INTEGRATING HUMAN RIGHTS MONITORING INTO THE NATIONAL HIV RESPONSE

EXPERIENCES OF SETTING UP REACT
AFSA is a development organisation that exists to support local, national and regional efforts to reduce new HIV, tuberculosis and sexually transmitted infections, address the social and structural drivers of HIV, remove barriers to the realisation of sexual and reproductive health rights, and build resilient communities.

Alliance Côte d’Ivoire operates in 39 districts in Côte d’Ivoire, focusing on HIV and human rights awareness-raising, advocacy on removing structural barriers to HIV prevention, treatment and care, and community systems strengthening. It works with key and marginalised populations, such as men who have sex with men, sex workers, prisoners, and victims of sexual violence (particularly young women and adolescent girls).

ENDA Santé Côte d’Ivoire is part of the Enda Tiers Monde network, and works to improve the health, social and economic conditions of all people, including people living with HIV and marginalised people in 39 districts. Enda Santé has a human rights documentation programme with community paralegals, complemented by 27 peer educators acting as focal points. The peer educators and paralegals collect data, which is then sent to Enda Santé for analysis.

Frontline AIDS wants a future free from AIDS for everyone, everywhere. Around the world, millions of people are denied HIV prevention, testing, treatment and care simply because of who they are and where they live.

As a result, 1.7 million people were infected with HIV in 2018 and 770,000 died of AIDS-related illness.

Together with partners on the frontline, we work to break down the social, political and legal barriers that marginalised people face, and innovate to create a future free from AIDS.
Marginalised people, such as lesbians, gay, bisexual and transgender (LGBT) people, sex workers and people who use drugs, are not only disproportionately affected by HIV, they are also highly vulnerable to violations of their human rights.

Stigma, discrimination and violence prevent them from accessing HIV and other health services – and it also restricts their access to legal support to address these violations of their right to health. Often, when marginalised people report human rights violations, their cases will not be adequately addressed by law enforcement and the justice system, which further hinders their access to health-related services.

Civil society has helped to overcome these barriers by empowering marginalised communities with knowledge about their health rights, and by sensitising healthcare workers, the police, and lawmakers to their rights. Yet the evidence showing the impact of these efforts, or data identifying where rights-barriers continue to persist, has been lacking. This insight is crucial for strengthening how health and other related services, such as access to justice, are designed, delivered, and monitored. Robust evidence is also needed for communities to hold governments to account.

Rights-Evidence-ACTion (REAct) is a community-based human rights monitoring and response programme, developed by Frontline AIDS. Civil society organisations use REAct to support people who are having difficulty accessing healthcare or legal services to do so. It also enables organisations to document these issues and use the information collected to make recommendations for policy and programming reforms, which could prevent similar violations from occurring in the future.

Using REAct to scale up human rights monitoring and responses

Community organisations have historically implemented REAct on a small-scale with great success. As the interest in rights-based approaches continues to grow in many countries, we will increasingly need robust data that demonstrates how rights-based programming enables individuals to access services. We will also need to be able to substantiate the need to increase investment in rights-based approaches. REAct can deliver both of these when implemented at scale.

The following case studies show how REAct is being embedded in the national HIV response in South Africa and Cote d’Ivoire, by integrating community-based human rights documentation and human rights responses into the national HIV monitoring system. They are intended as a resource for civil society organisations, governments and donors seeking to use rights-based monitoring to improve the impact of HIV programming.
Scaling up human-rights documentation will help strengthen the HIV response more broadly. If used efficiently, in conjunction with community participation and adequate investment, it will:

- Ensure that rights are promoted and protected, particularly for marginalised people who are particularly affected by HIV.
- Help to maximise the reach and impact of HIV programmes by improving access to, and uptake of, HIV prevention, testing, treatment, care, and support services.
- Address potential human-rights challenges, and prevent abuses that may occur in the context of HIV and health.
- Help to engage, empower and mobilise marginalised people in protecting and realising their rights.

REAct also creates an opportunity for state and non-state actors to cooperate, and to connect the data that has been generated with efforts to improve the overall quality of health systems.
Although South Africa has a generalised HIV epidemic, with 7.7 million people living with HIV\(^1\); prevalence rates are particularly high amongst LGBT people, sex workers, people who use drugs, women and young people.

South Africa has one of the most progressive constitutions in the world and a supportive law, policy and strategy framework for people living with HIV and LGBT people. Despite this, human rights violations against these groups persist. A 2019 assessment conducted by the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) found that sex workers experience discrimination and violence perpetrated by clients, the police, healthcare workers and the justice system, and there are strong currents of social exclusion, violence and verbal abuse against men who have sex with men, other LGBT people, and people who use drugs, particularly in smaller, non-urban areas.\(^2\) Laws against drug use limit the development of harm reduction interventions and also drive discrimination, violence and abuse against people who use drugs.\(^3\) Socio-cultural norms about sexuality and sexual behaviour also limit access to HIV and other sexual and reproductive health services for adolescent girls and young women.\(^4\)

It is this context that has led South African civil society and state actors alike to see both the systematic documentation of, and response to, rights violations – and the use of this data to inform better healthcare services, programmes and policies – as crucial.

Although South Africa has been implementing a human rights programme through the Global Fund, which includes paper-based documentation of human rights violations, this is limited to documenting cases only and does not include the identification and implementation of responses to rights violations. To address this gap, programmatic staff began looking for approaches that not only document rights violations but also ensure these violations are responded to and the evidence used for advocacy purposes.

This has led to a REAct project being established through the new national Global Fund grant. It is being grant-managed by the AIDS Foundation of South Africa (AFSA), one of the grant’s principal recipients, and implemented through several of its sub-recipients in different localities.

**Embedding REAct in the national HIV response**

REAct is not new to South Africa, having been implemented by several civil society organisations such as Positive Vibes before, but these projects have been relatively small, and for only a few years at a time. These activities have effectively piloted REAct in South Africa, indicating the system’s effectiveness and the potential.

> REAct allows for us to get a true picture of what is happening in South Africa with regard to human rights violations at a national scale, rather than giving an anecdotal picture only. It has provided us with a tool to document human rights violations nationally, with a standardised questionnaire for all stakeholders. The data collected through this will inform our human rights policies and programming, to ensure that the rights of all people are promoted and protected.”

Fezile Kanju, AIDS Foundation South Africa.
impact it could have if brought to scale. Although a number of small-scale, community-led monitoring projects are also taking place in South Africa, no systematic nationwide monitoring of human rights violations currently exists.

The vision is that, through the implementation of REAct, this national system will have been created by the time the Global Fund grant ends in three years. What South African stakeholders are working towards is the large-scale use of REAct by both civil society and state implementers to the extent that the system becomes embedded in the fabric of the national HIV response. Those working to scale-up REAct in South Africa are doing so because they see the potential it has to standardise the way data on human rights violations is collected across all institutions, enabling the human rights situation across the country to become clear.

To achieve national access, the South African National AIDS Council (SANAC) and its stakeholders have decided to expand REAct incrementally, monitoring its implementation closely and using the time to mobilise support from increasingly more stakeholders across the country; buy-in that will be essential to the programme’s success.

Keeping communities at the centre

To ensure marginalised people are instrumental in the national expansion of REAct, SANAC is collaborating with AFSA to coordinate civil society organisations, marginalised communities and the government to jointly create and implement human rights programming, including REAct.

Community-based organisations working with marginalised people and people living with HIV have been consulted and included in the programme design phase, alongside the Department of Health and Social Development, other government departments and ‘Chapter 9’ institutions. Communities and civil society organisations have also been invited to advise on the language used in the REAct questionnaire, and to highlight whether there are any areas relating to the South African context that are not currently covered, which it would be useful to collect data on.

Anecdotal evidence suggests that those who are new to REAct are already seeing its value. During a REAct training a number of participants said that, had they been using REAct previously instead of their own methods of community-led monitoring, they would not have struggled as much as they had.

Overcoming challenges

At first, AFSA faced some difficulty finding the right implementers to join to the programme. Initially, the vast majority of implementing organisations that were chosen focused on programming for people living with HIV. AFSA soon realised it needed to widen the range of implementers to reach people from other marginalised and criminalised communities.
There are a range of stakeholders in South Africa who are already monitoring and documenting human rights violations, including the Department of Justice and a number of non-government organisations. This created challenges in establishing buy-in from all stakeholders to use REAct.

Further challenges were created by organisations sending representatives to stakeholder consultations who were not in decision-making positions. To overcome this, AFSA intends to meet individually with each organisation to explain in more detail what the benefits of using REAct are.

**Sustainability**

Given the involvement of government departments, such as the Department of Health, the Department of Justice and the Department of Social Development, and the involvement of the SANAC, it is likely that a plan will be devised to continue implementing REAct after the Global Fund grant ends. Discussions on which institution will host REAct after the grant finishes are already underway; a further indication of the programme’s sustainability.

AFSA’s REAct programme data is currently being hosted by Frontline AIDS on Wanda, its information management system, which is built on the DHIS2 platform. In the short term, this works for their programme; AFSA can focus on implementation, whilst Frontline AIDS keeps track of the data. Access to that data is shared by AFSA and Frontline AIDS, and implementers can also see the data they are entering. When there is enough data to review, AFSA, its implementers and Frontline AIDS will meet to analyse the data and explore how it can be used.

In the long term, scale-up will require South Africa to take charge of its own national human rights documentation system. The vision is that the programme involves both civil society and state departments. It will be embedded into national processes and structures. This raises a few ‘do-no-harm’ questions that are currently being grappled with, such as who will host and manage the data and have access to it? How will marginalised people who provide their personal stories be assured of confidentiality and personal safety, especially when those violating their rights might be state actors? If marginalised people belong to a criminalised group, such as sex workers, how can they be assured that their data will not be used as evidence against them?

These are questions that every county seeking to scale-up human rights documentation systems will have to deal with. Because of this, marginalised people’s meaningful engagement, and a genuine willingness from state actors to partner with them, will be critical to the process. What is promising is that SANAC continues to bring together stakeholders to progress these conversations, slowly but surely, and has worked hard to ensure no actor has been left behind.

The strength of REAct is that it is a community-led, bottom-up process, which allows stakeholders and government to gain an understanding of human rights from a community perspective.”

Although there is no specific legislation on same-sex relations in Côte d’Ivoire, LGBT people and LGBT organisations experience abuse, harassment and violence, with little protection from the state. Sex work is also not illegal in Côte d’Ivoire but, because the laws surrounding sex work are vague, sex workers remain vulnerable to violence and harassment, including from police officers. People who use drugs are highly criminalised and face strong repression, discrimination and violence. Although opioid substitution therapy services have begun in some places, people who use drugs still complain of police harassment and having their syringes confiscated by the police.

Scaling-up REAct is in the early stages in Côte d’Ivoire. It is envisaged that making REAct more widely available will lead to the systematic documentation of human rights violations across the country, particularly outside larger cities, allowing for targeted interventions and policies to be put in place to protect and promote human rights.

The REAct scale-up will both feed into the Global Fund-supported human rights programme and strengthen it by helping to gather more granular data on the links between access to health and human rights violations.

Building relationships

Alliance Côte d’Ivoire (Alliance CI) and ENDA Santé Côte d’Ivoire (Ena Santé CI) are the key implementers of REAct in the country. As Alliance CI and ENDA Santé CI are in the development phase of their REAct programme, inception workshops have been used to build strong relationships with implementing partners and the Department of Health Information (Direction de l’Informatique et de l’Information Sanitaire [DIIS]), and to ensure continuous communication with Frontline AIDS, which provides technical advice on the use of REAct.

Alliance CI and ENDA Santé CI will be implementing REAct through a multi-stakeholder approach with other in-country community-based organisations. These organisations provide a range of support, including legal support for the filing of cases and complaints at court, support in cases of sexual violence against young women and adolescent girls, and support in cases that require medical care or basic healthcare services, including payment for medical consultations when needed.

State actor involvement has been strong. The Ministry of Health is involved at all stages, while the Ministry of Security provides support in issues related to gender-based violence. This collaborative way of working means civil society actors are better placed to hold the
state to account in cases of human rights violations. It has also resulted in marginalised communities and civil society working with government officials to use the evidence generated by REAct to design and implement human rights programming. Collaboration with Côte d’Ivoire’s national HIV programme is critical for strong government participation and support, and also increases the likelihood that the programme will receive continued support after the Global Fund grant ends, thereby ensuring the sustainability of REAct.

Addressing challenges

As REAct is scaled-up, the challenge of localising the REAct database will need to be addressed. Côte d’Ivoire law requires databases collecting personal data to be managed at the national level. However, REAct data is stored on cloud servers hosted in Europe, which in this case is problematic. To address this Alliance CI are working with national stakeholders such as the Direction de l’Informatique et de l’Information Sanitaire (DIIS) to set up their own instance of DHIS2, that is linked to the existing, national level DHIS2 system. The familiarity of the DHIS2 system with national stakeholders means that it has been easier to gain their support for and buy-in to REAct. This will also ensure sustainability in the scale up, as Alliance CI will be able to make use of this database even after a program has ended.

A separate national level monitoring tool that generates notifications of human rights violations is also being implemented in Côte d’Ivoire. This will work in parallel with the REAct tool, as the two systems are complementary – REAct’s value add is that it collects information at a community level, and that it not only documents human rights violations, but also has the capacity to propose an immediate follow-up response, whether it’s the provision of or referral to health, legal, and other services.

Improving data quality and security

Before REAct, Enda Santé CI used tablets to document rights violations. REAct is a vast improvement on this as the information management system it uses – a customisation of DHIS2 – is able to upload data immediately to a safe cloud server. Under the previous system, delays to uploading data had risked data security and also led to the duplication of records; challenges which have sharply decreased with the DHIS2 platform used by REAct.

“REAct provides confidentiality and security. It is well developed for case notification and will enable [us] to provide quick follow-up and referral for victims of human rights violations.”

Thierry Kouakou, Monitoring and Evaluation Officer, ENDA Santé Côte d’Ivoire.
We have drawn several lessons from these case studies about how and when to take REAct to scale. Before considering implementing at scale, ask yourself these questions.

1. Have you piloted REAct?
   Being ready to go to scale means you have already tested out REAct on a smaller scale with a few implementers and can use the lessons you have learnt from this to inform scale-up.

2. Do you have an in-depth understanding of the rights situation on the ground?
   This includes understanding what the rights-related barriers are, which populations are most affected, where people from these populations live, the services that people from these populations need, the services that are/are not available (e.g. health, legal, social), the existing policy and legal environment, and the current access-to-justice context.

3. Are marginalised communities, and the civil society organisations serving them, at the centre of this work?
   Marginalised communities must be at the centre of advancing their own rights and holding governments to account. REAct is a way for marginalised communities to meaningfully participate in rights advancement. It enables people in need of immediate services to access them, and also provides a way to gather evidence to prove to duty bearers why change is needed, where and how.

4. Do you have inclusive and meaningful networks and partnerships with the right stakeholders, underpinned by a common vision, shared commitment and distributed leadership?
   The process of establishing REAct in a country brings civil society, marginalised communities and government together in partnership, enabling evidence-informed discussions between civil society organisations and policy-makers, and creating inclusive and efficient partnerships. It can also result in government authorities reacting more robustly and rapidly to human rights violations because they are already a partner in the process. Collaborating closely with the government may also create sustainability for the programme, as it increases the likelihood of government funding at a later stage.

   Local programme strategies that, from the start, promote collaborative partnership, consultation and distributed leadership between state and non-state actors are more likely to achieve their objectives through REAct.
Do sustainable resources and institutional policy recognition for scaled-up implementation exist?

Even though many civil society organisations and governments are working hard to respond to rights-related barriers to HIV and other health conditions, the programmes they implement are often on a small scale and do not fully meet the national need. Adequate and sustained human and financial resources are required for scaled-up implementation of REAct. It is important for each country to map out the resources needed and to ensure that, as a partnership, these are available. The buy-in and involvement of government can ensure that sustainable funding is available for scale-up.

The implementation of REAct cannot be successful or sustainable unless it is in alignment with national health plans and responses. This is another reason why multi-stakeholder collaboration is key.

Can you ‘go solo’ on your server and data management system?

Frontline AIDS can host small-scale projects to help civil society organisations start to implement REAct. But, once scale-up begins, country partners will need to host REAct on a server of their own and establish their own instance of DHIS2, or another information management system of their choosing. Many Ministries of Health already use DHIS2 as their national health information system, which means the implementers are already familiar with the tool and it can be integrated or hosted nationally.

Have you considered all the risks involved, including ‘do-no-harm’?

There are considerable risks involved with scaling-up in collaboration with multiple state and non-state actors who will have varying degrees of access to REAct’s data, and varying levels of responsibility. It is important to consider whether the current environment is ‘enabling-enough’. For instance, are there strong data protection laws, constitutional rights protections, and strong ethics and data-management practices that can mitigate against further harm being done? This is an area that is being increasingly developed, as the data-related risks faced by both REAct clients and REAct implementers – and the need to mitigate against them – becomes clearer.
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References

1 See www.aids.org.za


4 Ibid.

5 Ibid.

6 'Chapter 9' institutions are a group of organisations established in relation to Chapter 9 of the South African Constitution, which seeks to guard democracy, and includes the South African Human Rights Commission and the Commission on Gender Equality.