBOs), and local communities. This objective aims to improve the identification, diagnosis, linkage to care, and retention of children aged 0-14 years in pediatric HIV treatment, care, and support within the target communities.
- Document best practices and lessons learned from community-based approaches for sustainable case finding, testing, and treatment of infants and children. This documentation will provide valuable insights into effective strategies and methods that can be shared and replicated in similar contexts.

4.1.1 Paediatric HIV Prevalence, Response and Recent Research in Zambia

HIV remains a significant public health challenge in Zambia, with women and children being among the most vulnerable groups. The overall HIV prevalence among adults in Zambia is 11%. Prevalence in Kafue district is one of the highest in the country at 17.1%.¹¹ Nationally, women of reproductive age (15-49 years) exhibit higher HIV prevalence rates at approximately 14%. The prevalence among the same age group in Kafue is believed to be proportionately high. This is due to the margin of deviation of the overall prevalence from the national prevalence. Nationally, among pregnant women, the prevalence increases to 16%, posing a considerable risk for mother-to-child transmission (MTCT). It grows proportionately higher in hotspots districts such as Kafue where fishing industry attracts high traffic of traders. Zambia has made substantial progress in reducing MTCT, particularly through interventions like lifelong ART for HIV-positive pregnant and breastfeeding women. Yet, pediatric HIV remains a pressing issue, as children continue to experience significant gaps in identification, treatment, and viral load suppression. Nevertheless, localized efforts in HIV and AIDS fight must be highlighted. A case in point is the BKTC project under PRICHO has already demonstrated progress by registering a remarkable jump in statistics for testing children for HIV from 26 in first quarter of 2024 to 698 in the second quarter. From these tests, 6% were diagnosed with HIV and immediately put on treatment.¹²

HIV in Children

Despite Zambia's strong commitment to tackling HIV, specific data on pediatric HIV reveals persistent gaps. According to UNAIDS, approximately **90,000 children (0-14 years)** were living with HIV in Zambia in 2023, but only about **60%** of these children were receiving ART. This leaves a significant treatment gap, particularly in rural and underserved areas. Furthermore, viral load suppression rates among children are substantially lower compared to adults, with only about **45%** of children on ART achieving viral suppression, compared to **90%** of adults (UNAIDS, 2023)¹³.

The problem is multifaceted. Delayed identification of HIV-positive children is one major issue. According to government data, early infant diagnosis (EID) rates stand at **70%**, leaving a significant number of infants undiagnosed during the critical early months of life. This is compounded by logistical barriers, such as long distances to health facilities in rural areas, which limit access to pediatric HIV testing and care. Studies suggest that Geographic and socioeconomic factors play a key role in the failure to retain children in care (Van Dijk et al., 2009)¹⁴.

Broad National Commitment and Strategic Focus

¹¹ Mweemba, C., Hangoma, P., Fwemba, I., Mutale, W., & Masiye, F. (2022). Estimating district HIV prevalence in Zambia using small-area estimation methods (SAE). *Population Health Metrics*, 20(1), 8.

¹² Kafue District News. <https://www.isk.gov.zm/?p=2729>. Cited on 26 November 2024.

¹³ UNAIDS. (2023). HIV and AIDS estimates in Zambia.

¹⁴ Van Dijk, J., et al. (2009). Barriers to Pediatric HIV Testing in Rural Zambia. *BMC Public Health*, 9(1), 310.

At the national level, Zambia's 8th National Development Plan (2022-2026) outlines a comprehensive approach to public health, with HIV prevention and management being a core priority. While the country's overall ART coverage is commendable, particularly among adults (98% of PLHIV are on ART), the disparities between adult and pediatric care remain stark. The national pediatric HIV response, therefore, requires more focused interventions to close this gap.

One such intervention is the Pediatric and Adolescent Change Package (2020), developed by the government to implement scalable, high-impact strategies. These strategies aim to improve testing, linkage to care, retention in care, and viral load suppression rates among children. However, recent evidence indicates that **adherence to ART among children** remains a major challenge, especially in community settings where resources are limited, and stigma is still prevalent. Studies (Bolton-Moore et al., 2022; Sutcliffe et al., 2023)¹⁵ highlight the need for community-based initiatives to address these barriers, particularly in rural settings where healthcare access is poor¹⁶.

Community-Based Interventions and Support

Community health workers (CHWs) are critical in the fight against pediatric HIV in Zambia. Research (Viljoen et al., 2021)¹⁷ shows that CHWs have had notable success in increasing pediatric HIV testing and treatment adherence by providing door-to-door services and ongoing counseling to families. These initiatives help reduce stigma and encourage caregivers to engage in long-term care for their children. The use of validated screening tools at the community level has also shown promise, particularly when CHWs are involved in administering them (Chaila et al., 2022)¹⁸.

Nevertheless, more needs to be done to strengthen these community-level efforts. The government's collaboration with international partners, such as the Global Fund¹⁹ and UNICEF, has been instrumental in scaling up these interventions, but further investment is needed to reach all vulnerable children, particularly those in rural areas.

While Zambia has made great strides in reducing MTCT and expanding ART coverage, the pediatric HIV response still faces significant challenges. These challenges include a lack of early diagnosis, insufficient ART coverage, and lower than projected viral load suppression rates among children. Addressing these issues requires targeted strategies, including enhancing community-based care, improving access to treatment in rural areas, and increasing adherence support for children living with HIV. With continued political commitment and collaboration among stakeholders, Zambia can bridge the gap in pediatric HIV care and work towards achieving its Vision 2030 of a nation free from HIV.

4.1.2 Findings for Zambia

Household Demographic Characteristics

In Zambia, primary data collection for the baseline assessment of the *Bringing Kids to Care Project* took place between May and July 2024. It focused on pregnant and breastfeeding women, caregivers of children aged 0-14 years, and children aged between 10 and 14 years. A total of 110 breastfeeding women 66 pregnant women and 193 caregivers were surveyed (Table 3).

Table 3: Survey Participants in Zambia

Category	Number of Survey Respondents
Lactating Women	110

¹⁵ Bolton-Moore, C., et al. (2022). Retention in Care for Pediatric HIV Patients in Zambia. *Journal of HIV/AIDS Research*, 35(4), 56-63.

¹⁶ Sutcliffe, C. G., et al. (2023). Adherence to ART Among Children in Zambia. *The Lancet HIV*, 7(5), e318-e328.

¹⁷ Viljoen, L., et al. (2021). The Role of Community Health Workers in Pediatric HIV Testing and Treatment. *PLoS One*, 16(2), e0246887.

¹⁸ Chaila, M., et al. (2022). The Use of Screening Tools for Pediatric HIV Testing in Zambia. *AIDS Care*, 30(7), 1285-1292.

¹⁹ <https://www.theglobalfund.org/en/hiv/aids/>

Caregivers	193
Pregnant Women	66

Demographic Characteristics of Survey Participants

Table 4 presents the demographic characteristics of the breastfeeding women and caregivers surveyed in Zambia. The median age of breastfeeding women was 27 years, while caregivers had a median age of 24 years. On average, both breastfeeding women and caregivers had two children each, and the majority of the respondents were married.

Table 4: Demographic Characteristics of Survey Participants in Zambia

Variable	Lactating Women (n=110)	Pregnant Women (n=66)	Caregivers (n=193)
Average age of respondent (years)	27 (22-33)	26 (19-32)	24 (11.5-33)
Average age of baby (months)	14 (7-18)	-	-
Duration of pregnancy	-	6 (3-8)	-
Average number of children	2 (1-4)	-	2 (1-2)
Household size	4 (4-8)	-	6 (4-9)

Education Levels and Main Occupation

The majority of all breastfeeding women, pregnant women and caregivers had received primary education. Breastfeeding women reported more reaching secondary education. Regarding occupation, 56.4% of breastfeeding women, 21% of pregnant women and 37.7% of caregivers engaged in farming, as the primary source of livelihood.

Table 5: Education Levels and Occupation of Survey Participants in Zambia

Variable	Lactating Women (%)	Pregnant Women (%)	Caregivers (%)
Education Level			
None	6.4	1.5	8.4
Primary	43.6	63.5	60.5
Secondary	50.0	33.3	31.1
Tertiary	-	1.5	-
Main Occupation			
Farming	56.4	21.2	37.7
Self-employed	16.4	31.8	3.6
Trader/piece work	20.9	18.2	13.8
Other	6.4	28.8	44.9

Marital Status

Table 6 shows the marital status of breastfeeding women, pregnant women and caregivers. Most respondents were married, with 66.4% of breastfeeding women, 69.7% of pregnant women and 66.5% of caregivers indicating they were currently in marital relationships.

Table 6: Marital Status of Survey Participants in Zambia

Marital Status	Breastfeeding Women (%)	Pregnant Women (%)	Caregivers (%)
Single	20.9	12.2	11.4
Married	66.4	69.7	66.5
Divorced	9.1	9.1	15.6
Widowed	3.6		6.6

4.1.3 Reported HIV status and HIV Knowledge Among Breastfeeding Women and Caregivers in Zambia

Table 7 below presents significant findings regarding the prevalence of HIV and knowledge of related issues among breastfeeding women, pregnant women and caregivers in Zambia. Among the breastfeeding women surveyed, 10% reported living with HIV, and all these individuals were on antiretroviral therapy (ART). This highlights a crucial aspect of HIV management: while a substantial number of breastfeeding women are receiving ART, it also indicates the ongoing challenge of addressing HIV in this demographic. Furthermore, two of these women reported having a child who is also HIV-positive, emphasizing the need for effective prevention strategies to reduce mother-to-child transmission (MTCT) of HIV.

Table 7: Reported HIV status and HIV knowledge among breastfeeding women and caregivers in Zambia

Variable	Breastfeeding women (n=110)	Pregnant Women (%)	Caregivers (n=193)
	n (%)	n (%)	n (%)
HIV status (positive)	10.1%	7 (10.6)	
On ART (yes)	100%	6 (85.7)	
Any side effects from ARVs (yes)	18.2%	0	
Counselling on living with HIV (yes)	63.6%	29 (43.0)	
Counselling on HIV & pregnancy (yes)	62.7%	32 (48.5)	
HIV transmission modes			
Unprotected sexual intercourse	100%		92.0%
Sharing needles	50%		86.0%
MTCT	100%		
Pregnancy			14.0%
Delivery			30.7%
Breastfeeding			14.0%
Children born HIV-free to HIV-positive mothers			
No			14.7%
Yes		48 (72.7)	117 (78.0%)
Don't know			20 (13.3%)
Child been tested for HIV (yes)			143 (74.1%)
Reasons for testing child			
Mother has/had HIV			12 (8.4%)
Frequent illness			27 (18.9%)
Advised by health care provider			72 (50.1%)
Other			49 (34.3%)
Has HIV positive child (yes)	2 (1.8%)		4 (2.1%)
Child on ART (yes)	2 (100%)		4 (100%)

Is the community aware?			1 (out of 4)
Consistently taking medication (yes)	2 (200%)		3 (75.0%)
Child psychosocial support (yes)	53 (48.2%)		
Counselling support on living with HIV+ child (yes)			1 (out of 4)
HIV Service delivery improvement (yes)			42 (25.2%)
Receive specific care from service providers			39 (23.4%)
Past 6 months received information on HIV			115 (68.9%)

In contrast, the data for pregnant women show that 11% (7 out of 66) reported living with HIV, with six of them confirming that they were on ART. The slightly higher percentage of HIV-positive pregnant women compared to breastfeeding women suggests that more needs to be done to engage pregnant women in testing and treatment programs. Both groups demonstrate a commitment to adhering to ART, which is essential for maintaining their health and minimizing the risk of transmitting the virus to their children.

Differences in HIV Counselling

The findings also indicate notable differences in the extent of HIV counselling received by pregnant versus breastfeeding women. Less than half (48%) of pregnant women reported having received counselling on living with HIV during their pregnancy, while 63% of breastfeeding mothers indicated that they had received such counselling. This discrepancy may point to systemic issues within healthcare service delivery. The lower rate of counselling for pregnant women may affect their ability to make informed decisions about their health and the health of their babies. In contrast, breastfeeding women, who may have already established care pathways, are more likely to seek out and receive counselling.

In addition, the data show that counselling related to HIV and pregnancy is critically important. The knowledge and support provided through counselling can empower women to manage their health conditions better and reduce the risk of transmission to their children. With a significant portion of pregnant women lacking this support, there is an urgent need for targeted interventions that ensure all pregnant women receive comprehensive counselling on HIV management.

Awareness of HIV Transmission Modes

The vast majority of participants (>90%) recognized unprotected sexual intercourse as the primary mode of HIV transmission. This level of awareness is encouraging and suggests that educational efforts around HIV transmission have been effective. However, understanding of other modes of transmission, such as sharing needles or mother-to-child transmission during pregnancy, delivery, or breastfeeding, could be further improved.

While both breastfeeding women and caregivers demonstrated a strong awareness of the risks associated with unprotected sex, the data on mother-to-child transmission showed room for improvement. Knowledge about MTCT varied, with 72% of pregnant women aware that they could deliver an HIV-free baby, compared to 78% of caregivers. This difference is notable, as it indicates that caregivers may have more access to information or support networks that enhance their understanding of prevention strategies.

Insights into Child HIV Status and Treatment

Among caregivers, 2% (4 out of 193) reported caring for a child living with HIV. Three of these children were aged between 10 and 14 years, while one was aged between 1 and 4 years. The presence of children living with HIV within caregiver families underscores the importance of ongoing support and healthcare resources for managing their health conditions.

All but one of these children were reported to be on ART and adhering consistently to their treatment regimens. This adherence is crucial, as consistent ART use can help manage the virus and improve the quality of life for these children. However, the fact that only two of the four children aged 10-14 years were aware of their HIV status is concerning. Knowledge of one's HIV status is vital for psychological wellbeing and effective self-management of the condition. It highlights a gap in communication and education that needs to be addressed, as children who understand their health conditions are more likely to engage in their treatment actively.

Psychosocial Support and Community Awareness

The findings indicate that psychosocial support is available, with 48.2% of caregivers reporting that their children receive such support. This kind of support is crucial for children living with HIV, as it helps them navigate the social and emotional challenges that can arise from their condition. The need for psychosocial support extends beyond just the children; caregivers themselves require emotional and practical support to manage their responsibilities effectively.

The question of community awareness regarding HIV status in families is also significant. Among caregivers with HIV-positive children, only one out of four reported that their community was aware of their child's status. This raises important considerations about stigma and discrimination associated with HIV. The lack of community awareness can lead to isolation and reduced access to social support systems, further complicating the challenges that families face.

In summary, the findings from Table 7 offer a comprehensive overview of the HIV prevalence and knowledge among breastfeeding women, pregnant women and caregivers in Zambia. While a considerable proportion of women are on ART and show an understanding of HIV transmission, significant gaps remain in counselling and awareness of mother-to-child transmission. The data also emphasize the need for improved communication regarding children's HIV status and the importance of psychosocial support.

Addressing these issues requires a multifaceted approach that includes enhancing healthcare access, providing targeted education and counselling, and fostering community awareness to reduce stigma. By implementing these strategies, we can work towards improving the health outcomes for women and children affected by HIV in Zambia and similar contexts.

4.1.4 HIV Testing Challenges and Community Outreach Efforts in Zambia

In Zambia, community-based HIV testing is a vital service, but it faces several obstacles, including **insufficient testing kits**, which greatly limit the capacity to serve rural populations. As highlighted in the report, a respondent from Kambale Clinic noted, "The most significant challenge we are facing is that we are lacking HIV testing kits" (Respondent from Kambale Clinic, as cited in BKTC Baseline Assessment, 2024). This shortage is a pressing issue, with many community health workers struggling to meet testing demands.

Despite these challenges, Zambia has introduced **door-to-door HIV testing**, which has improved access to testing for women and children. The PRICHO project is one such initiative that aims to reach all community members with HIV testing services, particularly in remote areas. Under national guidelines, all HIV-positive results from community-based testing must be confirmed at a health facility by professional laboratory staff. This ensures both accuracy and follow-up care for

those who test positive.

Community outreach activities, including **HIV testing at public events** such as markets and festivals, have proven to be effective in reaching large, diverse groups. However, funding limitations have impacted the consistency of these activities. The Government of Zambia and health partners have worked to extend community-based testing through outreach programs, but the **shortage of testing kits** remains a major hurdle. For example, a **2019 report** estimated that about 15% of community-based outreach programs faced interruptions due to shortages of kits, delaying testing services (Zambian Ministry of Health, 2019).

These efforts are essential to improving early detection of HIV, especially among women and children, as early ART initiation is critical for effective treatment. Nevertheless, the success of such programs largely depends on the availability of resources, including financial support and sufficient HIV testing supplies.

4.1.5 Retention in Care and Stigma Reduction Efforts in Zambia

Retention in care for individuals living with HIV in Zambia has been strengthened through **community health worker programs**. These volunteers play a significant role in referring newly identified HIV-positive individuals to nearby health facilities and ensuring they remain on antiretroviral therapy (ART). The baseline assessment found that in some cases, volunteers collect medication for patients who are unable to travel to the clinics, especially for those in rural areas, reducing transport costs and ensuring uninterrupted treatment.

A persistent challenge to **ART adherence** is the **stigma** surrounding HIV. According to the baseline assessment, "In case we are found positive, they might tell people in the community about our HIV status," a respondent expressed, reflecting fears of disclosure that often prevent people from seeking testing or treatment (BKTC Baseline Assessment participant, 2024). This stigma is deeply rooted in the community and continues to be a major barrier to both testing and adherence to ART. A **2020 survey** found that nearly 32% of people living with HIV in Zambia reported experiencing stigma at some point, which affected their willingness to adhere to treatment (UNAIDS, 2020).

Religious beliefs and **gender dynamics** further complicate retention in care. Some religious groups oppose modern medical treatments, including ART, while societal expectations limit male participation in HIV-related issues, making it more difficult for women to access HIV services freely. This dynamic often leaves women struggling to navigate treatment without adequate social support.

The **Zambian Government** has acknowledged the need for systematic efforts to reduce HIV-related stigma. According to the Ministry of Health (2019), there have been initiatives to build **family linkages and community-level support programs** to strengthen adherence. Health workers also play a crucial role in reducing stigma by educating patients and the wider community about HIV and ART. Despite these efforts, stigma remains a significant challenge that needs further attention to ensure that HIV-positive individuals, particularly women and children, remain in care and adhere to their treatment.

4.1.6 Focus on Children Living with HIV in Zambia

The *Bringing Kids to Care* (BKTC) project was designed to address the specific needs of children living with HIV (CLHIV) aged 0-14. However, analysis of the data indicates that more attention has been paid to caregivers and breastfeeding women, with insufficient direct focus on the children themselves. This section highlights the challenges faced by children living with HIV in Zambia, aligning with the core objectives of the BKTC project.

Demographic Characteristics of Children Living with HIV

In Zambia, children aged 0-14 years living with HIV represent a critical group in the fight against the epidemic. These children face several barriers, including stigma, access to treatment, and challenges related to disclosure of their HIV status. Within the BKTC project, efforts have been made to identify HIV-positive children through index testing strategies, especially among caregivers and women attending antenatal and postnatal clinics. However, the interventions must become more child-centered, focusing specifically on the health and psychosocial needs of these children.

One of the biggest challenges is the stigma surrounding HIV and the delayed disclosure of a child's status. Caregivers often delay informing children of their HIV status due to fear of negative reactions and community stigma. This delay can have severe consequences on the child's mental health, social integration, and adherence to antiretroviral therapy (ART). A significant number of children also face difficulties in maintaining consistent access to ART. Many children are lost to follow-up (LFU) as families move or fail to continue treatment due to logistical, financial, or awareness barriers. Caregivers noted that in some cases, children have to travel long distances to receive ART, while others may neglect the children's treatment needs due to competing health challenges of their own.

There is also a need for structured psychosocial support services tailored to children living with HIV. Currently, most support services target caregivers, pregnant women, and breastfeeding women, leaving a gap in addressing the emotional and psychological needs of children. Implementing age-appropriate programs for children to receive psychosocial support and cope with their diagnosis will be crucial for improving their well-being.

Summary of the Challenges and Gaps

Children living with HIV in Zambia face significant barriers to care, including stigma, inconsistent access to ART, and a lack of child-specific psychosocial support. By focusing more directly on these children, the BKTC project can make a more substantial impact on their health outcomes and quality of life.

4.1.7 Meeting basic needs and participation in village savings and loans in Zambia

The findings from Zambia highlight significant socio-economic challenges faced by both breastfeeding women and caregivers, particularly in meeting basic household needs. Nearly two-thirds (65.5%) of breastfeeding women reported experiencing inadequate food supply in their households, underscoring the high prevalence of food insecurity (Table 8). This figure is notably higher than the 46% of caregivers who also indicated difficulties in securing enough food for their families. The disparity between breastfeeding women and caregivers could be attributed to the increased nutritional demands on women who are breastfeeding, combined with limited financial resources.

Table 8: Variables related to breastfeeding women and caregivers in village savings and loans in Zambia.

Variable	Breastfeeding Women (n=110) (%)	Caregivers (n=193) (%)
Manage to meet food needs (yes)	20 (16.4)	58 (34.0)
Eat diversified diets (yes)	36 (36.0)	32 (19.2)
Knowledge of village savings & loans (yes)	31 (28.2)	62 (37.1)
Member of VSL	4 (12.9)	10 (16.1)
Member for past 12 months	2 (6.5)	11 (17.7)

Borrows money 12 months ago	2 (6.0)	6 (9.7)
Willingness to join VSL		
- Less willing		21 (16.7)
- Neutral		16 (12.7)
- Willing		58 (42.1)
- Very willing		36 (28.6)

Food insecurity not only impacts overall household well-being but also exacerbates the vulnerability of families, especially those with children living with HIV. Proper nutrition is a critical component of maintaining the health of both mothers and children, particularly in the context of HIV, where adequate food intake supports the effectiveness of antiretroviral therapy (ART) and enhances the immune system. The inability to meet basic food needs is therefore a serious concern that could hinder progress in improving health outcomes for this population.

In addition to addressing food security, the survey examined the level of awareness and participation in Village Savings and Loans (VSL) schemes among the respondents. These community-based financial groups serve as an important mechanism for providing access to small-scale credit, helping families manage current consumption needs or invest in income-generating activities. The data shows that only 28% of breastfeeding women were aware of the existence of VSL schemes in their localities, compared to 37% of caregivers. This suggests that a significant proportion of women are either unaware of these financial resources or have limited access to the necessary information.

Despite the relatively low level of awareness, there is a strong willingness among caregivers to participate in VSL groups. Among those who were aware of VSLs in their locality, 72% expressed a desire to join such schemes. This indicates a clear recognition of the potential benefits of VSL participation, particularly in improving household financial stability and meeting basic needs. However, the gap in awareness highlights a need for more targeted outreach and education efforts to ensure that women, especially breastfeeding mothers, are informed about the availability of VSL schemes and how to join them.

Interestingly, only 16.1% of caregivers and 12.9% of breastfeeding women were already members of VSL groups. This low level of participation may be attributed to a lack of understanding of how the groups operate, limited access to existing groups, or cultural and social barriers that prevent women from engaging in financial decision-making. Those who had joined VSLs in the past 12 months reported having utilized the loans for various purposes, including meeting immediate household needs or investing in small-scale economic activities. However, the limited membership in these schemes suggests that there is untapped potential for VSLs to play a greater role in alleviating the financial struggles faced by women and caregivers in Zambia. The findings also show that while willingness to join VSLs was high, actual participation remained low. This reflects a disconnect between interest in such financial schemes and access to them. It may indicate logistical barriers, such as distance to meeting locations, lack of knowledge on how to become a member, or challenges in meeting membership requirements, such as making regular contributions. These barriers need to be addressed to increase participation and ensure that more women can benefit from the financial and social support that VSLs provide.

The data from Zambia illustrates a clear need to strengthen access to financial services for breastfeeding women and caregivers. Increasing awareness about Village Savings and Loans schemes and addressing the barriers to participation could significantly improve the financial resilience of these vulnerable groups. By promoting greater involvement in VSLs, there is potential to help families better meet their basic needs, particularly in terms of food security, and enhance their ability to support children living with HIV. Expanding participation in VSLs could also

empower women by providing them with greater control over financial resources, thereby improving their overall socio-economic status and the well-being of their households.

4.1.8 Implementation Strategy of the Bringing Kids To Care Projects

Once launched, the Bringing Kids To Care (BKTC) project in Zambia will implement a multi-tiered approach, integrating national health policies with community-based interventions. The project aims to establish strong partnerships with the Zambian Ministry of Health at district levels to ensure that its interventions complement existing HIV response efforts. By collaborating with government health departments, the BKTC project will be able to streamline services and leverage existing structures, such as health facilities and community health workers, to identify, test, and retain children and women living with HIV in care.

A key component of the implementation strategy is the door-to-door HIV testing model, designed to reach remote communities that face geographical barriers and wildlife-related challenges. Community health workers will be trained under the project to conduct home visits, providing HIV testing, follow-up care, and adherence support. This localized approach will help reduce the logistical challenges that typically prevent access to healthcare in rural areas, ensuring that vulnerable populations are included in Zambia's national HIV response (UNAIDS, 2020).

Through the combination of government partnerships and community-driven efforts, the BKTC project is positioned to enhance HIV testing and treatment coverage in Zambia. It will fill critical gaps in service delivery by directly addressing the barriers that have historically hindered access to healthcare, particularly for women and children.

4.1.9 Relevance of the BKTC Project in the Zambian Context

The BKTC project is highly relevant to Zambia's healthcare needs, particularly in addressing the gaps in pediatric HIV care and preventing mother-to-child transmission (PMTCT). With the launch of the project, interventions will focus on reaching high-risk groups, including pregnant and breastfeeding women, who are often missed in traditional healthcare settings. This approach aligns with the government's strategic priorities of reducing child and maternal mortality and controlling the spread of HIV.

The project is designed to integrate community health services, which will provide localized, tailored solutions that meet the specific challenges of Zambia's healthcare landscape. In rural areas where transportation and stigma are barriers to care, the BKTC model will offer a viable strategy for increasing HIV testing and treatment uptake. By utilizing community health workers who are familiar with local dynamics, the project will promote health-seeking behaviors in areas that are hard to reach, contributing significantly to national health goals (PRIMROSE, 2019).

4.1.10 Synergy of BKTC Project Interventions with Existing Programs

The BKTC project will work in synergy with existing national HIV programs, including the UNAIDS 95-95-95 strategy, which focuses on ensuring that 95% of people living with HIV are diagnosed, 95% receive treatment, and 95% achieve viral suppression. The project will complement these efforts by focusing on children and women living with HIV, a demographic often overlooked in broader HIV responses.

BKTC will also collaborate with international organizations, such as Centre for Disease Control (CDC), the Global Fund and Centre for Infectious Disease Research in Zambia (CIDRZ), that are involved in similar HIV response initiatives in Zambia. By integrating its activities with these organizations, the BKTC project will ensure that its interventions enhance, rather than duplicate, existing programs. The use of community health workers to carry out door-to-door testing, for

example, will help reach populations that have traditionally been underserved by other programs, strengthening overall HIV response efforts (Global Fund, 2022).

4.1.11 Effectiveness of the BKTC Project

The anticipated effectiveness of the BKTC project lies in its focus on reaching vulnerable populations that are often excluded from mainstream healthcare services. Once launched, the project's door-to-door testing model will ensure that even remote and hard-to-reach communities are included in HIV prevention and treatment efforts.

Community health workers will be at the heart of the BKTC project implementation, serving as the primary link between rural communities and healthcare facilities. These workers will be trained to provide both pre- and post-test counseling, ensuring that those diagnosed with HIV are promptly initiated on antiretroviral therapy (ART). The effectiveness of the project will also be supported by its emphasis on continuous care and follow-up, which will help reduce the number of children and women lost to follow-up (UNAIDS, 2020).

However, to fully achieve its intended impact, the project will require adequate resources. Addressing potential challenges, such as the availability of testing kits and logistical support, will be crucial for maximizing the project's effectiveness in reaching its target populations.

4.1.12 Efficiency of the BKTC Project Interventions

The BKTC project is designed to operate efficiently by leveraging existing healthcare structures and collaborating with government and community partners. Upon its launch, the project will use community health workers as frontline agents, making HIV testing and care more accessible to those in remote areas. By working within established systems and reducing the need for patients to travel long distances to healthcare facilities, the project minimizes operational costs and maximizes its outreach.

While the door-to-door testing model is expected to improve efficiency, the project must address logistical challenges such as transportation and the availability of testing kits. Without sufficient resources to support these community-based efforts, there may be delays in service delivery. Ensuring a steady supply of testing kits and improving transportation options for healthcare workers will be key to maintaining the project's efficiency (PRIMROSE, 2019).

4.1.13 Sustainability of BKTC Project Interventions

Sustainability is a core focus of the BKTC project. The project aims to build local capacity by training healthcare workers and fostering community involvement, ensuring that HIV care can continue even after the project's initial phase ends. The door-to-door model, once established, will be integrated into local healthcare practices, providing a lasting solution for reaching underserved populations.

The project's sustainability will also be supported by strong collaboration with government health departments and local volunteers. By engaging communities in the planning and execution of the project, BKTC will foster a sense of ownership that is essential for the long-term success of its interventions. However, securing ongoing financial support will be critical to maintaining the project's momentum, especially in scaling up activities to reach more remote regions (Ministry of Health, 2021).

4.1.14 Impact Orientation of the BKTC Project

The BKTC project is designed with a clear orientation towards impact. Once launched, it will contribute to improving the health outcomes of children and women living with HIV by increasing access to testing, treatment, and retention in care. Through its community-focused approach, the

project will reduce barriers to healthcare and foster a more supportive environment for those living with HIV.

By involving children in their healthcare decisions and promoting greater community involvement, the BKTC project will help shift social norms, reduce stigma, and encourage long-term adherence to treatment. This community-driven model has the potential to create lasting, transformative change in Zambia's fight against HIV, ensuring that the project's impact extends far beyond its initial implementation.

4.1.15 Recommendations for Zambia

Recommendations for Engaging Pregnant Women in HIV Programs

1. Enhanced Counseling Services for Pregnant Women

- Ensure that all pregnant receive comprehensive information about HIV management, ART adherence, and mother-to-child transmission (MTCT) prevention.
- Ensure that pregnant women receive effective counselling techniques from capacitated healthcare providers on effective counselling techniques, focusing on the importance of ART adherence and the health implications for both mother and child.

2. Targeted Outreach Programs

- Mobilize community health workers (CHWs) to conduct outreach specifically targeting pregnant women, offering information on the importance of HIV testing and treatment, and facilitating access to services.
- Provide incentives (such as transportation support or food vouchers) to encourage pregnant women to engage in testing and adhere to ART.

Improving Awareness and Education

3. Educational Campaigns on Mother-to-Child Transmission

- Develop and disseminate educational materials that specifically address MTCT and the importance of ART in preventing transmission during pregnancy and breastfeeding. These materials should be culturally sensitive and accessible.
- Organize community dialogues that involve both pregnant women and caregivers, focusing on HIV transmission modes, prevention strategies, and the importance of early testing and treatment.

4. Utilization of Peer Support Networks

- Establish peer education programs where HIV-positive pregnant women and caregivers can share their experiences and knowledge, fostering a supportive environment that encourages testing and adherence to treatment.

Supporting Children Living with HIV

5. Child-Centered Interventions

- Shift the focus of the BKTC project to include interventions that are more direct for CLHIV, ensuring that their specific health and psychosocial needs are addressed. This can include tailored healthcare services and psychosocial support programs.
- Implement regular health check-ups for CLHIV to monitor their health status and ensure they are adhering to ART, with follow-ups conducted by CHWs.

6. Facilitating Disclosure of HIV Status

- Facilitate the creation of structured programs that guide caregivers on how to disclose a child's HIV status in an age-appropriate manner, providing resources and support to alleviate fears of stigma.
- Provide counseling services for children to help them understand their condition, fostering a sense of agency and encouraging adherence to their

treatment regimen. Children's Corner and youth-friendly health services can be the best platform for achieving the results

7. Strengthening Psychosocial Support Services

- Establish support groups specifically for children and adolescents living with HIV, where they can share their experiences and receive emotional support from peers. These support groups are also known as Adventure Unlimited.
- Integrate psychosocial support into routine healthcare for CLHIV, ensuring that both children and their caregivers receive the necessary emotional and practical assistance.

Addressing Stigma and Community Awareness

8. Community Awareness Campaigns

- Launch community-wide campaigns aimed at reducing the stigma associated with HIV, involving local leaders and influencers to promote acceptance and support for families affected by HIV.
- Utilize community events, such as health fairs and festivals, to disseminate information about HIV, focusing on the importance of testing, treatment, and support for families with HIV-positive children.

9. Engagement of Caregivers and Families

- Implement a family-centered approach to healthcare, ensuring that caregivers are involved in the treatment and support of CLHIV, and addressing their own health needs as well.

Provide caregivers with resources and training on managing the health of their HIV-positive children, including information on ART adherence and navigating healthcare systems.



Figure 3: Map of Malawi showing project districts

4.2 Malawi

Malawi is located in Southern Africa and shares its borders with Mozambique, Zambia, and Tanzania. As of 2022, the country's estimated population is 20.41 million, with an annual growth rate of 2.6% (National Statistics Office, 2018)²⁰. The Bringing Kids to Care (BKTC) project is implemented in three districts by the Coalition of Women Living with HIV/AIDS (COWLHA) and its partners. The study districts include Nkhata Bay in northern Malawi, as well as Chiradzulu and Thyolo in southern Malawi (see Figure 2). The project targets 6,396 children aged up to 14 years living with HIV.

COWLHA serves as the lead partner in supporting the implementation of the Kids Health Kids Rights project, which mirrors the Bringing Kids to Care model. Other partners in this initiative include Research for Equity and Community Health (REACH) Trust, the National Association for Young People Living with HIV (Y+), the Foundation for Community Support Organization in Chiradzulu, Mtisunge AIDS and Community Development Support Organization in Nkhata Bay, and Thunga Community Based Organization in Thyolo.

²⁰ National Statistics Office. (2018). *Malawi population and housing census 2018*

Coalition of Women Living with HIV/AIDS (COWLHA)

The Coalition of Women Living with HIV/AIDS (COWLHA) was established to amplify the voices of women and girls living with HIV, and by extension, their children, to address the multifaceted issues affecting them. Support groups have been a crucial entry point for engaging with members, providing a community-based platform for achieving mental health and well-being. COWLHA envisions a society where women and girls living with HIV attain healthy lives, are socio-economically empowered, and have their rights fulfilled. Its mission is to end AIDS in women and girls by ensuring accessible and quality HIV and AIDS service delivery while advocating for women's and girls' rights. In their strategic plan for 2023-2027, COWLHA emphasizes conducting high-level interventions in HIV as well as Reproductive, Maternal, Neonatal, Child, and Adolescent Health.

Kids Health Kids Rights Project

The Kids Health Kids Rights Project operates in the districts of Nkhatabay, Chiradzulu, and Thyolo. These districts were selected based on recommendations from the Malawi Government through the Directorate of HIV, STI, and Viral Hepatitis, which reported that they recorded the highest number of pediatric and adolescent HIV infections among children aged 0 to 14 years as of June 2023.

In 2022, Nkhatabay had 11,887 clients accessing antiretroviral therapy (ART). However, 5,020 clients defaulted on treatment, including over 1,000 children (Directorate of HIV, STI and Viral Hepatitis, 2022)²¹. Factors exacerbating the high HIV prevalence in this district include its proximity to Lake Malawi, where a significant proportion of the population engages in risky behaviors such as unprotected sex, substance abuse, and transactional sex. These behaviors increase the likelihood of HIV transmission and complicate efforts to provide adequate care (UNAIDS, 2022)²².

Chiradzulu has the highest pediatric HIV infection rate in Malawi, with an estimated prevalence of 1.10% among children aged 0-14 years. Contributing factors include prevalent transactional sex due to high poverty levels, which heighten the risk of HIV transmission among vulnerable populations. In Thyolo, numerous tea plantations lead to high mobility among male workers, often leaving their spouses at home without adequate child support. This situation increases the risk of contracting HIV and exacerbates the challenges faced by women left to care for their families alone. The HIV Landscape Analysis of 2022 by the Directorate of HIV, STI, and Viral Hepatitis reported that Thyolo experienced the fourth highest new HIV infections, with 1,026 cases.

The two-year project aligns with Aidsfonds' Bringing Kids to Care Model, aiming to eliminate vertical transmission of HIV and ensure that all children living with HIV and their mothers lead healthy, fulfilling lives. The project's specific objectives are as follows:

- To ensure that all children living with HIV are identified and supported to start and continue their treatment, enabling them to live healthy lives.
- To train healthcare providers in the provision of child-friendly health services, ensuring that care is both accessible and appropriate for young patients.
- To train mentor mothers to trace cases of loss to follow-up and provide counseling to pregnant and lactating mothers in collaboration with community health workers.

4.1.1 Paediatric HIV Prevalence, Response and Recent Research in Malawi

According to the latest data from UNAIDS (2023), Malawi has made significant strides in reducing mother-to-child transmission (MTCT) of HIV, achieving a vertical transmission rate of approximately 4.3%. However, despite these efforts, a considerable number of children are already living with HIV. The HIV prevalence among children aged 0–14 is estimated at 1.5%, which

²¹ Directorate of HIV, STI and Viral Hepatitis. (2022). *HIV landscape analysis report*.

²² UNAIDS. (2022). *Global AIDS update 2022: Confronting inequalities*.

translates to over 100,000 children living with HIV in Malawi (UNAIDS, 2023)²³. These figures highlight the need for a dual focus: preventing new infections through PMTCT initiatives while also addressing the care and treatment of children who are already HIV-positive.

The pediatric HIV response in Malawi is shaped by several key interventions, one of which is the implementation of the World Health Organization's (WHO) Option B+. This policy, introduced in 2011, mandates the initiation of lifelong antiretroviral therapy (ART) for all pregnant and breastfeeding women living with HIV, regardless of CD4 count. By 2022, 95% of pregnant women had been tested for HIV at antenatal clinics, with 91% of those testing positive being initiated on ART (Malawi Ministry of Health, 2022). Despite this high coverage, retention in care remains a challenge, particularly among breastfeeding mothers and children. Approximately 20% of children exposed to HIV are either lost to follow-up or do not receive the necessary treatment to ensure viral suppression (Malawi Ministry of Health, 2022)²⁴.

Pediatric HIV Care Beyond Vertical Transmission

While PMTCT programs have been central to Malawi's HIV response, the focus must expand to address children already living with HIV. A substantial number of children living with HIV were infected through other means, including sexual transmission in older children and adolescents. According to UNAIDS (2023), children and adolescents living with HIV in Eastern and Southern Africa face significant gaps in access to treatment, with only 57% of children living with HIV in Malawi receiving ART. This gap leads to poor health outcomes, including higher morbidity and mortality rates compared to adults.

Recent studies emphasize the importance of early infant diagnosis (EID) and regular follow-up to ensure that children living with HIV achieve viral load suppression (van Low et al., 2018)²⁵. However, logistical challenges such as limited access to healthcare facilities, delays in receiving test results, and socio-economic barriers contribute to delays in diagnosis and treatment initiation. Moreover, the loss to follow-up among children, particularly those beyond two years of age, is a critical issue. These children often "fall through the cracks" of the healthcare system once they are outside the age group of PMTCT programs, highlighting the need for community-level interventions to sustain their care (UNAIDS, 2023)²⁶.

The introduction of community-based pediatric HIV initiatives, such as the "Bringing Kids to Care" project, is a step toward closing these gaps. This initiative focuses on improving the identification, treatment, and retention of children living with HIV through partnerships with local communities, health workers, and caregivers. Additionally, the UNAIDS 95-95-95 targets — aiming for 95% of people living with HIV to be diagnosed, 95% of those diagnosed to be on ART, and 95% of those on ART to achieve viral suppression — remain a cornerstone of Malawi's HIV strategy. However, children are often overlooked in this model, with lower viral suppression rates compared to adults (UNAIDS, 2023).

Addressing Gaps in Pediatric HIV Care

To achieve better outcomes for children living with HIV, Malawi must address several critical gaps in the pediatric HIV care continuum. First, more robust efforts are needed to improve retention in care, particularly among children transitioning from PMTCT programs to regular HIV care. Second, community engagement must be strengthened to ensure that children living with HIV, especially those in remote areas, have access to life-saving treatment. Finally, there is a pressing need for

²³ Joint United Nations Programme on HIV/AIDS (UNAIDS). (2023). *Global AIDS update 2023*.

²⁴ Malawi Ministry of Health. (2022). *Malawi Integrated HIV program report*. Lilongwe: Ministry of Health.

²⁵ van Low, M., Kim, S., Smith, P., & Mbewe, R. (2018). Gaps in pediatric HIV care in Malawi. *Journal of Global Health Reports*, 2(1), 50-56.

²⁶ Joint United Nations Programme on HIV/AIDS (UNAIDS). (2023). *Global AIDS update 2023*

improved data collection and monitoring systems to track the progress of pediatric HIV interventions.

Innovative approaches, such as the integration of HIV services with other pediatric care programs, could also help reduce loss to follow-up and improve treatment adherence. Additionally, addressing socio-economic barriers, such as poverty and lack of transportation, will be crucial in ensuring that children living with HIV remain in care and achieve viral suppression. The availability of child-friendly ART formulations, along with the training of healthcare workers on pediatric HIV care, will further support the goals of universal HIV treatment and care for all children living with HIV in Malawi.

4.1.2 Findings for Malawi

Household Demographic Characteristics

In Malawi, primary data collection for the baseline assessment of the *Bringing Kids to Care Project* was carried out in May and July 2024. The survey targeted pregnant and breastfeeding women, caregivers of children aged 0-14 years, and children aged 10-14 years. The study involved 98 breastfeeding women and 107 caregivers (Table 9), which made up a significant portion of the total survey participants across the three countries (Malawi, Zambia, and Tanzania).

Table 9: Survey Participants in Malawi

Category	Number of Respondents
Breastfeeding Women	98
Caregivers	107

Demographic Characteristics of Survey Participants

Table 10 provides an overview of the demographic characteristics of breastfeeding women and caregivers in Malawi. The median age of breastfeeding women was 24 years, while caregivers were relatively older, with a median age of 39 years. Both groups had a median of two children each, and the household sizes ranged from 4 to 7 members.

Table 10: Demographic Characteristics of Survey Participants in Malawi

Variable	Breastfeeding Women (n=98)	Caregivers (n=107)
Age of respondent (years)	24 (14-42)	39 (21-61)
Age of baby (months)	9.5 (1-24)	-
Number of children	2 (1-4)	2 (1-3)
Household size	4 (4-7)	4 (4-7)

Education Levels and Main Occupation

In terms of education, most breastfeeding women and caregivers had received primary or secondary education, with a significant number involved in farming activities. Notably, 95% of breastfeeding women in Malawi identified farming as their main occupation, while 82% of caregivers were similarly engaged in farming (Table 11).

Table 11: Education Levels and Occupation of Survey Participants in Malawi

Variable	Breastfeeding Women (%)	Caregivers (%)
Education Level		
None	3	10
Primary	68	67
Secondary	25	22
Tertiary	3	-
Main Occupation		

Farming	95	82
Self-employed	35	11
Trader/piece work	26	7
Other	38	15

Marital Status

Table 12 shows the marital status of the breastfeeding women and caregivers. A large proportion of the participants were married, with 83% of breastfeeding women and 68% of caregivers being in marriage. Divorce and widowhood were less common among breastfeeding women, but the caregiver group saw a higher proportion of widowed participants.

Table 12: Marital Status of Survey Participants in Malawi

Marital Status	Breastfeeding Women (%)	Caregivers (%)
Single	11	5
Married	83	68
Divorced	4	15
Widowed	2	14

The survey findings highlight key demographic and socio-economic characteristics of breastfeeding women and caregivers in Malawi. A significant portion of the population is engaged in farming, and education levels vary across the surveyed groups. The data reveal critical insights into the living conditions, household structures, and livelihoods of participants, all of which have implications for the success of interventions under the *Bringing Kids to Care Project*.

4.1.3 Reported HIV status and HIV knowledge among breastfeeding women in Malawi

Table 13 provides critical insights into the prevalence of HIV and related knowledge among breastfeeding women surveyed in Malawi. The data indicates that a significant proportion, up to 55%, reported living with HIV and being on antiretroviral therapy (ART). This underscores the importance of ART in managing HIV, as it not only improves the health of the mothers but also reduces the risk of mother-to-child transmission (MTCT). However, 8.2% of these women indicated that they had a child living with HIV, highlighting that despite ART's effectiveness, the risk of transmission persists in some cases.

Table 13: Insights into the prevalence of HIV and related knowledge among breastfeeding women surveyed in Malawi.

Variable	Breastfeeding Women (n=98) (n=%)	Caregivers (n=107) (n=%)
	n (%)	n (%)
HIV status (positive)	54 (55%)	
On ART (yes)	100%	
Any side effects from ARVs (yes)	14 (25%)	
Counselling on living with HIV (yes)	52 (96%)	25 (100%)
Counselling on HIV & pregnancy (yes)	91 (93%)	
HIV transmission modes		
Unprotected sexual intercourse	89 (91%)	85 (79.4%)
Sharing needles	6 (6%)	13 (12.1%)
MTCT	2 (2%)	
Pregnancy		3 (2.8%)
Delivery		2 (1.9%)
Breastfeeding		1 (1.9)
Blood transfusion	1 (1%)	0

HIV free born from HIV-positive mother		
No	9 (9.2%)	7 (6%)
Yes	87 (88.8%)	98 (92%)
Don't know	2 (2%)	2 (2%)
Child been tested for HIV (yes)	54 (100%)	89 (83.2%)
Reasons for testing child		
Mother has/had HIV	54 (100)	10 (11%)
Frequent illness		14 (16%)
Advised by health care provider		4 (4.5%)
Born with it		49 (34.3%)
Community aware of child HIV status?		11 (44%)
Child aware of her HIV status (Yes)		17 (68%)
Consistently taking medication (yes)		25 (100%)
Counselling support on living with HIV+ child (yes)		25 (100%)
Wish for HIV Service delivery improvement (yes)		18 (16%)
Received specific care from service providers (yes)		25 (23%)
Past 6 months received information on HIV (yes)		59 (55%)

Almost all of the breastfeeding women surveyed (96%) had received counselling on how to live positively with HIV, which is crucial for their mental and emotional wellbeing. Additionally, a remarkable 93% reported having been counselled on HIV and PMTCT (Prevention of Mother-to-Child Transmission). This high level of counselling suggests that healthcare providers are making significant efforts to equip women with the necessary knowledge to manage their condition and understand how to reduce the risk of transmitting the virus to their infants. However, it is concerning that 9% of women were unaware that a baby could be born HIV-free from a mother living with HIV. This knowledge gap may hinder their ability to make informed decisions regarding their health and that of their children. Further examination of the data reveals that slightly more than half (84%) of the breastfeeding women had their sexual partners tested for HIV, although the majority (56%) reported that their partners were tested at different times. This could suggest a lack of coordinated health-seeking behaviour within couples, which may affect the overall health management of the family unit.

The data also provides insights into the caregivers' demographics, revealing that 92% cared for 1 to 3 children aged 0-14 years, with most children being between the ages of 3 and 14. The majority of these children (83%) were under the care of their mothers, with some being looked after by their grandmothers (8.3%), aunts (4.7%), or other family members. This family-centric approach to childcare reflects the importance of community and familial support in managing health issues, particularly in the context of HIV.

In terms of decision-making regarding healthcare, mothers were primarily responsible for seeking medical services for their children (45%), while 25% reported making these decisions jointly with their husbands. For mothers without husbands, siblings played a role in decision-making for healthcare (13%). This indicates that the presence of a supportive partner or family member can influence healthcare-seeking behaviours, which is vital for the wellbeing of children.

The survey also assessed healthcare-seeking behaviour of the caregivers by inquiring whether any child under their care had been ill in the past three months. Among the positive responses, a

staggering 96.8% reported visiting a hospital or health clinic, demonstrating a strong preference for formal medical care. Other avenues for care included community health workers (1.6%), purchasing medications from pharmacies (6.5%), and seeking prayer as a solution (1.6%). These less popular avenues were in addition to the health facility visits. The overwhelming preference for hospitals and clinics highlights the caregivers' trust in formal healthcare systems to provide effective treatment for their children.

Regarding the HIV status of children under the caregivers' supervision, 23.4% of survey respondents reported that their children were HIV-positive. All children living with HIV were on ART, reflecting self-consciousness about ART and the positive impact of healthcare interventions aimed at improving access to treatment for children. The reasons cited for testing children for HIV varied, with frequent illness accounting for 16%, being born with HIV for 2%, having a mother with HIV for 11%, and advice from healthcare providers for 8%. The data suggests a multifaceted approach to testing, combining symptoms with historical knowledge of HIV within the family. Some side effects from ART were reported among the children, including headaches (12%) and diarrhea (4%). While these side effects are not uncommon, they can affect adherence to treatment, making it essential for caregivers to receive proper education about managing such symptoms.

On the quality of HIV service delivery, 16% of the caregivers expressed a wish for improvements in the services they receive. The feedback indicated a strong need for nutrition interventions, as suggested by 30% of responses. Such interventions imply direct nutrition support in form of nutrient rich food items to families with pregnant women living with HIV. Other wishes concerned privacy at ART clinics; the need for house-to-house mass HIV testing campaigns by government and NGOs; consistent provision of information and supplies in healthcare facilities, and; improvements in mobility—such as providing bicycles—to help community health workers reach clients more effectively. Additionally, caregivers raised concerns about the confidentiality issues associated with delegating the distribution of medications to individuals not living with HIV.

Overall, the data from breastfeeding women and caregivers in Malawi highlights the complex interplay between HIV status, knowledge, and healthcare-seeking behaviours. While significant strides have been made in counselling and ART provision, there remain gaps in awareness about misconception of MTCT among pregnant women who discover their positive HIV status at pregnancy, and; the overall health care literacy among caregivers. Addressing these gaps through targeted education and community engagement will be essential in improving health outcomes for both mothers and their children.

4.1.4 Community HIV Testing in Malawi: Opportunities and Challenges

In Malawi, HIV testing at the community level has largely depended on **outreach events** organized by both the government and partners, such as the Malawi Aids Counselling and Resource Organisation (MACRO). These outreach programs, which typically coincide with community events like market days or festivals, offer a vital platform for increasing HIV testing among women and children. During these events, **AIDS talks** are delivered, and attendees are often encouraged to take part in testing or are provided with self-testing kits to use at their convenience. A positive HIV test must be confirmed through a confirmatory test at a health facility.

Through key informant interviews it was noted that participation in testing remains relatively low. Many people prefer to take information packs home rather than undergo immediate testing at the outreach sites. A health worker noted, "Not as many people generally test at such outreach activities, but they just get information packs and promise to get tested at health facilities" (Health Worker in Malawi, as cited in BKTC Baseline Assessment, 2024). This trend highlights the

need for more **targeted approaches** to increase uptake of testing services during these community-based events. This is one avenue for increasing the **Find** in Malawi.

The **Malawian Government** has identified large public gatherings as an effective way to reach diverse groups of people, especially in rural settings. District health facilities are encouraged to conduct testing at events with high attendance, such as market days, in an effort to maximize the positivity rate (Malawi Ministry of Health, 2020)²⁷. While testing kits are generally available in Malawi, there remains a need for further innovation to **enhance testing accessibility** and increase the rate of early diagnosis, particularly in harder-to-reach areas. Testing outreach programs open up testing to various categories of targets and non-target population hence enhancing the **Find**.

4.1.5 Addressing Stigma and Enhancing Retention in Care in Malawi

The baseline assessment in Malawi noted that retention in care for people living with HIV has been strengthened through **community-based support systems**. Programs that involve community health workers and HIV support groups have proven effective in ensuring that individuals remain on antiretroviral therapy (ART). These groups facilitate follow-ups, encourage adherence, and, in some cases, even **transport medications** to patients who are unable to visit health facilities, particularly in remote areas. This model not only ensures continuous treatment but also reduces the financial burden on families, as noted in the BKTC Baseline Assessment.

Nevertheless, stigma remains a barrier to effective HIV service delivery in Malawi. The **deep-rooted stigma** surrounding HIV continues to deter people from freely and confidently seek testing or adhering to treatment. During focus group discussions, many participants raised concerns about the social repercussions of being diagnosed with HIV. One respondent in Malawi said, "People are afraid of going for voluntary testing because of the fear that their HIV status will be disclosed in the community" (- Key informant interview with PMTCT Coordinator, BKTC Baseline Assessment, 2024). This stigma is a major contributor to non-adherence to ART and leads to high dropout rates, particularly in rural communities where the fear of judgment is pervasive. Moreover, **cultural and religious factors** exacerbate the challenges in HIV service uptake. Some religious groups in Malawi discourage the use of modern health services, including ART, while societal norms often make it difficult for women to openly seek HIV-related care. Some pregnant women may seek their partners' approval to initiate ART. The baseline assessment further found that men's resistance to participating in HIV programs further hinders women's access to testing and treatment services.

To tackle these issues, the **Malawian Government** and health partners have prioritized the need for **sensitization campaigns** that focus on destigmatizing HIV within communities. Additionally, by working with community leaders and community health workers, the government aims to strengthen **family and community-based interventions** to support ART adherence. These measures are designed to build trust in the health system and encourage those living with HIV to remain in care. However, overcoming stigma will require sustained efforts at both the local and national levels to ensure that HIV-positive individuals, especially women and children, can access and adhere to life-saving treatments without fear of discrimination.

4.1.6 Focus on Children Living with HIV in Malawi

The *Bringing Kids to Care* (BKTC) project in Malawi is designed to support children living with HIV (CLHIV) aged 0-14. This section highlights the critical challenges faced by children living with HIV in Malawi and recommends areas for improvement in the project's implementation.

Demographic Characteristics of Children Living with HIV

In Malawi, children aged 0-14 years living with HIV represent a highly vulnerable population that faces numerous barriers to accessing healthcare and treatment. Many of these children experience

²⁷ Malawi Ministry of Health. (2020). *Malawi National Strategic Plan for HIV and AIDS 2020–2025*. Lilongwe, Malawi.

stigma and discrimination, which can hinder their ability to seek necessary medical care. Although the BKTC project aims to identify and support HIV-positive children, efforts have largely concentrated on maternal and caregiver health, leaving CLHIV at risk of inadequate support.

One significant challenge is the delayed disclosure of HIV status to children. Caregivers often hesitate to inform their children about their condition due to fears of stigma and potential negative repercussions within the community. This delay can lead to feelings of confusion and mistrust among children, negatively affecting their mental health and social development when they go through accidental disclosure or learn about their condition from their friends in their community or at school. Additionally, children who are unaware of their status may struggle to adhere to their treatment regimens, which can jeopardize their health outcomes. In worst cases children can become suicidal.

Treatment adherence is another pressing issue for children living with HIV in Malawi. Many children are lost to follow-up (LFU) due to logistical challenges, such as the need for long-distance travel to access antiretroviral therapy (ART) and a lack of resources among caregivers. In some instances, caregivers prioritize their own health needs or those of other family members over the child's healthcare, resulting in inconsistent treatment and monitoring.

Moreover, there is a critical need for psychosocial support specifically aimed at children living with HIV. While caregivers and breastfeeding women receive various forms of support, children's emotional and psychological needs often remain unaddressed. Programs focused on age-appropriate disclosure, peer support, and counseling can play a significant role in improving the well-being of children living with HIV, helping them to cope with their condition and adhere to treatment.

Summary of the Challenges and Gaps

Children living with HIV in Malawi face challenges including stigma, delayed disclosure of their status, inconsistent access to ART, minimal integration with their peers of unknown HIV status, non-confidential services at clinics, and a lack of psychosocial support. By focusing more directly on the specific needs of CLHIV through tailored interventions, the BKTC project can significantly improve health outcomes and the overall quality of life for these children.

4.1.7 Implementation Strategy of the Bringing Kids To Care Projects in Malawi

The Bringing Kids To Care (BKTC) project in Malawi will be implemented through an integrated approach, combining national health policies with localized community-based interventions. The project is collaborating closely with the Ministry of Health, ensuring alignment with national HIV response strategies, including those targeting pediatric HIV care.

The door-to-door testing model, a core feature of the BKTC project, will be introduced to increase access to HIV services in remote and underserved areas. Community health workers will be trained to carry out home visits, offering HIV testing, follow-up care, and adherence support. This approach is designed to overcome logistical barriers such as long travel distances to health facilities, which have been a challenge in Malawi, particularly in rural communities of Nkhatabay as well as in Thyolo and Chiradzulu districts. Through close collaboration with government health facilities and support from international partners, the BKTC project will establish an effective system to identify and care for children and women living with HIV. By embedding the BKTC model within existing health systems, the project aims to extend its reach to communities that are often left behind, ensuring that vulnerable populations have continuous access to HIV services.

4.1.8 Relevance of the BKTC Project in the Malawian Context

The BKTC project is highly relevant to Malawi's healthcare needs, particularly in addressing the gaps in pediatric HIV care and PMTCT services. With high HIV prevalence rates, especially among

pregnant women and children, the project's interventions will be critical in improving early diagnosis and treatment. The project aligns with Malawi's national health priorities, which emphasize reducing child mortality and controlling the HIV epidemic.

The project will utilize community health workers, who are familiar with the local contexts, to promote HIV testing and treatment in hard-to-reach areas. By bringing healthcare services directly to households through its door-to-door model, the BKTC project will address one of the major barriers to healthcare access in Malawi—geographical isolation. This intervention will contribute significantly to increasing HIV testing coverage and ensuring that those diagnosed with HIV are retained in care, thus supporting national and international HIV targets.

4.1.9 Synergy of BKTC Project Interventions with Existing Programs

The BKTC project will work synergistically with existing national and international HIV programs in Malawi. The project will align with UNAIDS' 95-95-95 strategy, which aims to ensure that 95% of people living with HIV are diagnosed, 95% receive treatment, and 95% achieve viral load suppression.

In addition, the BKTC project will complement the work of other organizations, such as UNICEF and the Global Fund, which are also focused on HIV prevention and treatment children and pregnant and breastfeeding women. The use of community health workers for door-to-door testing and care retention will fill gaps left by existing programs, particularly in underserved regions. This collaboration will help to ensure a comprehensive and coordinated approach to addressing HIV in Malawi, improving the effectiveness of the overall response (Global Fund, 2022).

4.1.10 Effectiveness of the BKTC Project

The BKTC project is expected to be highly effective in reaching Malawi's most vulnerable populations. The project's door-to-door testing model will ensure that remote communities are included in HIV testing and treatment efforts, especially those who might otherwise not visit healthcare facilities due to distance or stigma.

Trained community health workers will serve as the link between rural communities and healthcare facilities, providing both pre- and post-test counselling, and ensuring that those diagnosed with HIV are initiated on antiretroviral therapy (ART). The project will also focus on retaining children and women in care, addressing a critical challenge in Malawi where many are lost to follow-up after diagnosis (UNAIDS, 2020). However, the project's effectiveness will depend on adequate resources, including testing kits and transportation for healthcare workers and community health workers. Addressing these challenges will be key to maximizing the project's potential impact.

4.1.11 Efficiency of the BKTC Project Interventions

The BKTC project, once launched, will leverage existing healthcare structures and collaborating with government partners. The project will use community health workers as frontline agents, delivering HIV testing and care directly to those in need of the services. This model minimizes the need for patients to travel to health facilities, thereby reducing operational costs and improving efficiency in service delivery. The door-to-door testing approach is a cost-effective solution, particularly in rural Malawi, where access to healthcare is limited by distance and terrain. However, the project's efficiency could be further enhanced by addressing logistical challenges, such as ensuring the availability of testing kits and providing transportation for healthcare workers and community health workers to reach remote areas.

4.1.12 Sustainability of BKTC Project Interventions

Sustainability is a key focus of the BKTC project. By training local healthcare workers and involving community members in the project's implementation, the project will ensure that HIV care

continues beyond its initial phase. The model will become integrated into local healthcare practices, allowing for the continuous identification and treatment of HIV-positive individuals, even in the most remote areas.

Additionally, the project's sustainability will be strengthened by close collaboration with government health departments and community health workers. Engaging communities in the planning and execution of activities will foster a sense of ownership, which is critical for long-term success. However, ensuring the project's sustainability will require ongoing financial support, particularly to maintain community outreach and availability of HIV testing kits.

4.1.13 Impact Orientation of the BKTC Project

The BKTC project is designed to have a significant impact on Malawi's HIV landscape. The project will improve health outcomes for children and women living with HIV by increasing access to testing, treatment, and care retention. By reducing logistical barriers to healthcare and involving communities in the fight against HIV, the project will help to reduce the stigma associated with the disease.

The project's community-driven model will foster greater participation in healthcare decisions, empowering children and women living with HIV to take charge of their health. Over time, this approach will create lasting changes in the way HIV is addressed in Malawi, contributing to long-term reductions in HIV transmission and improvements in health outcomes (Global Fund, 2022).

4.1.14 Recommendations for Malawi

The following recommendations can enhance the BKTC project's effectiveness in Malawi. These include (1) Addressing the specific barriers to HIV testing, (2) Tackling stigma, and (3) providing targeted support for children living with HIV, which can significantly improve health outcomes and foster a supportive environment for the impact population and the affected families.

Recommendations for Community HIV Testing in Malawi

1. Innovate Community Testing Approaches

- Deploy mobile testing units that can travel to hard-to-reach communities, providing opportunistic testing at local events like market days or festivals. This can reduce stigma by normalizing testing as part of community health conversations.
- Offer small incentives (e.g., food vouchers, transportation allowances) for individuals who test during outreach events to increase testing uptake and follow-through for confirmatory testing at health facilities.

2. Enhance Information and Education Campaigns

- Develop and distribute engaging, culturally sensitive educational materials in local languages that specifically address common misconceptions about HIV testing and treatment.
- Train CHWs to deliver targeted talks not only on HIV but also on the importance of testing and treatment during community gatherings, addressing misconceptions and stigma directly.

3. Strengthen Referral Systems

- Establish or strengthen a system where Community Health Workers (CHWs) can assist individuals who test positive at community events with transportation to health facilities for confirmatory testing and ART initiation, reducing barriers to care.

Addressing Stigma and Enhancing Retention in Care

4. Community-Based Stigma Reduction Initiatives

- Involve community and religious leaders in sensitization campaigns to destigmatize HIV. Their influence can foster a supportive environment for those seeking testing and treatment.
- Establish/strengthen peer-led support groups for individuals living with HIV, focusing on open discussions about their experiences, which can encourage others to seek care.

5. Integration of Men in HIV and Family Health Decisions

- Facilitate or support targeted outreach programs to educate men on their role in family health, particularly concerning women's and children's access to HIV services, thereby increasing their involvement in HIV testing and treatment decisions.

Focused on Children Living with HIV

6. Facilitate Age-Appropriate Disclosure

- Facilitate workshops aimed at educating caregivers on best practices for disclosing HIV status to children in a supportive, age-appropriate manner to combat delayed disclosure.
- Create materials that help caregivers communicate HIV-related information effectively, addressing common concerns and promoting trust and understanding.

7. Improve Access to Psychosocial Support Services

- Implement targeted psychosocial support programs designed for CLHIV, including counseling sessions and peer-led support groups that address their unique emotional needs.
- Engage or collaborate with schools to establish support structures and safe spaces for children living with HIV to share their experiences and receive guidance from trained counsellors.

8. Enhance Follow-Up and Adherence Strategies

- Strengthen the role of CHWs in performing regular follow-ups for CLHIV to monitor treatment adherence and provide the necessary support, including home visits to ensure access to ART.
- Provide resources and training for caregivers on the importance of adhering to ART for their children and managing any logistical challenges that may interfere with access to treatment.

9. Address Logistical Barriers to Treatment

- Set up a community-led transport program that assists families in accessing ART, especially for those in remote areas who face significant travel challenges.

Explore and advocate for the establishment of localized ART distribution points through community health centers or pharmacies that are more accessible for families, village clinics are possible alternatives in this case.

4.3 Tanzania

4.1.15 Overview

The United Republic of Tanzania is located in Eastern Africa, bordered by Kenya and Uganda to the north, Rwanda, Burundi, and the Democratic Republic of Congo to the west, and Zambia, Malawi,

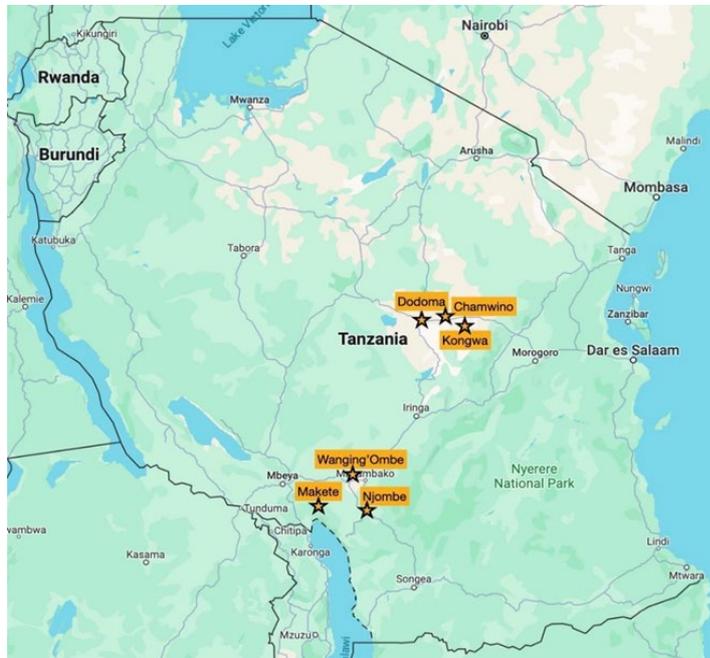


Figure 4: Map of Tanzania showing project districts

and Mozambique to the south. Its eastern border lies along the Indian Ocean, which boasts a coastline of 1,424 km. As of 2022, Tanzania's estimated population stands at 61.7 million, reflecting a 37% increase since 2012 (National Bureau of Statistics [NBS], 2022)²⁸. Among this population, an estimated 0.1% of children under the age of 15 are living with HIV, and 66% of them are on ART. (UNAIDS, 2023)¹.

The BKTC project is implemented by Action for Community Care (ACC) in six districts of Tanzania, including Dodoma City, Kongwa, and Chamwino in Dodoma Region, as well as Njombe Town, Makete, and Wanging'ombe in Njombe Region (see Figure 4). The project will cover an area of 28,362 km² with a total population of 2,178,015. In

the latter districts, ACC collaborates with the organization Support Makete to Self-Support (SUMASESU) to enhance the reach and effectiveness of their interventions.

Action for Community Care (ACC)

Action for Community Care (ACC) is dedicated to empowering vulnerable communities in Tanzania by ensuring access to essential health services and support systems. Established in 2019, ACC builds on over a decade of impactful work initiated by Sharing Worlds Tanzania. The organization aims to improve the quality of life for disadvantaged groups through focused interventions in health, education, livelihood, and social protection.

ACC's mission is to foster a supportive environment where community members can access the resources they need to thrive. The organization emphasizes the importance of collaboration, working closely with local communities, government agencies, donors, and other stakeholders to address pressing issues such as HIV/AIDS, gender equality, and economic empowerment. With a commitment to advocacy and service delivery, ACC aims to create a society where everyone, especially children and young mothers, can lead healthy and fulfilling lives.

Imarisha Afya Project

The Imarisha Afya Project is designed in alignment with the Kids to Care Model, prioritizing community leadership in its implementation. By actively engaging local representatives through a variety of community structures—such as Community Health Workers, Women and Children Protection Committee members, religious leaders, groups of people living with HIV, champions

²⁸ National Bureau of Statistics (NBS). (2022). *Tanzania in figures 2022*.

and mentor mothers, teenage clubs, and caregiver support groups—the project fosters a collaborative approach. This model ensures that the voices and needs of the community are at the forefront, enhancing the effectiveness and sustainability of health initiatives.

In total, 360 community representatives (60 per council) will be identified and engaged in the project implementation. The project aims to reach 3,000 children aged 0-14 years living with HIV and 3,500 young mothers living with HIV aged 10 to 24 years. An age-appropriate response will be tailored to address the specific needs of children and young mothers living with HIV.

Project Goals and Objectives

Main Goal: Ensure that children living with HIV aged **0 to 14** are identified, receive appropriate HIV services, and lead healthy lives.

Objectives

- Identify all **3,000 children** living with HIV, ensuring they start treatment and receive support to continue their care.
- Enhance community knowledge and capacity to identify children aged **0-14 years** living with HIV and link them to appropriate services.
- Strengthen collaboration between community organizations and health facilities to provide comprehensive HIV services to children.
- Ensure young mothers living with HIV and caregivers of children living with HIV are treatment literate and actively support their children's treatment.
- Advocate for increased access to and availability of ART for children aged **0-14 years** living with HIV.
- Equip consortium members and partners with the necessary knowledge and skills regarding pediatric HIV and monitor project progress.
- Promote the sustainability of pediatric HIV interventions in the targeted areas.

The BKTC project is specifically implemented in Dodoma and Njombe regions. Dodoma, as the capital city, was chosen due to its high-risk factors associated with significant population movement and exposure to HIV. Compared to other regions, Dodoma experiences a higher treatment gap among children aged 0-14 years and pregnant and breastfeeding women. The ART coverage among children in Dodoma is 68.2%, while Njombe has 79.1%. This indicates that a larger number of children living with HIV in Dodoma are currently not receiving the necessary treatment.

4.1.16 Paediatric HIV Prevalence, Response and Recent Research in Tanzania

Tanzania ranks fifth globally for the number of children living with HIV (CLHIV), with an estimated 68,000 children infected as of 2023 and with 5700 new infections (UNAIDS, 2023)²⁹. However, only 68% of these children have been identified, and ART (antiretroviral therapy) coverage for children aged 0–14 stands at 66%. Tanzania has made significant progress, particularly in maternal ART coverage, which has reached 92%. The mother-to-child transmission (MTCT) rate has improved from 10.7% in 2022 to 8% by the end of 2023, and early infant diagnosis (EID) has also improved from 55%, to 71% (UNAIDS, 2023).

Breaking these statistics down by specific districts four years ago, **Dodoma City**, had better healthcare infrastructure and consequently a higher pediatric ART coverage of 74%. However, in more rural districts like **Kongwa** and **Chamwino** (also located in the Dodoma region), ART coverage dropped to 60% and 57%, respectively (PEPFAR, 2020). No recent PEPFAR data was available at the compilation of this report. Nevertheless, improvements in national ART coverage currently at 82% (UNAIDS, 2023) suggest corresponding improvements in all regional towns including **Njombe**, **Makete**, and **Wanging'ombe** in the Southern Highlands. Four years ago, these

²⁹ UNAIDS (2023) Retrieved on 22 Oct. 2024 from <https://www.unaids.org/en/regionscountries/countries/unitedrepublicoftanzania>

towns recorded pediatric ART coverage ranging between 55% and 65% (EGPAF, 2020)³⁰. Njombe, a high-prevalence area, has struggled with higher MTCT rates due to gaps in PMTCT services, particularly in rural and hard-to-reach communities (UNAIDS, 2022). But new national statistics promise improved trends at 8% (UNAIDS, 2023).

Barriers and Challenges in Pediatric HIV

While the scale-up of universal ART for pregnant women has reduced the number of new infant infections, progress has stagnated in recent years. More than 50% of pediatric HIV transmissions in Tanzania occur because mothers either dropped off ART during pregnancy or breastfeeding, or they were infected during breastfeeding (UNAIDS, 2022). This has resulted in a significant number of children being diagnosed later in childhood, often when they are older than 5 years and have missed crucial interventions during infancy. Currently, early infant diagnosis is at 71% (UNAIDS, 2023)¹.

From 2016 to 2020, there was a **15% increase** in newly diagnosed children aged 5 years and older, particularly in rural areas like **Makete** and **Wanging'ombe**, where PMTCT and EID programs have faced logistical challenges (PEPFAR, 2020). There is a need for targeted case-finding strategies for school-aged children and adolescents (EGPAF, 2020)³¹. Efforts to improve EID for children in the 1–4 age band are still critical, but the growing population of older children and adolescents living with undiagnosed HIV requires urgent attention. In areas like **Kongwa** and **Chamwino**, where access to healthcare is limited, innovative case-finding approaches are necessary to improve identification, treatment, and retention of children in HIV care (CHAI, 2019)³².

Promising Approaches in Pediatric HIV Care

Several promising approaches have emerged from recent studies and successful programs in Tanzania and other African countries. These strategies are particularly relevant for rural districts like **Njombe** and **Makete**, which face unique challenges in pediatric HIV management. One such approach is the **streamlined ART delivery model**, which includes:

- **Nurse-conducted visits** with referrals to physicians for complex cases (EGPAF, 2020).
- **Multi-disease chronic care** management that integrates HIV care with services for other conditions such as hypertension and diabetes (PEPFAR, 2020).
- **Family-centered appointments**, allowing parents, caregivers, and children to attend the same appointment. These can help reduce the burden on families and improve retention in HIV care (CHAI, 2019).
- **Three-month ART refills** and **appointment reminders**, which have been shown to improve adherence in rural areas like **Wanging'ombe** (PEPFAR, 2020).
- **Community health worker (CHW)-led support**, which played a critical role in reducing virological failure in trials like the Zambia Education Network for Implementation Science Training in Health (**ZENITH**) study in Zimbabwe. Similar CHW-delivered models are being piloted in **Kongwa** and **Chamwino**, showing promise in improving pediatric HIV outcomes (UNAIDS, 2022).

These approaches not only increase retention but also improve viral suppression rates among children. For example, in **Dodoma City**, the introduction of **family-centered care** and **community outreach** has led to a **10% increase** in ART adherence among children under 14. Similar models could be adapted for more rural districts like **Njombe**, where community engagement and outreach have been limited (PEPFAR, 2020).

³⁰ Elizabeth Glaser Pediatric AIDS Foundation. (2020). Pediatric HIV Program Report - Kenya.

³¹ Joint United Nations Programme on HIV/AIDS (UNAIDS). (2023). *Global AIDS update 2023*.

³² CHAI. (2019). Malawi Pediatric HIV Program Data. Clinton Health Access Initiative.

The National Response and Government Initiatives

Tanzania has aligned its pediatric HIV response with global targets set by UNAIDS, particularly the **95-95-95 goals** (95% of all people living with HIV diagnosed, 95% on ART, and 95% virally suppressed). The government's **National HIV and AIDS Strategic Plan (NHASP)** outlines specific objectives for improving pediatric HIV services (PEPFAR, 2020). These include:

- Expanding **PMTCT services** in rural and underserved areas like **Kongwa** and **Chamwino** to ensure more women and infants are reached.
- Increasing **EID coverage**, with a target of reaching at least 80% of HIV-exposed infants by 2025.
- Strengthening **community health services** to enhance pediatric HIV care, with a focus on leveraging the role of community health workers in rural districts such as **Njombe** and **Makete** (UNAIDS, 2022).
- Integrating **HIV care into routine maternal and child health services**, which is especially important in rural districts where access to specialized HIV care is limited.

Tanzania has partnered with international organizations such as **PEPFAR**, and **EGPAF** to scale up pediatric HIV interventions. PEPFAR has provided livelihood support to people living with HIV in addition to making testing services and treatment options available for both children and pregnant women. As a child focused organization, EGPAF has provided HIV treatment options for children and pregnant women and These partnerships have led to significant improvements in the training of healthcare workers and the availability of diagnostic tools in key districts like **Dodoma City** and **Wanging'ombe** (EGPAF, 2020).

Recent Research and Evidence-Based Interventions

Recent research has identified several key gaps in pediatric HIV care in Tanzania, particularly in rural districts. For example, a 2022 study in **Njombe** revealed that only **40% of mothers** in rural communities accessed PMTCT services within the first trimester, a crucial period for preventing mother-to-child transmission (UNAIDS, 2022). This highlights the need for targeted outreach and education programs in these areas.

In districts like **Makete**, where ART adherence rates are lower, innovative approaches such as **long-acting injectable ART** may be explored to improve retention. Early trials show that long-acting ART could reduce the treatment burden on families where among other things they would only visit the clinic once in two months and not worry about remembering to pack drugs when they travel.

Other promising interventions include the integration of **HIV testing into school health programs**. A pilot program in **Dodoma City** saw a **20% increase** in the identification of HIV-positive adolescents when testing was offered during routine school health checks (PEPFAR, 2020). Expanding this program to districts like **Kongwa** and **Chamwino**, where school attendance rates are high, could significantly improve case-finding efforts. To meet the 95-95-95 targets for pediatric HIV, Tanzania must continue to address the unique challenges faced by both urban and rural districts. Districts like **Dodoma City** have made significant progress, but rural areas such as **Kongwa**, **Chamwino**, **Njombe**, **Makete**, and **Wanging'ombe** still face substantial barriers in pediatric HIV care. By expanding PMTCT services, improving case-finding strategies, and integrating HIV care into broader health services, Tanzania can make significant strides toward closing the pediatric HIV treatment gap.

4.1.17 Findings for Tanzania

Household Demographic Characteristics

In Tanzania, primary data collection for the baseline assessment of the *Bringing Kids to Care Project* was conducted in May and July 2024. The study focused on pregnant and breastfeeding women, caregivers of children aged 0-14 years, and children aged 10-14 years (Table 14). The survey

included 116 breastfeeding women and 88 caregivers, representing a significant portion of the overall sample from the four countries (Tanzania, Zambia, Indonesia and Malawi).

Table 14: Survey Participants in Tanzania

Category	Number of Respondents
Breastfeeding Women	116
Caregivers	88

Demographic Characteristics of Survey Participants

Table 15 provides an overview of the demographic characteristics of the breastfeeding women and caregivers surveyed in Tanzania. The median age of breastfeeding women was 26 years, while the median age of caregivers was 27 years. On average, breastfeeding women had three children, while caregivers had two. The household sizes ranged from 4 to 7 members.

Table 15: Demographic Characteristics of Survey Participants in Tanzania

Variable	Breastfeeding Women (n=116)	Caregivers (n=88)
Age of respondent (years)	26 (16-36)	27 (21-55)
Age of baby (months)	12 (2-25)	-
Age of the child (years)	2 (1-6)	2 (1-14)
Number of children	3 (1-5)	2 (1-4)
Household size	5 (4-7)	4 (4-7)

Education Levels and Main Occupation

In terms of education, the majority of breastfeeding women and caregivers had either primary or secondary education (Table 16). Farming was the predominant occupation for both breastfeeding women and caregivers, with 44% of both groups involved in this sector.

Table 16: Education Levels and Occupation of Survey Participants in Tanzania

Variable	Breastfeeding Women (%)	Caregivers (%)
Education Level		
None	9	10
Primary	54	67
Secondary	36	22
Main Occupation		
Farming	44	44
Self-employed	15	15
Trader/piece work	28	28
Other	13	13

Marital Status

Table 17 highlights the marital status of the breastfeeding women and caregivers surveyed in Tanzania. Nearly half (47%) of the breastfeeding women were married, while 56% of caregivers reported being married. Tanzania also recorded a significant number of single breastfeeding women (30%) and a notable proportion of widowed caregivers (32%).

Table 17: Marital Status of Survey Participants in Tanzania

Marital Status	Breastfeeding Women (%)	Caregivers (%)
Single	30	10

Married	47	56
Divorced	16	16
Widowed	7	32

The findings from Tanzania provide valuable insights into the socio-economic and demographic conditions of breastfeeding women and caregivers. The data reveal significant variations in education, occupation, and marital status, which can influence the success of the *Bringing Kids to Care Project*. With many participants engaged in farming and varying levels of education, the project can tailor its interventions to address the specific needs of these communities while leveraging community health workers' experience from previous engagement in community focused HIV initiatives.

4.1.18 Community HIV Testing in Tanzania: Expanding Outreach and Overcoming Barriers

The baseline assessment found that efforts to increase **community-based HIV testing** in Tanzania have made significant progress through the support of health partners and district health facilities. Various **outreach programs** have been developed, allowing government health personnel to engage with communities directly. These initiatives are critical for reaching women and children in rural and underserved areas, particularly those who may have limited access to health facilities.

One of the key strategies employed in Tanzania is conducting HIV testing during **community events** such as market days and local festivals. These events are ideal for reaching large, diverse groups of people, as they draw attendees from various age groups and geographic regions. The Tanzanian government, in partnership with local health organizations, has recognized the importance of targeting such events to **maximize HIV testing uptake** (Tanzania Ministry of Health, 2021).

However, there are still challenges to expanding HIV testing coverage. While Tanzania's HIV infection rate has been steadily declining, there are concerns about reaching **remote and hard-to-reach populations**, where healthcare access remains limited. The baseline assessment found that although HIV testing kits are generally available, the sustainability of outreach programs depends heavily on external funding. Without consistent financial support, health workers face difficulties in maintaining regular outreach efforts, which are essential for increasing HIV testing and early diagnosis.

Therefore, to further improve community HIV testing, Tanzania needs to enhance **targeted outreach activities**, particularly in rural areas, and ensure continuous funding for community health programs. These efforts are crucial for identifying women and children with unknown HIV status, thereby enabling timely access to treatment and care.

4.1.19 Retention in Care and Combating Stigma in Tanzania's maternal and paediatric HIV Response

In Tanzania, the retention of people living with HIV in care is supported by strong **community health networks** and collaborations with local health partners. **Community health workers** play a pivotal role in ensuring that children and pregnant and breastfeeding women testing positive for HIV are referred to health facilities for treatment. These workers also conduct follow-ups to ensure that patients remain on **antiretroviral therapy (ART)** and adhere to their prescribed regimens.

Despite these efforts, **stigma** remains a significant challenge to HIV service delivery in Tanzania. The baseline assessment found that many individuals still fear the social consequences of being diagnosed with HIV, leading to reluctance in seeking testing or adhering to treatment. Stigma is especially pervasive in rural communities, where HIV-positive individuals may face **discrimination**

and **social isolation**. As one focus group participant noted, "People are afraid that others will talk about them if they find out they are taking HIV medication" (BKTC Baseline Assessment, 2024). This fear continues to act as a barrier to both testing and retention in care.

Gender dynamics further complicate the situation. In Tanzania, **women**—particularly those in rural areas—often face societal pressures that hinder their ability to access HIV services. Many women are reluctant to seek treatment openly due to concerns about their **family's or community's reaction**, while men's involvement in HIV-related issues remains limited. This dynamic not only affects women's access to treatment but also the overall success of HIV intervention programs.

To address these challenges, the Tanzanian Government, along with its partners, has implemented **community sensitization campaigns** aimed at reducing HIV-related stigma. These campaigns involve working closely with local leaders, health workers, and community-based organizations to promote **awareness and education** on the importance of HIV testing and adherence to treatment. Additionally, **peer support groups**, such as mentor mothers, have proven to be effective in helping HIV-positive women access and remain on ART. These groups provide emotional support and assist in addressing stigma within communities (Tanzania Ministry of Health, 2021)³³.

While progress has been made, continued efforts are needed to combat stigma and ensure that **women and children** living with HIV can access and adhere to treatment without fear of discrimination. Building trust in the healthcare system and fostering **community-level engagement** will be essential to improving retention in care and ensuring long-term success in Tanzania's HIV response.

4.1.20 Focus on Children Living with HIV in Tanzania

The *Bringing Kids to Care* (BKTC) project in Tanzania was designed to find and support children living with HIV (CLHIV) aged 0-14. This section emphasizes the critical challenges faced by children living with HIV in Tanzania and suggests areas where the project can improve to align more closely with its core objective of providing comprehensive care to these children.

Demographic Characteristics of Children Living with HIV

In Tanzania, children aged 0-14 years living with HIV represent a vulnerable population. The baseline assessment found that these children face significant barriers, including stigma, difficulties in accessing antiretroviral therapy (ART), and challenges related to disclosing their HIV status. Although the BKTC project has made efforts to identify HIV-positive children through maternal and postnatal health clinics and index testing strategies, these interventions must be fully explored to ensure that they ultimately target the children themselves and not caregivers.

Delayed disclosure of a child's HIV status may have serious consequences in a child's emotional wellbeing. The baseline assessment found that caregivers and healthcare providers in Tanzania often delay informing children about their status due to fear of stigma and potential negative reactions. This delayed disclosure can have long-term consequences on the child's mental health, social development, and adherence to ART. Children who are not aware of their HIV status may struggle to understand the need for regular medication, leading to poor adherence and increased risk of disease progression.

Additionally, treatment adherence among children living with HIV remains a significant challenge. Many children are lost to follow-up (LFU) as their families move, or caregivers lack the resources and knowledge to ensure the child continues treatment. In some rural areas, accessing ART requires long-distance travel, which further complicates adherence. Caregivers reported challenges

³³ Tanzania Ministry of Health. (2021). *Tanzania National Multisectoral Strategic Framework for HIV and AIDS 2020–2025*. Dar es Salaam, Tanzania.

in prioritizing the child's healthcare needs over their own, especially in families where multiple members may be living with HIV.

Moreover, psychosocial support specifically for adolescent children living with HIV is minimal in Tanzania. The baseline assessment found that while caregivers and pregnant women receive substantial support, there is a gap in addressing the emotional and psychological needs of children. Adolescent child-centered counseling and peer support groups could help children in the age range of 10-14 cope with their diagnosis, fostering a better understanding of their condition and promoting ART adherence.

Summary of the Challenges and Gaps

Children living with HIV in Tanzania face a range of challenges, from stigma and delayed disclosure of their status to inconsistent access to ART and a lack of psychosocial support. Addressing these gaps by focusing more directly on children through tailored interventions will significantly improve their health outcomes and overall quality of life.

4.1.21 Reported Prevalence of HIV and HIV knowledge among Breastfeeding Women in Tanzania

Table 18 provides insights into the prevalence of HIV among breastfeeding women and caregivers surveyed in Tanzania, along with their knowledge and experiences concerning HIV prevention, treatment, and transmission. The results offer a glimpse into the challenges faced by women living with HIV and highlight areas where interventions can improve their knowledge and health outcomes.

Table 18: Insights into the prevalence of HIV among breastfeeding women and caregivers surveyed in Tanzania

Variable	Breastfeeding women (n=116) n (%)	Caregivers (n=88) n (%)
HIV status (positive)	84 (72)	
On ART (yes)	100%	
Any side effects from ARVs (yes)	33 (25)	23 (29)
Counselling on living with HIV (yes)	84 (100)	79 (100)
Counselling on HIV & pregnancy (yes)	116 (100)	
HIV transmission modes		
- Unprotected sexual intercourse	116 (100)	62 (70.5)
- Sharing needles	3 (3)	2 (2.3)
MTCT		
- Pregnancy	23 (19)	
- Delivery		
- Breastfeeding		24 (26)
- Blood transfusion	1 (1)	0
HIV free born from HIV+ mother		
- No		
- Yes	116 (100)	77 (87)
- Don't know		11 (13)
Child tested for HIV (yes)	54 (100)	88 (100)
Reasons for testing child		
- Mother has/had HIV	54 (100)	40 (45)
- Frequent illness		21 (24)
- Advised by health care provider	105 (91)	2 (2.3)
- Born with it		14 (16)

- Other	5 (4)	
Has HIV positive child (yes)	16 (14)	
Child living with HIV	8 (14)	79 (90)
Child on ART (yes)	16 (100)	79 (100)
Consistently taking medication (yes)	16 (100)	79 (100)
Partner tested for HIV too		
- Yes	41 (37)	
- No	52 (46)	
- Do not remember	20 (17)	
- Not applicable	3	
If partner was tested at the same time		
- Yes	35 (85)	
- No	6 (15)	
Community aware of child's HIV status (yes)		32 (36.4)
Child aware of his/her HIV status (yes)		32 (36.4)
Consistency in taking ART		
- Yes	16 (14)	79 (100)
- No	100 (86)	
Source of advice on HIV test (frequency)		
- Health worker	105	
- Sex partner	6	
- Mother	11	
- Volunteer worker	5	
- Support group member	3	
- Others	14	
Wish for HIV service delivery improvement (yes)		53 (60)
Received specific care from service providers (yes)		19 (22)
Past 6 months received information on HIV (yes)		56 (64)

A significant 72% of breastfeeding women surveyed were living with HIV, indicating a high prevalence within the group. Encouragingly, all women reported being on antiretroviral therapy (ART), a positive sign that they are receiving the necessary treatment to manage the virus. ART plays a crucial role in suppressing the viral load, which not only improves the health of the mothers but also reduces the risk of mother-to-child transmission (MTCT) of HIV during pregnancy, childbirth, and breastfeeding. Despite these efforts, 14% of the women had a child living with HIV, suggesting that MTCT still occurs in some cases, which may be due to inconsistent adherence to ART, late initiation of treatment, or gaps in healthcare services. Additionally, the data shows that 25% of the women experienced side effects from ARVs, which could contribute to challenges in maintaining strict adherence to their medication regimens.

Counselling and Knowledge on HIV and PMTCT

All breastfeeding women reported receiving counselling on living with HIV and prevention of mother-to-child transmission (PMTCT), demonstrating widespread access to essential health education services. Counselling is critical for helping women understand how to reduce the risk of HIV transmission to their children and manage their condition effectively. However, the findings also reveal gaps in knowledge, particularly regarding the potential for HIV-free births. Only 19% of women were aware that a baby can be born HIV-free from a mother living with HIV, highlighting a

substantial misunderstanding about the efficacy of PMTCT interventions. This points to a need for more focused education campaigns that emphasize the success rates of PMTCT programs, especially when women adhere to ART throughout pregnancy and breastfeeding.

HIV Transmission, Awareness and Testing of Partners

The study also assessed knowledge of HIV transmission modes, with 100% of breastfeeding women identifying unprotected sexual intercourse with an HIV infected person as a mode of transmission. However, only 3% recognized sharing needles as a risk factor. This limited understanding of other transmission routes could impact broader prevention efforts within their communities.

One key area of concern is the low rate of HIV testing among sex partners. Only 37% of the women reported their partners having tested for HIV. Among these, only 14% were tested at the same time as their sex partners. These figures suggest a gap in couple-based testing and counselling services, which are critical for reducing the risk of HIV transmission between partners and for fostering shared responsibility in managing the condition. Encouraging partner testing and improving couple-based interventions could help in addressing these gaps. Therefore, the project must look into further integration of affected couples in the ART protocols to win psychosocial and emotional support. These are important for enhancing ART adherence mainly in discordant couples.

Child Testing and Outcomes

All the breastfeeding women had their children tested for HIV, which is a positive sign of proactive health-seeking behavior. This high testing rate is likely influenced by the mothers' own HIV status and their concern for their children's well-being. Of the children tested, 14% were found to be HIV positive, and all of these children were on ART, with consistent medication adherence reported at 100%. This reflects strong efforts in ensuring that HIV-positive children receive the necessary care and treatment.

However, the low awareness about HIV-free births among mothers underscores the need for reinforcing messaging around the effectiveness of ART and PMTCT measures. Mothers who fully understand that HIV transmission can be prevented with proper treatment are more likely to adhere to ART during pregnancy and breastfeeding, ultimately reducing the likelihood of transmission to their children.

Caregivers' Perspectives

The data on caregivers, a smaller subset of the study population, provides additional insights into HIV care and knowledge within families. All caregivers (100%) had their children tested for HIV, and 90% reported having a child living with HIV, reflecting a similar prevalence of HIV in children as seen among breastfeeding women. Additionally, all children living with HIV were on ART, with consistent adherence (100%).

Caregivers also reported experiencing side effects of ARVs in their children (29%), highlighting the importance of ongoing monitoring and support for families dealing with HIV. Side effects can affect adherence to treatment, and providing comprehensive healthcare services to address these challenges is crucial for maintaining the health of both the children and their caregivers.

Caregivers demonstrated higher awareness about the possibility of HIV-free births compared to breastfeeding women, with 87% knowing that a baby can be born HIV-free from a mother living with HIV. This indicates that caregivers may be receiving more targeted education on PMTCT or may have better access to information. However, gaps in knowledge still exist, as 13% were uncertain about this possibility.

The findings from Table 18 highlight significant progress in terms of ART access, counselling, and child testing among breastfeeding women and caregivers in Tanzania. However, they also underscore the need for improved education on PMTCT and HIV transmission routes, as well as increased partner involvement in testing and counselling. Enhancing couple-based testing services and reinforcing messages about the effectiveness of ART in preventing MTCT could have a profound impact on reducing HIV transmission rates and improving the health outcomes of both mothers and children.

Addressing the reported side effects of ARVs and ensuring consistent medication adherence are additional priorities for health services. By addressing these gaps, healthcare providers can help improve the overall effectiveness of HIV treatment and prevention programs in Tanzania.

4.1.22 Implementation Strategy of the Bringing Kids to Care Project in Tanzania

The **Bringing Kids To Care (BKTC) project** will be implemented through a multi-faceted approach, engaging both national and local stakeholders in HIV programming. The implementation begins with solid partnerships at the district level, where HIV programming for community interventions takes shape. These partnerships, already established with the Ministry of Health, reflect the extensive groundwork laid by implementing partners, ensuring alignment with Tanzania's national HIV policies (Ministry of Health, 2021).

The project will launch with a **door-to-door HIV testing model**, specifically targeting rural and underserved communities. This model will rely heavily on **community health workers**, trained to conduct home visits for testing, counselling, and follow-up care. By addressing the logistical challenges of accessing healthcare in remote areas, such as long distances to health facilities, the project aims to increase testing and care for children, pregnant and breastfeeding women living with HIV. This comprehensive approach leverages existing health infrastructure, allowing the project to scale interventions while reducing stigma through localized care.

Additionally, the BKTC project's collaboration with district health offices will ensure the integration of community-driven interventions into the broader healthcare system, allowing for a coordinated and sustainable approach to pediatric HIV care and prevention of mother-to-child transmission (PMTCT) (UNAIDS, 2020).

4.1.23 Relevance of the BKTC Project in the Tanzanian Context

The BKTC project is highly relevant to Tanzania's national health priorities, particularly in filling gaps related to pediatric HIV care and PMTCT services. Tanzania has made considerable progress in its HIV response, but challenges persist, especially in reaching children and women in remote regions. The project's focus on **door-to-door testing** and retention in care will help overcome the geographic and economic barriers limiting healthcare access in these areas (Ministry of Health, 2021) by also engaging more community health workers.

By deploying community health workers who understand local dynamics, the BKTC project will foster health-seeking behavior, addressing the needs of children pregnant and breastfeeding women who are often lost to follow-up. In particular, the BKTC model supports **long-term assistance**, not only for treatment but also for **psychosocial support**, ensuring that children living with HIV receive appropriate care and disclosure about their status according to their stage of development (EGPAF, 2019).

4.1.24 Synergy of BKTC Project Interventions with Existing Programs

The BKTC interventions are designed to align with Tanzania's national strategies, including the **UNAIDS 95-95-95 targets** aimed at achieving global HIV goals. The project will complement ongoing HIV prevention and treatment efforts by government entities and international partners,

such as UNICEF and the Global Fund. Its community-centered approach, particularly through door-to-door testing, fills crucial service delivery gaps in underserved regions (Global Fund, 2022). The collaboration between the BKTC project and other established HIV initiatives ensures synergy and maximizes impact, creating a robust framework for reaching vulnerable populations, especially children who are often underrepresented in HIV care efforts (UNAIDS, 2020).

4.1.25 Effectiveness of the BKTC Project

The project is expected to be highly effective in reaching Tanzania's most vulnerable groups, particularly children, pregnant and breastfeeding women in remote and marginalized communities. By leveraging a **door-to-door testing model**, the project will ensure that HIV testing and treatment services are brought directly to those who need them most, circumventing traditional barriers to care like stigmas. The training of community health workers will strengthen this effort, allowing them to provide pre- and post-test counselling and ensure that those diagnosed with HIV are promptly initiated on treatment (UNAIDS, 2020). Moreover, the project addresses **key logistical challenges**, such as the availability of testing kits and transportation for health workers, to ensure effective service delivery in rural areas. This comprehensive approach will help retain women and children in care, a crucial step toward improving long-term HIV outcomes in Tanzania.

4.1.26 Efficiency of BKTC Project Interventions

Efficiency is central to the BKTC project's strategy, leveraging existing health systems to minimize costs while delivering services directly to communities. The **door-to-door model** significantly reduces the burden on individuals, particularly in rural areas where access to healthcare is often limited. This model not only increases service reach but also reduces travel costs and time for patients, further enhancing the project's efficiency. While efficient, the project will need to address **operational challenges**, including ensuring adequate transportation and testing kits, to maintain smooth service delivery. Continuous support for community health workers, including financial and logistical backing, is crucial to the project's ongoing success.

4.1.27 Sustainability of BKTC Project Interventions

The sustainability of the BKTC project is rooted in its community-driven approach and strong collaboration with government health services. By training local health workers and involving community members in the project's execution, the BKTC model ensures continuity of care even after the project ends. The project will build local capacity to sustain HIV care delivery, integrating door-to-door testing into routine health services, particularly in hard-to-reach areas. Additionally, the project's partnerships with both national and international donors will provide the financial and technical support necessary for long-term impact, ensuring that services can be scaled and maintained beyond the project's initial phases.

4.1.28 Impact Orientation of the BKTC Project

The **Bringing Kids To Care project** is designed with a strong impact orientation, targeting vulnerable populations such as children and women living with HIV. By increasing access to testing and treatment through community-based interventions, the project is expected to significantly improve health outcomes. The **door-to-door testing** model reduces stigma, encourages care retention, and empowers individuals to take control of their health, leading to better overall outcomes in pediatric HIV care (Global Fund, 2022). Over time, the project is expected to contribute to a reduction in HIV transmission rates and improve the quality of life for children and women living with HIV, making it a critical component of Tanzania's overall HIV response.

4.1.29 Recommendations for Tanzania

The following are specific, focused, and problem-based recommendations to enhance the Tanzania BKTC project's effectiveness for children living with HIV (CLHIV) and their caregivers:

Recommendations for Community HIV Testing in Tanzania

1. Tailored Community Outreach Programs

- Leverage community events, such as market days and festivals, to conduct targeted HIV testing campaigns. Ensure that these events include educational sessions that address the importance of testing, specifically targeting women and caregivers of CLHIV.
- Set up mobile clinics equipped with testing kits to reach remote and underserved areas, offering convenient access to HIV testing and treatment initiation.

2. Sustainable Funding for Outreach Initiatives

- Work in partnership with local businesses, NGOs, and international donors to secure long-term funding for community health programs. This could include establishing a fund specifically for HIV outreach initiatives to ensure continuity of services.
- Provide incentives for community health workers (CHWs) to encourage their engagement in outreach activities, ensuring they are motivated to promote testing and follow-up care.

Retention in Care and Combating Stigma

3. Stigma Reduction Campaigns

- Implement or support ongoing community sensitization campaigns that involve local leaders and influencers to educate the public about HIV, aiming to reduce stigma and encourage open discussions about the disease.
- Expand peer support groups, such as mentor mothers and youth ambassadors, to provide emotional and practical support for HIV-positive individuals, particularly women and children, helping them navigate stigma and adhere to treatment.

4. Engagement of Men in HIV Care

- Develop initiatives that specifically engage men in discussions about HIV prevention and care, emphasizing their role in supporting their partners and children, which can help reduce barriers faced by women in accessing services.

Focused on Children Living with HIV

5. Facilitate Age-Appropriate Disclosure

- Conduct capacity-building initiatives for caregivers and healthcare providers on how to disclose HIV status to children in a supportive and age-appropriate manner, emphasizing the importance of honesty and trust.
- Create resources, such as storybooks or guides that caregivers can use to help explain HIV to children, making the conversation easier and less intimidating.

6. Strengthen Treatment Adherence Strategies

- Implement a systematic follow-up process where CHWs regularly check in with families of CLHIV to monitor adherence to ART and address any barriers they may face, such as transportation or financial issues.
- Establish adherence support groups specifically for children and adolescents living with HIV, providing a safe space for them to share experiences, learn from peers, and receive encouragement.

7. Improve Access to Psychosocial Support

- Introduce and galvanize counseling services tailored to adolescents living with HIV, focusing on their unique emotional and psychological needs. This could include group therapy sessions or individual counseling.
- Collaborate with schools to create supportive environments for CLHIV, including advocating for training teachers on how to support students living with HIV and integrating health education into the curriculum.

8. Address Logistical Barriers to Treatment

- Develop community-led transportation programs to assist families in accessing ART, particularly in rural areas where travel poses a significant barrier to care like in Njombe.

Establish additional ART distribution points within communities, such as pharmacies or health posts, to make it easier for families to access medications without long-distance travel.

4.4 Indonesia/West Papua

4.1.30 Overview

Indonesia is an archipelagic country in Southeast Asia, home to more than 275 million people (Indonesian Statistics Agency, 2023), with over 60% of the population residing on Java Island. The most eastern region of the country is Papua, located in the western part of the island of New Guinea, sharing a land border with Papua New Guinea to the east. The provinces of West Papua and Southwest Papua are in the northwestern part of this region, covering an area that accounts



for 5.25% of the total land size of the country, with approximately 0.43% of the population, or about 1.18 million people, residing there as of 2022³⁴.

According to the Ministry of Health's data, there are around 26,000 people living with HIV (PLHIV) in Papua, with 16,000 of these individuals having progressed to the AIDS phase. Integrated Biological and Behavioral Surveillance indicates that the majority of infections occur among native Papuans, with a prevalence rate of 2.9% compared to 0.4% among non-Papuans. This data

Figure 5: Map for Indonesia showing project districts

suggests that HIV is evolving into a generalized epidemic in the region, significantly increasing the risks for women and children (UNAIDS, 2022)³⁵.

The latest report from the District Health Office in Sorong indicates a 3% positivity rate among children aged 0–19 years and 1% among pregnant women. In Manokwari, the rates are reported at 3% for children and 2% for pregnant women.

³⁴ Indonesian Statistics Agency. (2023). *Population statistics 2023*

³⁵ UNAIDS. (2021). *Global AIDS update 2021: Confronting inequalities*

The CHAMPION-ID project, which stands for **Child and Adolescent HIV Access and Retention in Indonesia**, is implemented in two provinces within 12 districts and one municipality. Specifically, the project focuses on the districts of Manokwari and Sorong Municipality (see Figure 5), where targeted interventions will be conducted to address the unique challenges faced by communities in these areas.

Indonesia AIDS Coalition (IAC)

Indonesia AIDS Coalition (IAC) is the implementing partner for the BKTC model in Indonesia. Established in 2011, IAC is a community-based organization dedicated to improving transparency, accountability, and public participation in AIDS programs through collaboration with various stakeholders, including both government and non-government entities. IAC was formed in response to the challenges faced by PLHIV in accessing public services, including healthcare, social services, and financial assistance. IAC operates as a mobilizing force for PLHIV, advocating for their rights and raising awareness through various campaigns and platforms, both digital and community-based. The organization has played an active role in national AIDS prevention programs and has contributed to the development and implementation of these initiatives.

CHAMPION-ID Project

The CHAMPION-ID project aims to improve access to HIV care and support for children living with HIV (CLHIV) and pregnant women living with HIV by empowering communities to find, support, and retain these populations in care. The project focuses on ensuring that all CLHIV receive the necessary support to start and continue their treatment, leading to healthy lives.

Activities specific to this objective were implemented at the district level, namely in Sorong City (Southwest Papua) and Manokwari Regency (West Papua). There are 4 CHW in Sorong City and 3 CHW in Manokwari Regency with a total of seven community health workers. The community health workers were recruited in both districts, operating under the supervision of a field coordinator. These workers delivered educational messages emphasizing the importance of knowing one's HIV status and the need to initiate and adhere to treatment. Initial training was conducted at the project's outset to build capacity for providing services tailored to CLHIV and pregnant/lactating women living with HIV (WLHIV).

Outreach activities would be supported by educational materials to facilitate knowledge sharing and community engagement. To ensure retention in care, monthly support group meetings would be organized for the caregivers of women and children, providing essential psychosocial support and treatment knowledge sharing. This community-based model has been successfully implemented with other population groups and has yielded positive results.

The BKTC model is collectively referred to as the Bringing Kids to Care Project across the various implementing countries, with the working name for the initiative in Indonesia being CHAMPION-ID. Together, these projects aim to create a comprehensive and sustainable approach to pediatric HIV care, ensuring that children and their families receive the necessary support to thrive.

4.1.31 Paediatric HIV Prevalence, Response and Recent Research in Indonesia/West Papua

The HIV epidemic across the vast archipelago of Indonesia is highly heterogeneous. Indonesia comprises 26% of the Asia-Pacific regional total of new HIV infections among children. This is because new HIV infections are declining at a slow rate (UNAIDS, 2024)³⁶. In 2022, the prevalence of HIV remained low in much of the country, with rates of less than 0.5% in populous regions like Java and Borneo (UNAIDS, 2022)³⁷. However, in West Papua, the prevalence of HIV is starkly higher at 5%, reflecting a concentrated epidemic in the easternmost provinces (Riono &

³⁶ https://www.unaids.org/sites/default/files/media_asset/2024-unaids-global-aids-update-asia-pacific_en.pdf

³⁷ UNAIDS. (2022). *Global HIV & AIDS statistics – Fact sheet*. Retrieved from <https://www.unaids.org/en/resources/fact-sheet>

Challacombe, 2020)³⁸. The Papua provinces of Indonesia have a significantly higher HIV prevalence compared to other regions in the Asia-Pacific, including the neighboring country of Papua New Guinea, which shares similar cultural and geographic characteristics. This disparity illustrates the unique challenges facing West Papua and highlights the need for a targeted response.

Prevention of Mother-to-Child Transmission (PMTCT) Indicators

Indonesia's Prevention of Mother-to-Child Transmission (PMTCT) program has faced considerable challenges, particularly in 2022, with concerning poor indicators. Only 18% [15-20%] of pregnant women in need of ART (antiretroviral therapy) received treatment (UNAIDS, 2022). Early infant diagnosis also remained alarmingly low, with just 8% [7-10%] of infants born to HIV-positive mothers receiving early diagnosis (UNAIDS, 2022)³⁹. These numbers are particularly worrying given that early diagnosis is critical for the timely initiation of treatment and improving survival rates in infants.

The final vertical transmission rate, which includes transmission during breastfeeding, remains unacceptably high in Indonesia. In 2022, the rate stood at 29.84% [28.14-31.30], far higher than neighboring countries such as Thailand (1.96% [1.84-2.10]) and Malaysia (1.82% [0.58-2.71]) (UNAIDS, 2022). This high rate of mother-to-child transmission highlights the ongoing gaps in Indonesia's PMTCT efforts and the need for enhanced support for pregnant and breastfeeding women living with HIV.

Barriers to ART Uptake Among Pregnant Women in West Papua

A qualitative study highlighted social and cultural barriers limiting the uptake of ART among pregnant women (Sianturi et al., 2019). Women have expressed doubts on the efficacy of ART, while others reported unsupportive partners and concerns about the stigma and discrimination they would face within their communities if they were known to be receiving HIV treatment (Sianturi et al., 2019)⁴⁰. Moreover, ethnic tensions and discrimination within the health system itself have contributed to the poor adherence to ART among Papuan ethnic groups compared to non-Papuans (Lumbantoruan et al., 2018)⁴¹. Healthcare providers' attitudes towards Papuans, influenced by long-standing political and social conflict, have added to the complexities in HIV prevention and care services. This context of ethnic marginalization plays a significant role in undermining trust in the healthcare system, which in turn affects the success of HIV response in all target groups including pediatric and adolescent children. Furthermore, Suantari, 2021⁴² observed that misconceptions about HIV transmission and stigma against PLWHA were persistent in Indonesia and most prevalent among uneducated and living in poverty hence undermining ART interventions. Recommendations from this suggested a focus on educational programs or interventions to increase public knowledge and awareness, promote compassion towards PLWHA, as well as respect for their rights.

Policy Shifts and the EMTCT Framework

In 2023, Indonesia made a significant shift by adopting the World Health Organization's (WHO) Asia-Pacific Framework for Triple Elimination of Mother-to-Child Transmission (EMTCT) of HIV, syphilis, and Hepatitis B. This framework represents a more integrated approach to maternal and child health, focusing not only on HIV but also on syphilis and hepatitis B, which are prevalent in

³⁸ Riono, P., & Challacombe, S. J. (2020). HIV in Indonesia and its impact on oral health. *Oral Diseases*, 26(1), 37-46. <https://doi.org/10.1111/odi.13135>

³⁹ UNAIDS. (2022). *Global HIV & AIDS statistics – Fact sheet*. Retrieved from <https://www.unaids.org/en/resources/fact-sheet>

⁴⁰ Sianturi, E. I., Sari, N. P., Oktaviana, W., & Siregar, A. Y. M. (2019). Challenges of prevention of mother-to-child transmission of HIV in Papua, Indonesia: A qualitative study. *BMC Public Health*, 19(1), 1323. <https://doi.org/10.1186/s12889-019-7647-2>

⁴¹ Lumbantoruan, C., Kermode, M., Giyai, A., Komaru, Y., & Ang, A. (2018). Understanding the barriers to the implementation of prevention of mother-to-child transmission (PMTCT) of HIV program in Papua and West Papua provinces, Indonesia: A qualitative study. *Journal of Public Health Research*, 7(2), 119-125. <https://doi.org/10.4081/jphr.2018.1355>

⁴² Suantari D. Misconceptions and stigma against people living with HIV/AIDS: a cross-sectional study from the 2017 Indonesia Demographic and Health Survey. *Epidemiol Health*. 2021;43. e2021094. doi: 10.4178/epih.e2021094

Indonesia (UNAIDS, 2020)⁴³. The integration of testing and treatment for these diseases into antenatal care (ANC) services is expected to improve maternal and infant health outcomes by addressing multiple infections simultaneously.

The EMCT framework replaces the previous PMTCT program that had been in place since 2013 and was exclusively focused on HIV testing (Munro & McIntyre, 2016)⁴⁴. The move towards a more holistic and integrated model of care aims to reduce the barriers to testing and treatment for pregnant women, particularly in underserved regions like Papua. By integrating testing for multiple infections into ANC services, the government hopes to increase coverage and improve health outcomes for both mothers and their infants.

Indonesia's adoption of the EMCT framework reflects the country's commitment to tackling the triple burden of HIV, syphilis, and hepatitis B among pregnant women. However, successful implementation of this framework will require overcoming the significant barriers that have hampered past PMTCT efforts, particularly in regions like Papua where stigma, discrimination, and healthcare access issues remain pervasive. Greater community engagement, improved healthcare worker training, and sustained efforts to reduce ethnic disparities in healthcare are critical to ensuring that the EMCT framework can deliver on its promise. The ongoing challenges in PMTCT underscore the need for innovative strategies that are sensitive to Indonesia's diverse social, cultural, and political landscape. As the country continues to confront its HIV epidemic, targeted interventions that address the unique needs of high-burden areas such as Papua will be essential for reducing mother-to-child transmission rates and improving health outcomes for women and children.

4.1.32 Reported Prevalence of HIV and HIV knowledge in Indonesia/West Papua

In the methodology outlined, the setup in Indonesia, particularly in West Papua, did not allow for the quantification of variables but instead focused on identifying existing trends and understanding how different groups have integrated pediatric HIV responses into their communities. This qualitative approach helped to shed light on the challenges faced by breastfeeding women and female caregivers in accessing HIV-related information and testing services, particularly within the context of strong social and familial constraints.

A significant barrier identified was the role of male family members in decision-making. In many cases, women require approval from a male family member—often a husband or father—to access HIV testing and healthcare facilities that are nationally approved. This patriarchal gatekeeping severely limits women's autonomy over their health, making it difficult for them to seek out information, get tested, or receive treatment. For women living with HIV, this lack of independence contributes to delayed diagnoses, limited awareness of their HIV status, and insufficient access to care for both themselves and their children.

This social dynamic also impacts family-level HIV awareness. Because women are often restricted from freely seeking healthcare, their HIV status may remain unknown to themselves and their families. As a result, women are unable to take proactive steps to prevent the transmission of HIV to their children or to ensure timely access to antiretroviral therapy (ART) for those who need it. This gap in knowledge perpetuates the cycle of pediatric HIV transmission and undermines national efforts to reduce the incidence of mother-to-child transmission (MTCT).

During group discussions, the social constraints became even more evident. Many women refrained from fully expressing their thoughts and experiences due to fear of reprisal from their

⁴³ UNAIDS. (2020). *Global HIV & AIDS statistics – Fact sheet*. Retrieved from <https://www.unaids.org/en/resources/fact-sheet>

⁴⁴ Munro, A., & McIntyre, J. A. (2016). Triple elimination of mother-to-child transmission of HIV, syphilis and hepatitis B virus in the Asia-Pacific region. *Bulletin of the World Health Organization*, 94(8), 602-605. <https://doi.org/10.2471/BLT.16.173682>

spouses. Although their husbands were not present during the discussions, the cultural fear of backlash for speaking openly about sensitive issues like HIV was palpable. This silence is reflective of deeper systemic issues, where women's voices are suppressed within both the family unit and the broader community. The inability to speak candidly in group settings impairs the effectiveness of these sessions, as women may withhold critical information or insights that could otherwise inform the development of more supportive and inclusive healthcare interventions.

The fear of reprisal not only hinders open dialogue but also diminishes the potential for peer support, which is crucial in HIV care and prevention efforts. In communities where stigma around HIV is already pervasive, the added layer of fear within the household compounds the difficulties women face. For meaningful change to occur, it is necessary to address these deeply ingrained cultural norms that restrict women's access to healthcare and prevent them from participating in open discussions about their health.

In conclusion, the findings from West Papua illustrate that social and familial barriers play a significant role in limiting the effectiveness of pediatric HIV responses. The need for male approval and the fear of spousal reprisal creates substantial obstacles for women seeking to engage with HIV-related services. Moving forward, strategies to combat pediatric HIV must not only focus on healthcare provision but also on transforming these cultural norms. Programs that emphasize male involvement in health education, promote gender equality, and create safe spaces for women to speak freely are essential for improving access to HIV testing and treatment. Without addressing these social constraints, efforts to reduce pediatric HIV transmission will remain incomplete.

4.1.33 Community HIV Testing in Indonesia/West Papua: Addressing Geographic and Socio-Cultural Barriers

In Indonesia, particularly in the **West Papua region**, community HIV testing faces significant hurdles due to a combination of geographic isolation and deeply ingrained socio-cultural barriers. The HIV epidemic in West Papua is particularly concerning, as the region is characterized by limited healthcare infrastructure and **socioeconomic challenges**, which severely limit access to testing and treatment services. Furthermore, **low awareness** of HIV transmission and prevention continues to be a barrier, especially in rural and remote communities.

Unlike other parts of Indonesia where community-based testing initiatives are more common, **rural values** in West Papua have historically hampered openness about HIV. The lingering **stigma** surrounding the virus, reminiscent of attitudes from the 1990s and early 2000s, continues to deter individuals from seeking testing. This stigma is compounded by traditional cultural norms that foster **secrecy and fear of social judgment**. Consequently, testing for the general population in the region is often untargeted, leading to a **low positivity rate** and missed opportunities for early diagnosis, especially among women and children.

The geographic isolation of **West Papuan communities** further complicates access to HIV testing. Many of these areas are remote, with little to no access to healthcare facilities. Pregnant and breastfeeding women, in particular, face considerable barriers to **accessing antenatal care** and HIV testing services, as many must travel long distances to the nearest health centers. Moreover, the region's limited road infrastructure and **harsh terrain** make it difficult for health workers to conduct outreach programs effectively.

The **BKTC model**, which promotes community-based HIV testing, has been introduced in West Papua, but its implementation has faced challenges due to the unique cultural and geographic landscape. There is a need for more tailored, **localized strategies** that take into account the specific barriers faced by West Papuan communities. These strategies could include **mobile testing units**, culturally sensitive **education campaigns**, and partnerships with local leaders to build trust in the health system.

4.1.34 Retention in Care and Combating HIV Stigma in West Papua

Retention in care for people living with HIV in **West Papua** remains a major concern, largely due to the **stigma** surrounding the disease and the limited availability of health services. Many individuals who test positive for HIV struggle to remain in care because of the **fear of social repercussions**. As one respondent from the BKTC Survey (2023) noted, "People are afraid to continue treatment because they believe others in the community will find out about their status." This **stigma** leads to high dropout rates from antiretroviral therapy (ART), particularly among women who are often the primary caregivers in the household and are expected to maintain secrecy about their health status.

In addition to stigma, **religious and cultural beliefs** in the region can act as barriers to seeking and adhering to HIV treatment. Some religious groups discourage the use of modern medicine, promoting spiritual healing instead. This makes it difficult for healthcare providers to gain the trust of certain communities and ensure that patients adhere to ART. Moreover, the **lack of trust** in health workers, fueled by concerns about confidentiality, has been a recurring issue. Many West Papuans are reluctant to engage with the health system due to fears that their HIV status will not remain private.

The **limited healthcare infrastructure** in West Papua further exacerbates retention challenges. Health facilities are often understaffed, and access to **HIV medications** can be inconsistent, particularly in remote areas. While **community health workers** have been trained to support HIV-positive individuals, their ability to reach all affected people is constrained by the region's difficult terrain and scattered population. To improve retention in care, there is an urgent need for **community-based interventions** that focus on reducing stigma and increasing **education about HIV treatment**. Initiatives such as **peer support groups** and **community sensitization programs** have shown promise in other regions and could be adapted to the unique cultural context of West Papua. Furthermore, increasing the availability of **mobile health services** and strengthening partnerships with **local leaders** could help bridge the gap between health workers and the communities they serve.

Efforts to **combat stigma** must be prioritized, as stigma remains one of the most significant barriers to HIV care in West Papua. Building trust through **culturally sensitive approaches** and ensuring the **confidentiality** of health services are essential steps in improving the retention of HIV-positive individuals in care and reducing the region's HIV burden.

4.1.35 Meeting basic needs and participation in village savings and loans in Indonesia/West Papua

The economic circumstances of breastfeeding women and caregivers were significantly influenced by the financial capacities of their partners or families. Many women expressed a strong interest in participating in village savings and loans (VSL) schemes as a means to enhance their financial stability and support their households. However, a prevalent challenge was the lack of information on how to engage with these schemes, leaving many women uncertain about the steps required to participate effectively.

Despite their willingness to join VSLs, these women often struggled to meet their dietary needs adequately. While most reported being able to meet basic food requirements, there were still gaps in accessing sufficient and nutritious food. This situation highlights a critical disconnect: even when food is available, the quality and nutritional value may not be sufficient to support the health and well-being of mothers and their children, particularly those living with HIV. Without the necessary resources and knowledge, many breastfeeding women and caregivers find themselves navigating a complex landscape of economic and health challenges, underscoring the need for targeted support and education to empower them in their financial and nutritional pursuits.

4.1.36 Implementation Strategy of the Bringing Kids To Care Project in Indonesia/West Papua

The **Bringing Kids To Care (BKTC)** project in **Indonesia/West Papua** is uniquely tailored to address the region's specific challenges, including geographic isolation, socio-economic disparities, and deeply ingrained stigmas surrounding HIV. In contrast to other countries, where the focus might primarily be on scaling up existing health infrastructure, the implementation strategy in Indonesia/West Papua must address the **logistical difficulties** posed by the region's remote, often inaccessible terrain.

The project will utilize a **community-based approach**, working closely with local healthcare providers and outreach workers to bring HIV services directly to rural areas where access to healthcare is severely limited. The **door-to-door testing model**, while effective in other regions, must be adapted to West Papua's unique geographic constraints, where some communities are accessible only by boat, adding a layer of complexity to service delivery. This will require additional planning and resources to ensure the project's success in reaching the most isolated populations.

4.1.37 Relevance of the BKTC Project in Indonesia/West Papua

In **Indonesia/West Papua**, the BKTC project addresses significant gaps in HIV care, particularly among pregnant women and children. Unlike other countries where testing is more widespread, **HIV testing remains largely untargeted** in West Papua, and cultural stigmas continue to impede open discussions about the disease. The project's interventions are designed to **break down these cultural barriers**, working closely with local leaders and healthcare providers to foster trust within communities.

The project's focus on **pregnant women** is especially critical in West Papua, where many women prefer to seek antenatal care (ANC) from private providers, who are not fully integrated into the national HIV response. This often leads to missed opportunities for HIV testing during pregnancy. By collaborating with both public and private health care providers, the BKTC project will ensure that more women are tested and receive the care they need, significantly improving PMTCT outcomes.

4.1.38 Synergy of BKTC Project Interventions with Existing Programs

In **Indonesia/West Papua**, the BKTC project will complement the **national policy on maternal and child health**, which seeks to eliminate triple diseases (HIV, Hepatitis B, and syphilis) through pregnancy testing. The project's interventions will fill critical gaps in the existing health framework, particularly in reaching women who are not accessing public health services. By working alongside specific populations of interest such as **female sex workers**, the project will further expand its reach, ensuring more comprehensive coverage for vulnerable groups.

Additionally, the project will collaborate with international donors and non-governmental organizations (NGOs) already operating in West Papua. These partnerships are essential in a region where **resource limitations** and **logistical hurdles** complicate service delivery. By aligning with these programs, the BKTC initiative will reinforce ongoing efforts to improve HIV care, particularly among women and children in remote areas (Global Fund, 2022).

4.1.39 Effectiveness of the BKTC Project in Indonesia/West Papua

In Indonesia/West Papua, the effectiveness of the BKTC project will depend heavily on its ability to overcome **geographic and socio-cultural challenges**. The project's door-to-door testing model, while successful in other regions, must be adapted to meet the **specific needs of West Papua's remote communities**. Outreach workers will play a critical role in navigating difficult terrains and engaging with communities that have traditionally been hesitant to participate in HIV testing due to stigma.

The **training of local outreach workers** will be key to the project's success. In West Papua, these workers will not only provide testing and follow-up care but also serve as **trusted intermediaries**, helping to reduce the stigma surrounding HIV. Their role in maintaining long-term relationships with community members is crucial, especially in a context where trust in healthcare providers is often lacking (Ministry of Health, 2021).

4.1.40 Efficiency of BKTC Project Interventions in Indonesia/West Papua

Implementing the BKTC project efficiently in **West Papua** presents unique challenges due to the region's **geographical isolation** and the limited availability of healthcare resources. The door-to-door model will require **significant logistical planning**, particularly in areas where the only mode of transportation is by boat, making some communities difficult to reach. Additional resources will be needed to support transportation, ensuring that health workers can consistently reach these remote populations.

Despite these challenges, the project's **collaborative approach** with local health authorities and community leaders will maximize the efficient use of resources, ensuring that services reach those most in need. By leveraging local knowledge and networks, the BKTC project aims to minimize operational delays and ensure timely service delivery, even in the most isolated areas.

4.1.41 Sustainability of BKTC Project Interventions in Indonesia/West Papua

The sustainability of the BKTC project in Indonesia/West Papua hinges on **community ownership** and the establishment of long-term partnerships with local health providers. By **training local health workers** and fostering collaboration with community members, the project will build a foundation for sustainable HIV care that can continue beyond the project's lifespan. However, the sustainability of these efforts will require ongoing support from international donors, as **local healthcare systems** remain underfunded and overburdened.

One major challenge to sustainability in West Papua is the **persistent stigma** surrounding HIV, which complicates care retention. The BKTC project will work to address this by integrating **community education programs** that promote understanding and reduce discrimination against people living with HIV. These efforts, combined with the support of **peer outreach workers**, will ensure that community members continue to receive care and support even after the project ends (Global Fund, 2022).

4.1.42 Impact Orientation of the BKTC Project in Indonesia/West Papua

The BKTC project's impact in **Indonesia/West Papua** is expected to be profound, especially in improving HIV outcomes for women and children in **remote and marginalized communities**. By bringing healthcare services directly to these populations, the project will help reduce the **stigma associated with HIV** and encourage more individuals to seek testing and treatment. In the long term, the project's focus on **community-driven care** will empower local communities to take an active role in their health outcomes, promoting **greater HIV awareness and reducing transmission rates**. The **involvement of local outreach workers** in the care process will also foster a more supportive environment for people living with HIV, helping to eliminate the social isolation and discrimination that often accompany an HIV diagnosis.

4.1.43 Recommendations for Indonesia/West Papua

Several recommendations can be proposed to improve HIV awareness, testing, treatment, and overall health outcomes for women and children in Indonesia/West Papua. These recommendations aim to address the identified barriers and enhance the effectiveness of HIV interventions in the region.

1. Empower Women through Education and Advocacy

- Develop and implement community-based health education programs targeting women, focusing on HIV knowledge, testing, and treatment options. These programs should be designed to foster a supportive environment where women can learn and discuss their health needs without fear of reprisal.
- Engage local leaders and community influencers to advocate for women's autonomy in health decision-making. This could involve public campaigns that promote gender equality and challenge patriarchal norms that restrict women's access to healthcare.

2. Engage Men and Families in HIV Awareness

- Create initiatives that actively involve men in discussions about HIV, maternal health, and family planning. Educating men about the importance of supporting women's health decisions can help reduce gatekeeping behaviors and promote shared responsibility for family health.
- Design family-oriented interventions that encourage open dialogue about health issues within the household. This could include workshops or group sessions where families can learn together about HIV prevention and care.

3. Enhance Accessibility to HIV Testing and Treatment

- Establish mobile health clinics that can reach remote communities, providing HIV testing and counseling services. These units can also offer educational resources and support for women and families.
- Train and deploy more community health workers who are familiar with local cultures and languages to build trust within communities and facilitate access to healthcare services.
- Facilitate child-centered interventions to achieve monthly check-ups, timed and targeted psychosocial counselling critical for decision-making and treatment adherence.

4. Address Stigma through Community Engagement

- Launch campaigns aimed at reducing stigma associated with HIV through storytelling, testimonials, and education. Highlight positive stories of individuals living with HIV who are successfully managing their health.
- Establish peer support groups for people living with HIV, particularly for women. These groups can provide emotional support, share experiences, and encourage adherence to treatment.
- Stakeholders in Indonesia must focus on address social stigma in the community, at workplace and religious institutions where the infected and affected are subjected to rejection, exclusion and limitation in events gathering, economic opportunities, socialization and service delivery.
- It is good to mention about what kind of stigma and discrimination which patients experienced and whether the stigma and discrimination solely coming from the health facilities or only a number of staffs so that we can address on how to address the issue.

5. Integrate Economic Empowerment Initiatives

- Provide training and resources to help women understand how to participate in VSL schemes effectively. This could include workshops on financial literacy and the benefits of savings groups.
- Implement programs that address the nutritional needs of breastfeeding women and children, especially those living with HIV. This could involve partnerships with local agricultural initiatives to improve access to nutritious food.

6. Strengthen Healthcare Infrastructure

- Advocate for increased investment in healthcare infrastructure in West Papua, ensuring that facilities are adequately staffed and equipped to provide comprehensive HIV services. This will particularly help to address the serious concerns regarding lengthy the time it takes to receive the EID test results which has negative impact regarding treatment adherence and relevance for EID.
- Implement strict confidentiality protocols in healthcare settings to ensure that individuals feel safe seeking care and that their privacy is respected.

7. Enhance Community Engagement and Trust Building

- Meaningful and actively involve local leaders and respected community figures in the planning and execution of the BKTC project. Their endorsement can help build trust and reduce stigma, facilitating greater acceptance of HIV testing and treatment within the community.
- Develop and weave culturally sensitive communication strategies that resonate with local beliefs and practices. Utilize local languages and culturally relevant materials to ensure that information about HIV and available services is accessible and relatable. This as well is vital for adolescents managing stigma and disclosure issues.

8. Strengthen Training and Support for Outreach Workers

- Develop and implement robust training programs for outreach workers that not only cover technical skills for HIV testing and counseling but also focus on communication strategies to address stigma and engage effectively with community members.
- Establish and implement a system of ongoing support and supervision for outreach workers to address challenges they may face in the field. Regular check-ins and feedback can help maintain morale and effectiveness.
- The partner organization must support government to interrogate how existing government policies and community programs align with the Bringing Kids to Care objectives by modeling the program successes influenced by success stories and case studies.

9. Adapt Service Delivery Models to Geographic Challenges

- In addition to the door-to-door testing model, consider implementing flexible service delivery options, such as community health fairs or pop-up clinics, to reach more individuals in remote areas. These clinics can also provide community-based education, offer treatment for other common illnesses, and collaborate with local health workers to ensure continuity of care.
- Explore and develop the use of mobile technology to facilitate communication between outreach workers and healthcare providers, ensuring timely follow-up and support for individuals who test positive for HIV.

10. Integrate HIV Services with Existing Healthcare Frameworks

- Strengthen collaboration with private healthcare providers to ensure that antenatal care (ANC) services include comprehensive HIV testing and counseling. This integration can help capture women who might otherwise avoid public healthcare services.
- Advocate for the alignment of the BKTC project with the national health policies and programs aimed at reducing maternal and child health issues. This can enhance resource mobilization and facilitate smoother implementation.

11. Focus on Education and Stigma Reduction

- Launch targeted community education campaigns to raise awareness about HIV, its transmission, and the importance of testing and treatment. Use storytelling and testimonials from community members to humanize the issue and reduce stigma.

- Establish peer support networks for individuals living with HIV, particularly women and mothers. These networks can provide emotional support, share experiences, and encourage adherence to treatment.

12. Ensure Sustainability through Local Capacity Building

- Invest in empowering and capacitating local healthcare providers to ensure they have the skills and knowledge to continue providing HIV care after the BKTC project concludes. This includes training on the latest treatment protocols and patient management strategies.
- Foster a sense of community ownership by involving community members in decision-making processes related to health services. This can lead to more sustainable health interventions that are tailored to local needs.

13. Monitor and Evaluate Impact Continuously

- Develop clear metrics for monitoring the effectiveness of the BKTC project, focusing on key indicators such as HIV testing rates, treatment adherence, and community engagement levels. Regular evaluations can inform adjustments to the program as needed.
- Implement feedback mechanisms that allow community members to share their experiences and accountability regarding the services provision.

Key collaborates must help government identify areas for improvement and enhance monitoring, evaluation and learning by Integration of systemic gaps due to limited quantitative data in country to aid validation of claims and evidence gathered through qualitative means.

5 General Findings

Apart from country specific findings, the general findings from the countries involved in the baseline assessment—Zambia, Malawi, Tanzania, and Indonesia/West Papua—reveal several key insights related to pediatric HIV care, challenges in accessing antiretroviral therapy (ART), and gaps in the prevention of mother-to-child transmission (PMTCT) of HIV. Across all countries, there are persistent barriers related to treatment adherence, testing, and socio-economic constraints.

- i. **HIV Prevalence and ART Coverage:** In Zambia, around 0.4% of children aged 0-14 years are living with HIV, but only 60% of these children are receiving ART. Malawi and Tanzania showed similar patterns, with most women attending antenatal clinics being tested for HIV. Early infant diagnosis at 71% in Tanzania poses a significant risk of vertical transmission among HIV exposed infants. On ART coverage, there is remarkable progress in the project districts across all the countries. But a few pockets of challenges concern ART adherence due to a number of factors such as stigma, remoteness, lack of transport money.
- ii. **Demographic Characteristics:** Across Zambia, Malawi, and Tanzania, the median age of breastfeeding women ranged between 24-27 years, and household sizes averaged between 4-7 members. In all countries, a large proportion of the population is involved in farming, with up to 95% of breastfeeding women in Malawi identifying it as their main occupation.
- iii. **Barriers to HIV Care:** Across all countries, rural populations face significant challenges in accessing HIV care. Factors such as long distances to healthcare facilities, lack of transportation, and socio-economic barriers, including food insecurity, hinder adherence to ART. In Zambia, only 75% of children on ART have achieved viral load suppression.
- iv. **PMTCT and Knowledge Gaps:** The knowledge of PMTCT programs varied widely. In Zambia, while almost all breastfeeding women recognized unprotected sexual intercourse as a transmission mode, only 2% were aware of the risk of mother-to-child transmission during pregnancy and delivery. Similarly, in Malawi, gaps in understanding how HIV-free births can be achieved were evident, with only 19% of women aware of the possibility.
- v. **Community Engagement and Support Systems:** Community health workers play a crucial role in improving ART adherence through outreach and counseling, yet there is a need for more personnel to address the growing demand for services. Participation in community-based financial groups such as Village Savings and Loans (VSL) was limited, but willingness to join was high, indicating a potential area for expanding financial support to improve household resilience.

The data from these countries highlights the need for comprehensive interventions that address medical, social, and economic barriers to improve pediatric HIV outcomes.

6 Summary of Challenges in HIV Care

- i. **Geographical and Transport Challenges:** Long distances to reach communities, particularly in rural and remote areas, were a significant issue. Steep or rough terrain in regions such as West Papua and parts of Malawi, where access to communities is sometimes only possible via boat, further complicated outreach efforts.
- ii. **Stigma and Societal Barriers:** Stigma surrounding HIV remains one of the most prominent challenges. This stigma prevents individuals, including caregivers, from accessing or participating in HIV services, even when they are available in the community. Fear of discrimination further hampers engagement with HIV testing and treatment initiatives.
- iii. **Shortage of Resources:** Insufficient HIV testing kits, particularly at the community level, was identified as a significant barrier to scaling up HIV services. The inadequacy of these supplies limited the ability to carry out testing comprehensively.
- iv. **Limited Male Involvement:** The low involvement of men in pediatric HIV activities, particularly in prevention of mother-to-child transmission (PMTCT) programs, remains a key barrier. This lack of male participation affects family dynamics and impedes the effectiveness of HIV-related interventions

7 General Recommendations for Aidsfunds

Below are General Recommendations for Aidsfunds in supporting local project implementers in Zambia, Malawi, Tanzania, and Indonesia/West Papua;

i. Ensure Consistent and Sufficient Resource Allocation

One of the key challenges faced by local implementers is the shortage of essential resources such as HIV testing kits, ART medications, and transport for community outreach. Implementers in **Zambia, Malawi, Tanzania, and Indonesia/West Papua** often operate in resource-limited settings. Therefore, increasing financial and logistical support will enable local teams to deliver HIV services to wider communities.

ii. Strengthen Capacity Building through Training and Skills Development

Through local partners Aidsfunds should invest in **capacity building** for community-based organisations and stakeholders like government who are reaching out to children, pregnant and breastfeeding women. Some of these capacity building initiatives should be tailored towards child friendly options at the health facilities.

iii. Provide Technical Support for Monitoring and Evaluation (M&E)

Effective **monitoring and evaluation (M&E)** is critical for the success of HIV programs. Aidsfunds should support local implementers in building robust M&E systems by offering **technical assistance** in **data collection, analysis, and reporting**. Introducing **digital platforms** and **mobile data tools** will allow for real-time tracking of key indicators such as HIV testing rates, ART adherence, and retention in care. Regular **feedback loops** and evaluations will help identify challenges early and allow local teams to make informed decisions on project adjustments.

iv. Support Culturally Tailored Interventions

Each country has unique cultural, religious, and social dynamics that impact how HIV programs are received by communities. Aidsfunds should work with local implementers to design **culturally sensitive interventions** that resonate with specific populations. This includes providing resources for **community dialogues, peer-led education programs, and engaging local leaders** (such as religious or traditional leaders) to ensure that interventions are appropriate and accepted by target communities.

v. Increase Support for Male Engagement Initiatives

Across all four countries, **low male involvement** in HIV care, particularly in PMTCT programs, continues to be a challenge. Aidsfunds should fund **male-targeted interventions** that focus on educating men about HIV, promoting their involvement in family healthcare, and reducing stigma. Collaborating with local partners to develop **male peer-support groups, father-to-father programs, and male champion initiatives** will encourage men to play an active role in preventing HIV transmission and supporting their families.

vi. Strengthen Partnerships with Local Governments and Health Authorities

Aidsfunds should support local implementers in building strong partnerships with **local governments, health authorities, and community stakeholders** to align project activities with national HIV strategies. Engaging these stakeholders early in the project ensures **policy support, resource allocation, and scalability** of successful interventions. Aidsfunds can also provide

advocacy support to local implementers to ensure that HIV care remains a priority on government health agendas.

vii. Provide Flexibility in Funding for Adaptive Project Management

Local implementers often face unforeseen challenges such as resource shortages, logistical issues, or changes in the local context. Aidsfonds should provide **flexible funding mechanisms** that allow implementers to adapt their strategies in real-time. This flexibility will enable local teams to respond to emerging needs, reallocate resources as necessary, and innovate without bureaucratic delays. **Rapid response funds** for urgent needs, such as medical supplies or transportation for remote outreach, will also be critical.

8 Conclusions

Based on the findings of the baseline assessment, several critical conclusions can be drawn regarding pediatric HIV care in Zambia, Malawi, Tanzania, and Indonesia/West Papua. First and foremost, despite progress in the fight against HIV, **significant gaps remain in the care for pediatric and adolescent populations**. Some children living with HIV, are still not receiving the antiretroviral therapy (ART) **due to cracks in the healthcare systems**. This is especially concerning given the remarkable strides towards global targets for **95-95-95** (diagnosis, treatment, and viral suppression) set by UNAIDS and WHO.

One of the central challenges is the **inconsistency in ART coverage**, particularly among pregnant and breastfeeding women. Although HIV testing during antenatal care is widely available, some women fail to adhere to ART during and after pregnancy, leading to **ongoing transmission risks and children being born with HIV**. This highlights the critical need to **support initiatives aimed at improving access to and adherence to ART** for mothers to effectively prevent mother-to-child transmission (MTCT).

The report also identifies several socio-economic and structural barriers that prevent children and women from accessing care. These include **long distances to health facilities, lack of transportation, inadequate financial support systems like credit (VSLs), and stigma associated with HIV**. These factors disproportionately affect rural populations, further complicating efforts to ensure that children living with HIV receive timely treatment and remain in care. Community health workers (CHWs) play a pivotal role in bridging some of these gaps, particularly in **hard-to-reach areas**. However, the current capacity of CHWs is often **insufficient** to meet the growing demand for their services due to hilly and rocky terrain in some of the project areas like in Malawi and in Indonesia. This report emphasizes the need for **more robust community support systems** and the **scaling up of community-based interventions** to improve **identification, testing, and retention in care**. Additionally, the report highlights a **need for comprehensive psychosocial support**, particularly for children and adolescents living with HIV. Addressing their emotional and psychological needs is crucial for **fostering adherence to treatment and improving long-term health outcomes**. There is also a need for **more child-centered care strategies**, especially in terms of HIV status disclosure and age-appropriate health education.

Furthermore, strengthening ART access and adherence, by **expanding and enriching** community-based care; addressing socio-economic barriers, and; enhancing psychosocial support systems are all critical steps toward achieving the global goals for pediatric HIV response. These efforts are critical to **realise positive health outcomes for children and pregnant and breastfeeding women in HIV care**.

9 Appendix

9.1 Baseline Assessment Team

S/N	NAME	Current residence
1.	Tawina Jane Kopa-Kamanga	Australia
2.	Martin Tembo	Malawi
3	Penjani Kamanga, PhD	Malawi
4	Paulo Mpazi	Tanzania
5	Elihuruma Laizer	Tanzania
6.	Chiza Kumwenda, PhD	Zambia
7.	Annisa Rahmalia, PhD	New Zealand
8.	Mawar Nita Pohan	Indonesia

9.2 Proposed Work plan

S/N	Task	Period	No of days
1.	Submission of technical and financial proposals	By 3 January 2024	-
2.	Briefing with Aidsfonds to review terms of the contract	Mid- January 2024	1
3.	Meet with Aidsfonds to review the terms of reference	3rd week of January 2024	1
4.	Desk review of key documents by core team	3rd to 4th week of January 2024	3
5.	Draft and circulate inception report (to include research framework) for review and comments	5th week January and 1st week February 2024	3
6.	Consolidate comments and share final inception report with Aidsfonds	1st week February 2024	2
7.	Training on data collection methodologies and bookings for meetings and interviews	2nd week February 2024	3
8.	Data Collection	3rd week February to 5th week February 2024	12
9.	Data management and analysis	1st week March 2024	4
10.	Development of draft baseline report	2nd week March	4
11.	Submit the draft baseline report	3rd week March 2024	1
12	Revise the first draft baseline report according to comments by Aidsfonds and partners	5th week March 2024	3
13	Submit final baseline report	By 1 May 2024	1

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