

# The HIV response in conflict:

## Lessons learnt from South Sudan



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Only 13% of pregnant women living with HIV in South Sudan have access to PMTCT services.

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# About the International HIV/AIDS Alliance

We are an innovative alliance of nationally based, independent, civil society organisations united by our vision of a world without AIDS.

We are committed to joint action, working with communities through local, national and global action on HIV, health and human rights.

Our actions are guided by our values: the lives of all human beings are of equal value, and everyone has the right to access the HIV information and services they need for a healthy life.

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Cover photo: Only 13% of pregnant women living with HIV in South Sudan have access to PMTCT services.  
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## Summary

After two prolonged periods of civil war, South Sudan became an independent state in July 2011. Two years later this fragile state was once again plunged into conflict, destroying the country's fledgling infrastructure and causing further massive internal displacement.

What does the current conflict mean for the 150,000 people living with HIV in the country? Or the 900,000 internally displaced people, the vast majority of which are living in camps where HIV vulnerability and risk is thought to increase? In the past decade South Sudan had made significant steps towards providing comprehensive HIV services, yet the current conflict has seen health services hugely disrupted or entirely suspended. Food insecurity is rife and in many areas water and sanitation services have broken down.

This case study examines the experience of the lead agency working on strengthening civil society's response to HIV in South Sudan, the Alliance for Community Health Initiatives (ACHI), an Alliance Linking Organisation. It assesses ACHI's role within the HIV response, the difference it made for people living with HIV and those most at risk to it, and the challenges faced by the organisation as the crisis unfolded. It also examines the interaction between civil society, local and national government and international donors during this period, and identifies key learning and future priorities to ensure HIV prevention, care and support services, informed by the experiences of PLHIV, are better integrated into disaster preparedness planning.

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## Key lessons

- In South Sudan, the international community is heavily focused on the current humanitarian crisis with little focus on both HIV and sexual and reproductive health (SRH). This is having a detrimental impact on both the health of people living with HIV (PLHIV) and is also affecting the prevalence rates of HIV and other sexually transmitted infections (STI), which evidence suggests dramatically increases in camps for internally displaced people (IDP).
- Civil society organisations such as the Alliance for Community Health Initiatives (ACHI) have local expertise, on-the-ground agility and established networks, and can adapt to the changing circumstances that conflict brings.
- Local organisations and networks, including PLHIV networks, need to be better linked to national and local disaster preparedness training and systems so they are fully equipped to respond to the needs of communities in crisis.
- Donors need to be able to react more quickly and provide more immediate and flexible funding channels to enable civil society to carry out a better-coordinated response.
- Contingency plans need to be developed in countries at risk of conflict so that the needs of PLHIV are met during a crisis.
- Co-ordination needs strengthening between the UN, INGOS, the government and local civil society.

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## The Alliance in South Sudan

The International HIV/AIDS Alliance (the Alliance) is a global network of nationally based, independent, civil society organisations united by a common vision of a world without AIDS. The Alliance is committed to joint action, working with communities through local, national and global action on HIV, health and human rights.

The Alliance opened a country office in South Sudan in 2005 following the signing of the Comprehensive Peace Agreement (CPA), which officially brought 22 years of civil war to an end.

The country office transitioned to ACHI, an autonomous Alliance Linking Organisation, in 2013.

ACHI has a memorandum of understanding with the government naming it as the lead agency working on strengthening civil society's capacity in the HIV response.

ACHI currently supports 92 CBOs across 23 counties in eight of South Sudan's ten states.

ACHI played a leading role in the formation and subsequent capacity building of the South Sudan Network of people living with HIV in 2007.

Building the capacity of local and central government structures, as well as civil society, for an integrated HIV response is at the heart of ACHI's approach. This has included strengthening the capacity of six county HIV and AIDS commissions and two state HIV and AIDS commissions to improve coordination and service provision to adults and children in the Equatoria states.

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## 1) Background and context

The recent history of Southern Sudan is one of upheaval, punctuated by three phases of civil war. The first, between 1955 and 1972, ended with the Addis Ababa Agreement. The second, between 1983 and 2005, ended with the signing of the CPA. In January 2011, South Sudan seceded from the Republic of Sudan and in July of the same year became an independent country. But in 2013, conflict once again broke out and continues daily despite a ceasefire signed in Addis Ababa in early 2014.

This fragile state faces major challenges in establishing peace and stability, developing infrastructure, managing population movement and displacement, ensuring food security, developing human resources, establishing and building governance structures and systems, providing education, water and sanitation and delivering health services.

Before the latest bout of civil war, 4.5 million out of an estimated population of 11.8 million were in need of humanitarian assistance, of which 4.1 million were food insecure. In addition, South Sudan was already hosting around 263,000 refugees and 125,000 people were internally displaced<sup>1</sup>. This included some 70,000 returnees from Sudan, surviving under very resource poor conditions<sup>2</sup>.

Escalating armed conflicts between the army and non-state actors as well as inter-communal disputes have led to the current conflict. Violence, which started in Juba in December 2013, has spread out to the states of Jonglei, Unity and Upper Nile. This has seen the number of IDPs rocket to 900,000 as of March 2014. A further 123,400 have sought refuge elsewhere, mostly in Uganda and Kenya with a smaller number in Ethiopia. The conflict continues to destroy the social fabric and infrastructure of South Sudan and cause massive displacement.

### HIV in South Sudan

- Prevalence is estimated at 2.6%<sup>3</sup>.
- This translates to 150,000 PLHIV of which 20,000 are under 15 years.
- The epidemic is generalised, with pockets of high concentration among key populations (KPs) identified as sex workers and their clients, the military, long distance truck drivers, IDPs, returnees, refugees and young people.
- Prevalence among the military is estimated at 4.3%<sup>4</sup> although sex, age, rank, education and religious affiliation are key factors of prevalence within this group.
- Communities around urban centres, cross-border points and transport corridors tend to have higher HIV prevalence than those in remote and inaccessible areas. For example, prevalence is higher along the borders with the Democratic Republic of Congo (DRC) and Uganda and in the capital city of Juba.

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<sup>1</sup> South Sudan CAP 2013 Mid-Year Review, June

<sup>2</sup> South Sudan Consolidated Appeal Mid Year Review 2013

<sup>3</sup> ANC report 2012

<sup>4</sup> SPLA HIV Serobehavioural Survey 2010

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- Internal displacement also leads to a greater likelihood of involvement in risky sexual behaviours as many IDPs and refugees lack access to specific protection and official status<sup>5</sup>.

South Sudan has weak health systems, and limited human resources, organisational and technical capacity to respond to HIV. Key factors contributing to the HIV epidemic include the early age of first sex, low level of knowledge about HIV transmission and prevention, low level of condom use, rape and sexual gender-based violence, a high rate of STIs and high levels of stigma. The signing of the CPA in 2005 saw many people return to South Sudan from countries with high HIV prevalence.

In the past decade South Sudan has made significant steps towards providing comprehensive HIV services including voluntary counselling and testing (VCT), prevention of mother-to-child transmission (PMTCT) services and antiretroviral treatment (ART). The HIV and AIDS Strategic Framework 2008-2012 was the first national HIV plan for South Sudan and focused on establishing the policy and institutional frameworks needed for a multi-sectoral response. However, adequate funding within the national budget has been an issue and many challenges remain.

### Challenges to responding to HIV in South Sudan

- Access to services is limited.
- There are weak health and community systems, which are central to effective service delivery.
- High rates of new HIV infections.
- There are limited and low levels of ART enrolment.
- Only 13% of pregnant women living with HIV have access to PMTCT services.
- AIDS related deaths have almost doubled between 2001 and 2012 (6,900 to 13,000).
- A high number of returnees, IDPs and refugees further impact the HIV epidemic.

### Financing

South Sudan has limited infrastructure and poor health services. Health sector financing has not been prioritised compared to other sectors and financial management in health is weak. Just 4% of government budget is allocated to health. The latest costed National Strategic Plan for HIV (NSP) has an 80% funding shortfall. The country is highly reliant on external funding to support the HIV response in particular the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) and the Global Alliance on Vaccine Initiative (GAVI).

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<sup>5</sup>Spiegel PB (2004); HIV/AIDS among conflict-affected and displaced populations: Dispelling myths and taking action. Disasters, 28(3):322-339



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Donor funding has been organised by geographic area to avoid duplication. Each donor covers a specified number of states. USAID is providing US\$50 million a year for training, supportive supervision and rehabilitation in two states. In six states, the Health Pooled Fund (HPF), made up of funding from DFID, CIDA, AUSAID, the EC and SIDA, is providing US\$150 million for service delivery. This includes primary healthcare and county hospitals, capacity building and systems strengthening at central and decentralised levels, and transition to government managed health services. The World Bank is working in the two remaining states. USAID/CDC have agreed to provide resources for paediatric treatment.<sup>6</sup>



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<sup>6</sup> Acronyms stand for DFID (The UK Department for International Development), CIDA (Canadian International Development Agency), AUSAID (the Australian Agency for International Development), EC (the European Commission), SIDA (the Swedish International Development Corporation Agency), USAID (US Agency for International Development), CDC (the US Centre for Disease Control).

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## 2) The 2013 civil war

The insecurity in South Sudan, which began in December 2013, has led to 900,000 people, mainly from the states of Upper Nile, Jonglei, and Unity, becoming internally displaced. The main IDP sites are UN bases in Bentiu, Bor, Juba, Malakal, Awerial, Mayom and Twic county. Of the 130 IDP camps that now exist only 60 – less than half – are accessible to humanitarian agencies due to their remoteness and insecurity. Approximately 300,000 people have been reached with some assistance<sup>7</sup> but the basic needs of around two thirds remain unmet. In addition to IDPs there are a large number of refugees, 90% of whom originate from Sudan with several thousand more coming from the DRC, Ethiopia and the Central African Republic. These refugees are located in camps in the following states and share the same challenges as IDPs:

- Upper Nile State: 117,832 people
- Unity State: 73,983 people
- Central Equatoria State: 16,864 people
- Western Equatoria State: 9,325 people
- Jonglei State: 3,067 people<sup>8</sup>

South Sudan is still in active conflict despite a ceasefire agreement signed in early 2014. In this context, vulnerability to HIV increases. The SPHERE standards<sup>9</sup> note that mass displacement may boost HIV vulnerability and risk due to separation from family members, breakdown of community cohesion, and the disintegration of norms regulating social and sexual behaviour. Young people and KPs already at higher risk of HIV infection see this risk rise yet further.

Gender-based violence (GBV) is a clear vulnerability factor for HIV transmission. Women who have experienced violence are as much as three times more likely to be infected with HIV than those women who have not, for reasons that are both physical and psychological. Forced sex increases the risk of HIV transmission for women due to tears and lacerations and women living under the threat of violence are less able to protect themselves from a heightened risk of HIV infection.<sup>10</sup>

In some facilities such as the Bor Unity, Malakal and Leer hospitals, service delivery has been entirely interrupted by the present conflict. Services for PLHIV, including ART distribution and CD4 monitoring, have been severely interrupted and a number of patients lost to follow up. There have been no new enrolments into ART.

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<sup>7</sup> Data from the January 2014 rapid assessments undertaken by the taskforce – in draft form still

<sup>8</sup> UNHCR webpage

<sup>9</sup> <http://www.sphereproject.org/handbook/>

<sup>10</sup> UNAIDS: Women, Girls and HIV Fact Sheet (Geneva: UNAIDS, 2010)

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### 3) The experience of ACHI and partners

USAID supported the Alliance to begin work in South Sudan in 2005 following the CPA. The increasing number of returnees from higher prevalence countries saw the threat of a heightened epidemic surface. Many HIV responses in Southern Sudan had adopted a relief approach with an emphasis on rapid decision-making and response, and short-term programming. The movement from humanitarian to long-term development work had barely started, and even where it had it was led by international agencies. Local organisations were greatly in need of support to build their technical, organisational and institutional capabilities in order for them to develop, manage, implement, monitor and sustain effective responses in HIV prevention, care and mitigation. There was a clear need for the Alliance model, which places community action at the heart of the HIV response.

Following baseline assessments in South Sudan, and finding an absence of a local civil society through which to tackle HIV, the Alliance set up a country office with a focus on strengthening local civil society to respond to HIV.

In 2013, the transition of the country office into ACHI, a local autonomous Alliance Linking Organisation, was completed. The organisation currently supports 92 CBOs across 23 counties in eight of South Sudan's ten states. ACHI now facilitates a strong network of civil society, government providers, community leaders and key international stakeholders (e.g. United Nations Population Fund and USAID) to deliver integrated community health services. It supports well-functioning CBOs and has created an enabling environment by strengthening the ability of communities to influence national programming and policies. ACHI is currently working in partnership with UNFPA to respond to the structural issues that make young women and girls more vulnerable to HIV in Western Equatoria State.

The ACHI implementation model not only supports existing CBOs, clubs and organisations, it enables groups to form in places where they never previously existed. This often fragmented, community-based work is supported by the leading role ACHI takes in consolidating the civil society response to HIV and community health at the national level. ACHI worked with the Ministry of Health, South Sudan AIDS Commission, UNAIDS, UNDP and other partners to form the South Sudan Network of people living with HIV in 2007. The Network has 33 member associations in four states. ACHI provided capacity building to the network including strategic planning, and setting up governance and finance systems. However a lot of work still needs to be done to improve the coordination between network members, the Ministry of Health and other stakeholders, and to increase engagement and investment in the networks.

#### Enabling environment and advocacy

By developing a strong working relationship with the government, ACHI has developed an influential advocacy role. Previously, ACHI and the Alliance were successful in increasing political, financial and programmatic commitment to marginalised groups by ensuring their needs were represented in policies. ACHI has now built on this achievement to ensure that government and humanitarian agencies on the ground are sensitive to PLHIV's needs and recognise the urgency in filling in any service gaps.

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## 4) Good practices, lessons learned

The technical expertise of ACHI's staff has enabled the organisation to adopt a flexible, responsive approach to the current conflict. ACHI's position as the leading civil organisation in South Sudan's HIV response has resulted in it coordinating the civil society response within the IDP camps in collaboration with other partners. ACHI has been responsible for identifying the CBOs working in IDP camps then consolidating and coordinating efforts in order to avoid duplication.

Most of the CBOs working in the camps do not sit on the government's national taskforce so ACHI is extremely well positioned to represent their views in this forum and feed crucial information from the Ministry of Health (MoH) and South Sudan AIDS Commission (SSAC) back to them.

### ACHI's role

- ACHI was well positioned to be called upon to coordinate the civil society response within the camps in collaboration with other partners.
- Both ACHI and the Alliance's past experience in advocating on behalf of marginalised groups has resulted in government and humanitarian agencies on the ground being more sensitive to the needs of PLHIV and recognising the urgency in addressing service gaps.
- When the crisis unfolded, ACHI's designation of a security focal person, its liaison with UN security and the government, and its rapid implementation of a security plan ensured personnel were protected and security decisions well-informed.
- ACHI was involved in key decision-making with the MoH and SSAC.
- ACHI played a leading role in coordinating the civil society response within the camps to ensure non-duplication of efforts.
- ACHI was able to be the civil society voice at national level where other civil society organisations did not have access.
- ACHI was one of the national NGOs charged with carrying out the rapid assessments in the IDP camp in Juba. Staff gave their time to carry out this assessment and have participated in a reprogramming and planning meeting with the MoH and SSAC (see Section Six).



HIV prevention outreach work

## Learnings

- Where there are few implementing partners and a fragmented civil society response, community participation should be embraced as part of programming.
- Developing the capacity of and utilising local expertise is critical when working in a fluid and fast-changing environment.

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## 5) Gaps, unmet needs, missed opportunities

The international community is heavily focused on the current humanitarian crisis with little focus on HIV. The UN High Commission for Refugees (UNHCR) recently made a plea for US\$55 million for the response. Increasingly however UNAIDS is providing HIV-specific support in the three greater Equatoria states although the ever-changing environment makes programming difficult.

The most effective way to respond to a humanitarian crisis such as this is to provide on-the-ground services but funding for ACHI is extremely limited, which means it has been unable to respond as effectively to people's needs as it would like. ACHI's request to donors to re-programme funding has yet to be acted upon, leaving the organisation severely restricted in its ability to respond. This frustrating situation means the organisation needs additional support to position itself to deliver services, protect its staff and maintain its management structure. This has had a detrimental impact on staff morale.

Assessments conducted by the UN and various NGOs on the needs of IDPs found that HIV and SRH are not being addressed. Worse still, there is a lack of data detailing the HIV and SRH needs of displaced populations across the country, yet this is crucial to understanding how to mount an effective response.

### Key findings

- HIV programming is not an immediate priority in a humanitarian setting where issues of food insecurity and outbreaks of disease take precedence.
- Neither ACHI nor the Alliance was prepared for the sudden escalation of the recent conflict. Donor inaccessibility and non-responsiveness has limited ACHI's ability to work to the best of its abilities.
- Data on the risk factors and prevalence of HIV among populations of humanitarian concern, essential to developing effective programmes, is limited.
- The national, regional and local HIV information management, monitoring and evaluation systems are limited, impacting on data availability.
- There is limited funding and capacity for HIV programming among humanitarian agencies. Similarly, the integration of HIV programmes with other relevant programming, such as protection, GBV, and nutrition, is limited.
- HIV programming in South Sudan is carried out against the backdrop of limited government funding and a very strong reliance on the Global Fund. The government's contribution for its national programme is less than 3% of all funds. This places great importance on the role of development partners in funding HIV programmes, a scenario that is expected to persist.
- In the current situation it has been difficult, where CSOs are weak, to provide services at the community level. In these instances ACHI needs to be ready to provide direct services for interim periods. In these instances, ACHI needs to shift its strategy from working through CSO partners to becoming a direct implementer.

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## 6) Current situation, future priorities and needs

During the current conflict, the MoH and SSAC have been coordinating the response for HIV and health specific needs. In January 2014, they convened a national taskforce and requested that development partners carry out rapid assessments of the needs of IDPs in four camps. ACHI undertook assessments in the IDP camp in Juba and found that, among other issues:

- No partners on the ground are addressing HIV or SRH needs.
- Access to essential services such as HIV testing and counselling, ART, PMTCT, condoms and STI management is inadequate.
- Storage and distribution of supplies to and from the central warehouse is difficult.
- There is no comprehensive data on the number of PLHIV affected by the current conflict although it is known that at least 1,117 PLHIV from Bentiu, Malakal and Bor, who were accessing ART facilities in September 2013, no longer have access.
- Laboratory tests for diagnosis and treatment monitoring are not being performed routinely.
- Often PLHIV cannot access food, further exacerbating the issue of adherence.
- There is a need to carry out an SRH needs assessment to provide a better understanding of the gaps in the SRH response and feed into partner plans, particularly those providing integrated services.
- Cases of transactional sex, exploitation, and rape used as an instrument of warfare were evident.
- Patients from conflict states are attempting to access services in neighbouring countries such as Uganda and Kenya without treatment documents.
- In view of previous extensive looting of assets, major funding is needed to secure core transport pipelines for emergency supplies.

**Requirements for HIV prevention and treatment is likely to increase significantly due to the growing number of people who have been displaced**

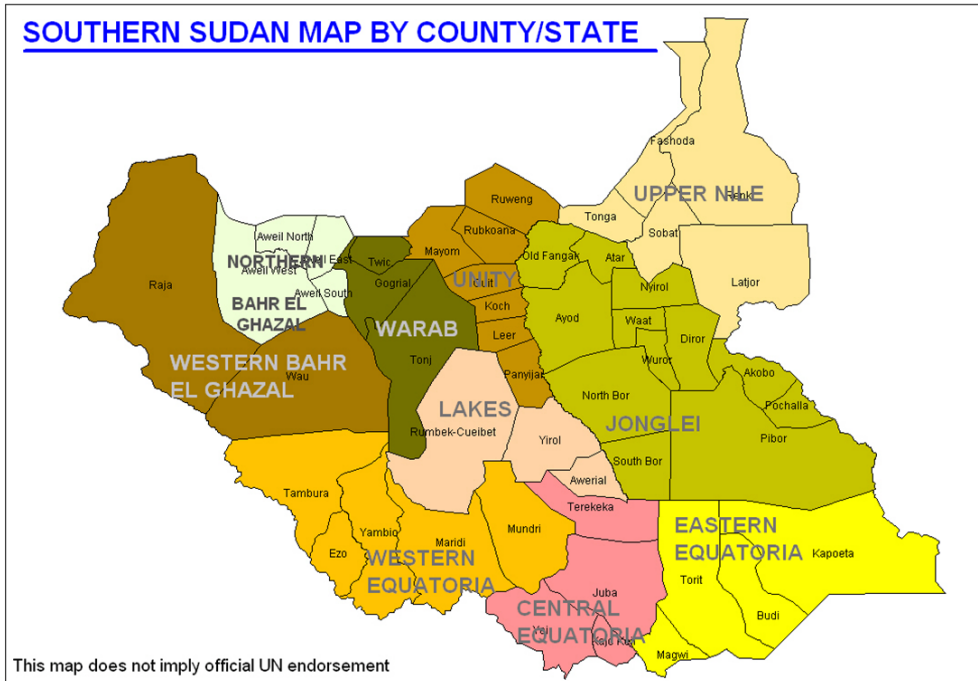
### **Issues that need to be addressed:**

- Improvement to HIV programming in crisis situations is needed. This includes coordination, leadership and accountability, needs assessments, information management, implementation arrangements, monitoring, evaluation and funding.
- There is a lack of preparedness and inadequate capacity to handle HIV needs in emergency settings.

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- A recent assessment on HIV programmes in three states found current programmes are limited and fragmented, with little accountability and few reporting mechanisms in place.
  - There is lack of access to treatment, care, food and nutrition for PLHIV already on long-term therapies especially in Jonglei, Unity and Upper Nile. Access has also been affected in other areas including the Central Equatoria states.
  - There is limited access to central stores, and transport of supplies to most parts of the country remains challenging due to irregular UN flights and continuous clashes on various routes. Coordination for resupply is poor.
  - HIV programming should be mainstreamed into the humanitarian response in line with the four activity areas as set out by international guidelines such as SPHERE (health: facility-based HIV prevention, HIV care and treatment; protection/GBV; food security; livelihoods, and nutrition).



## Annex 1: Map of South Sudan by county and state



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