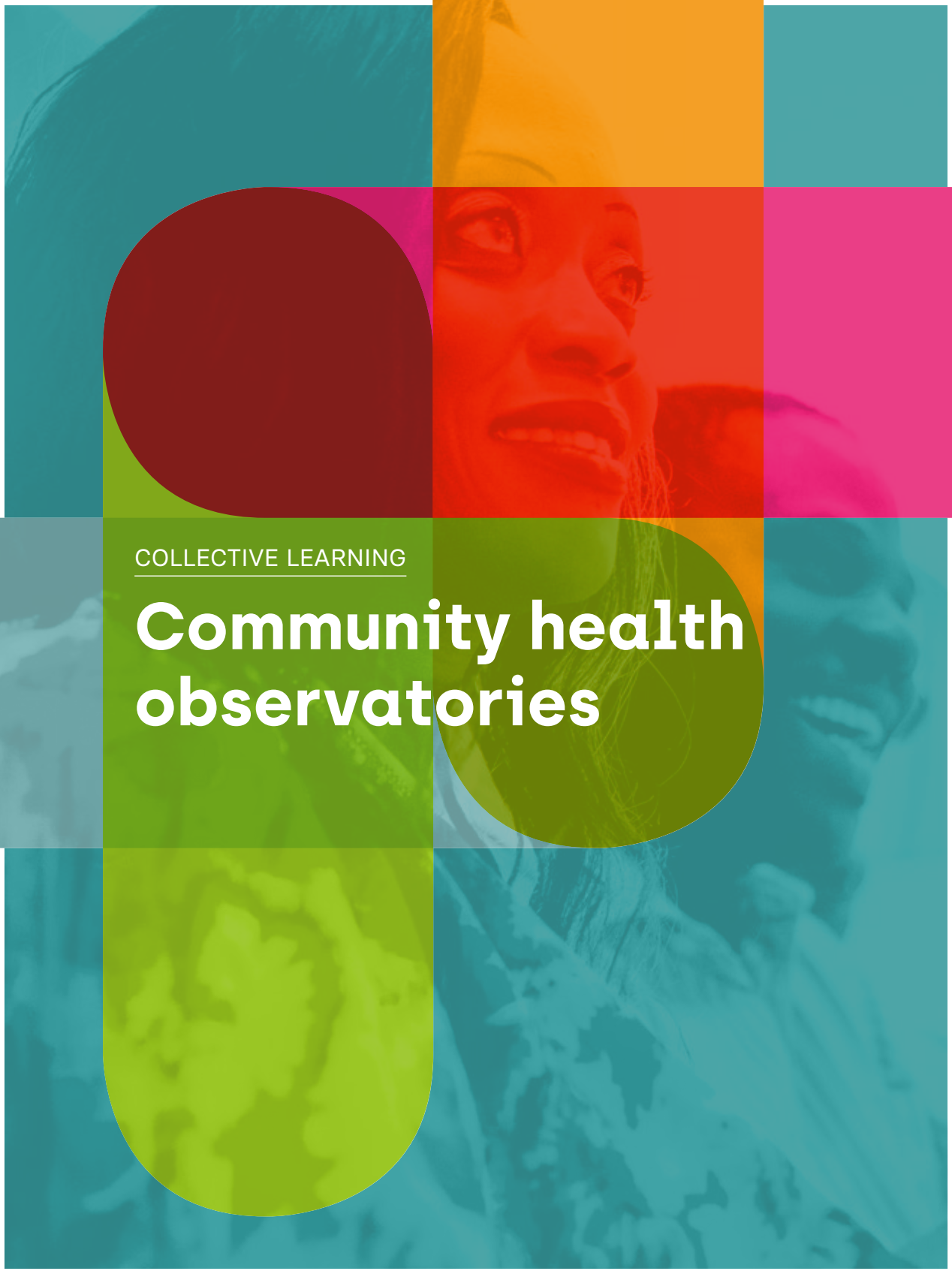


COLLECTIVE LEARNING

Community health observatories

INITIATIVE 5%
SIDA, TUBERCULOSE, PALUDISME

EXPERTISE FRANCE

The 5% Initiative was launched in 2011 and is France's indirect contribution to the Global Fund. Its mission is to support eligible countries — namely francophone countries to develop and implement Global Fund-supported programs. The 5% Initiative's work takes three forms, known as "channels."

- Channel 1 mobilizes expertise on short-term assignments to provide tailored technical assistance to build the capacity of partner countries around specific needs: support to access, manage and implement Global Fund grants, or to manage health commodity supply chains, etc.
- Channel 2 allows the 5% Initiative to fund catalytic projects over two to three years. Projects are selected through calls for proposals to develop innovative activities or conduct operational research to improve responses to the three pandemics.
- A new funding channel was created in 2018 to respond to strategic challenges related to the changing needs and priorities of relevant countries, the Global Fund and France.

The 5% Initiative operates under the supervision of the French Ministry of Europe and Foreign Affairs (MEAE). Strategic management of the 5% Initiative is led by Expertise France, the French public agency for international technical assistance.

Documenting, reporting and developing systems to improve quality and access to health

A collective production to understand observatories and establish a citizen watchdog approach

A quick **overview...**

Background

Over the past fifteen years, many citizen and community-led watchdog observatories have been established, driven in particular by the emergence of "patient-experts" in the fight against AIDS and by the promotion of community health. Observatories play two roles: mechanisms to monitor and evaluate health systems that complement top-down approaches to monitoring; and citizen movements that give a voice to patients. They are attracting increasing interest due to the answers they provide to improve the fight against AIDS, malaria and tuberculosis.

Collective learning

Since 2018, the 5% Initiative has been undertaking a learning process to draw on the experience of observatories it has supported in Benin, Burkina Faso, Cameroon, the Central African Republic, Egypt, Guinea, Lebanon, Madagascar, Morocco, Mauritania, Niger, the Democratic Republic of the Congo, Chad and Tunisia, to identify things they have in common, differences and challenges they face.

What observatories have in common:

1. They are centered on local, community and citizen involvement

2. They aim to sound the alarm on problem areas and to collect valid information on the state of access and quality of health services, which they disseminate on a regular basis at various different levels

3. They create dialogue between stakeholders and strengthen advocacy at all levels of the health pyramid

4. They contribute to improving health systems by highlighting the accountability of all actors

5. They are located within the health system and provide a complementary alternative to institutional information systems.

Observatories come in many different forms determined by various factors — their origins, the relationship between civil society and the government, the position of community organizations in health systems — and experience tensions around:

- Maintaining the necessary independence alongside the need to have dialogue with the health authorities. Depending on the methods they have adopted, observatories tend to rely on observations provided by the community or by specialist data collectors to feedback open information (through a toll-free telephone line, smartphone applications) or through systematic and regular data collection...
- Differences between observatories started locally by patient organizations and observatories led by donors or international NGOs, based on previous experience.

Despite the growing interest in these mechanisms from health authorities and the Global Fund, there remain some concerns about the sustainability of observatories and their sustainable integration into the wider health environment.

Overview

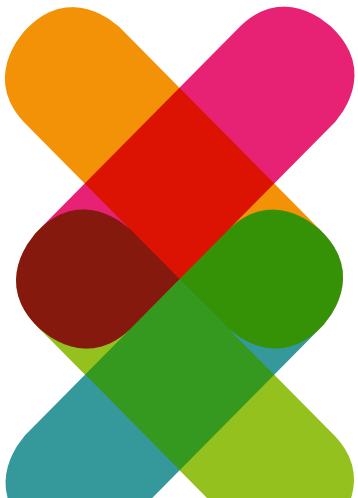
INTRODUCTION

Observatories at the crossroads of strategic health system challenges

Since the early 2000s, around 20 community observatories focusing on access to health have emerged in different parts of Africa. In areas where dysfunctional health systems, in particular supply chain management issues, continue to persist (medical drugs and inputs stockout, delivery of expired medication, shortages and unreliability of equipment for laboratory diagnosis and treatment monitoring, poor service experience for patients, failure to provide free care...), there is increasing interest in observatories as they respond to two major challenges:

- **Equitable access to health services:** They provide a mechanism that enables civil society to express their opinions and participate, thus strengthening the role of communities and the rights of patients;
- **Sustainable health systems strengthening:** They represent a structured mechanism providing alternative data from the field to monitor public policies and health programs.

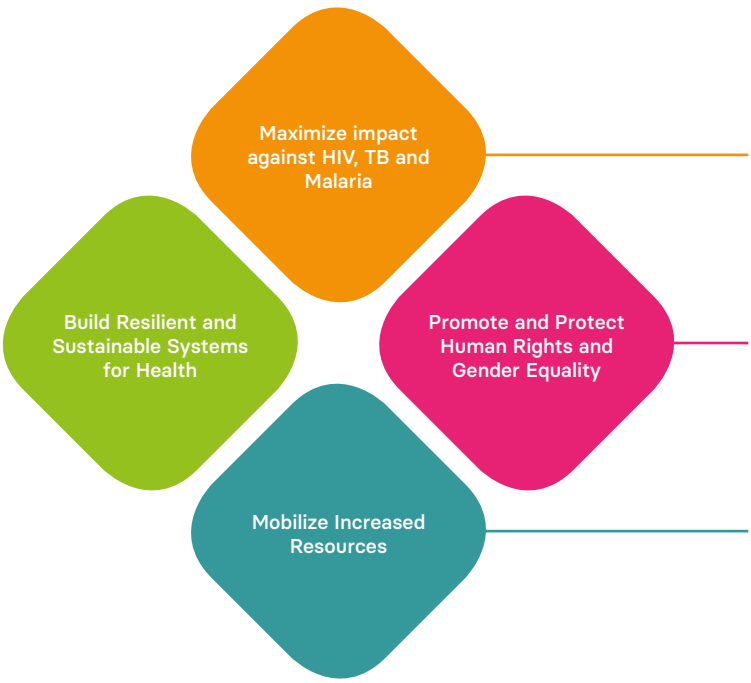
The need to understand and possibly model the way observatories operate cannot however overlook the fact that they take many different forms and trajectories; and that it is necessary to understand how each has adapted to its environment in line with its vision and resources.



Observatories sit at the intersection of the Global Fund to Fight HIV, Tuberculosis and Malaria's strategic objectives, and are a relevant solution to the challenge of integrating community contributions into health systems.

Global Fund strategy

Contribution of observatories



Increase implementation of interventions supported by strong data

Establish and scale-up programmes that combat human rights issues

Strengthen health data systems and the capacity of countries to analyse and use data

Collective learning to develop theoretical and operational benchmarks

The current scientific literature on the subject is almost nonexistent; and although some observatories have modelled and shared their approach, there are few examples to draw from. While it is necessary to produce resources on the way observatories operate and contribute to their development, exploring the variety of experiences offers great learning opportunities.

The 5% Initiative (implemented by Expertise France) has supported the development of several observatories since 2014, which is the basis for this mutual learning exercise.

Launched in April 2018, this mutual learning exercise combining field visits, participatory workshops and evaluations makes it possible to:

- Identify common issues,
- Share the responses developed by each of the observatories and collectively learn from them,
- Produce shareable knowledge.

"OUR DIFFERENCES ARE OUR RESOURCE"!

This slogan, which was suggested by one of the workshop participants, summarizes the spirit of collective learning: it helps to demonstrate the great wealth of the observatories, to respect their diversity while providing learning tools for actors who are interested to find out more, to build partnerships with others or develop a dynamic adapted to their context. Collective learning is about peer learning!

Who is this guide for?
What is in it?

Learning means putting key actors at the heart of analyzing their experiences and producing knowledge. What you are about to read is the result of a collective process carried out by people involved in observatories. It is not a study or a research report that gives an objective critical angle. This document is true to the word of those involved, and is a reflection of the reality of observatories, the operational issues they face and the solutions they have put in place.

- This booklet provides the keys to understanding observatories, their differences and commonalities, and how they work on a daily basis. It is aimed at a broad readership that would like to understand, in a few pages, the essentials of these innovative mechanisms. As a product of a collective learning process, this document combines definitions with quotes from people involved in the daily operation of observatories.

- In addition to the booklet, a collection of six practical guides provides those who would like to initiate an observatory dynamic with concrete benchmarks in the field of information collection, training, mobilization, reporting, positioning and advocacy.

Historical landmarks
Where do community health observatories come from?

Observatories are a recent development in health systems. These mechanisms are considered part of "Community-based Monitoring" and provide participatory governance to improve the management of access to quality health care. Looking back at how they came about allows us to understand the legacies that are shaping observatories today.

A brief overview of the currents of thought that have permeated health policies since the 1970s reveals that the question of community participation has fluctuated constantly over the years between affirmation and disinterest, between utilitarian and militant visions.

1970s / 80s

In sub-Saharan Africa, in the immediate aftermath of independence, the concept of "Health for All" was the rule, and free healthcare was the most common system in place. The free provision of care was seen as a fundamental achievement in the liberation of people from colonization (Tizio et al.). However, the deteriorating economic situation in these countries during the 1970s and 1980s, characterized, among other things, by worsening health conditions, led the leaders of these countries, as well as international bodies, to question the provision of free healthcare. It was through the Alma-Ata Declaration in 1978 that African states decreed the end of free health care and promoted the decentralization of health management to the district level. The involvement of health users became an intervention concept as the Declaration decreed that every human being has the right and duty to participate individually and collectively in the planning and implementation of their health care. From that moment on, the role of users and communities was strengthened — at various levels depending on the country — in managing their own health but also in demanding accountability.

1980s / 90s

Sustained activism took place as a result of the HIV epidemic, through the mobilization of people directly affected by the disease. A utilitarian approach to community participation led by the World Bank prevailed: the integration of communities appeared to be effective in terms of results and costs. In reality, dialogue was established with actors with the skills to be heard, including NGOs, but it often excluded the most vulnerable and disadvantaged.

However, in 1987, the Bamako Initiative broke away from this "top-down" tradition: by putting the notion of primary health care on the agenda and the focus back at the local level, re-emphasizing the importance of prevention and affirming the central role of communities.

2000's

The creation of the Global Fund to Fight HIV, Malaria and Tuberculosis, in 2002, reflected the return of a less top-down approach: although funds are amassed at the international level, decision-making takes place at country level, and country coordination mechanisms (CCM) bring together representatives from the health authorities, civil society and people affected by the three diseases. The Global Fund initially supported a "treatment at any cost" approach, but later integrated more crosscutting issues related to primary health care.

A new window of opportunity emerged for communities holding experiential knowledge and that were able to identify health priorities. The community also emerged as a solution to the unresolved health human resources crisis in developing countries.

Challenges of a community approach

Observatories are therefore at the intersection of two approaches: a utilitarian vision that considers community participation as a means to improve health systems and a more militant approach that makes empowerment of users an end in itself.

While both approaches recognize that communities hold lay knowledge from their everyday experiences that is useful to observe developments, document practices and monitor the effects of health programs, they both have their own vision of health democracy. The so-called utilitarian approach tends to consider observatories as alternative monitoring and evaluation tools, useful for steering public policy, within the framework of established priorities. For advocates of empowerment, observatories serve to carry the voice of patients, to strengthen their participation in decision-making processes, at all stages of the chain of governance. The role of patients, the distribution of resources and decision-making power are crucial for both approaches.

Unequal power relations persist: involving communities, but in what way?

Any participation involves arbitration on the issue of representation: who can speak for communities? The emergence of community health workers in the late 1970s has long been the only response of health systems to some form of community participation. Community health workers play the role of conduit between health systems and communities, but this dual allegiance actually tends to move them out of the community and into the health system. This approach does not solve the question of representativeness and the selection of representatives either: who chooses them, who trains them, who supervises them? Is it the community or the health system? Examples of management committees that aim at wider community participation but are composed of prominent public figures, warn of the risk of “elitization” of the community.

The role of experiential knowledge in health systems governance

Community knowledge must find its place and legitimacy in an environment where other actors who are recognized for their expertise are present. How should we articulate experiential and scientific knowledge in health governance? What is the trade-off between opposing opinions and representations, how can we ensure neutrality and avoid conflicts of interest? The answer to this question determines the nature of community participation, which can range from simple observation to full participation in decision-making processes.

Two forms of community participation coexist in light of these challenges.

- The first involves pools of community health workers who identify patients in need of care, provide first aid and organize health education sessions in the field. Health providers transfer some of their skills and responsibilities to community workers, with supervision provided by the health authorities.
- The second approach, which is common among observatories (but is not always the approach used), implies that civil society actors, people living with an illness or groups of users, organize themselves to rely on the experiential knowledge of all, in order to assess delivery of care and the effectiveness of health systems. Individuals engaged in this dynamic do not replace health workers but act on another level — governance and decision-making. The empowerment process takes place in four stages: individual, collective, collaborative and productive[1]. In this way, communities assert themselves as the driving force behind the health system.

The 4 stages of empowerment

INDIVIDUAL

A person is diagnosed with an illness and discovers the limitations of care provided

Then refuses to accept such a situation and set out to get more information

COLLECTIVE

Exchanges with a community of patients

Learns from peers and through training

COLLABORATIVE

Participates in a specialist group

Signs up as patient resource or expert

PRODUCTIVE

Assesses services and heath products

Designs innovative solutions and a conducive governance environment

The “expert patients” or “citizen-user-patient” model is the legacy of community actors. These roles have played and continue to play a crucial role in guiding and evaluating public health policy. Observatories are part of this history of reviewing and rewriting this militant model and thus represent particularly suitable objects of study to reveal the relationship between governments and development aid actors, and communities. Both the result and the reflection of this relationship, observatories are in the South, in all their diversity, a form of ownership and reinterpretation of the concept of empowerment through information.

1 M.-G. Fayn, V. des Garets, A. Rivière, “Mieux comprendre le processus d’empowerment du patient”, Recherches en Sciences de Gestion-Management, n°119.

Observatories: key definitions

Although community health observatories are increasingly being cited by the international community for their strategic relevance, it is necessary to identify key determining factors to have a shared understanding of what an observatory is. We suggest the six key areas below to provide an understanding:

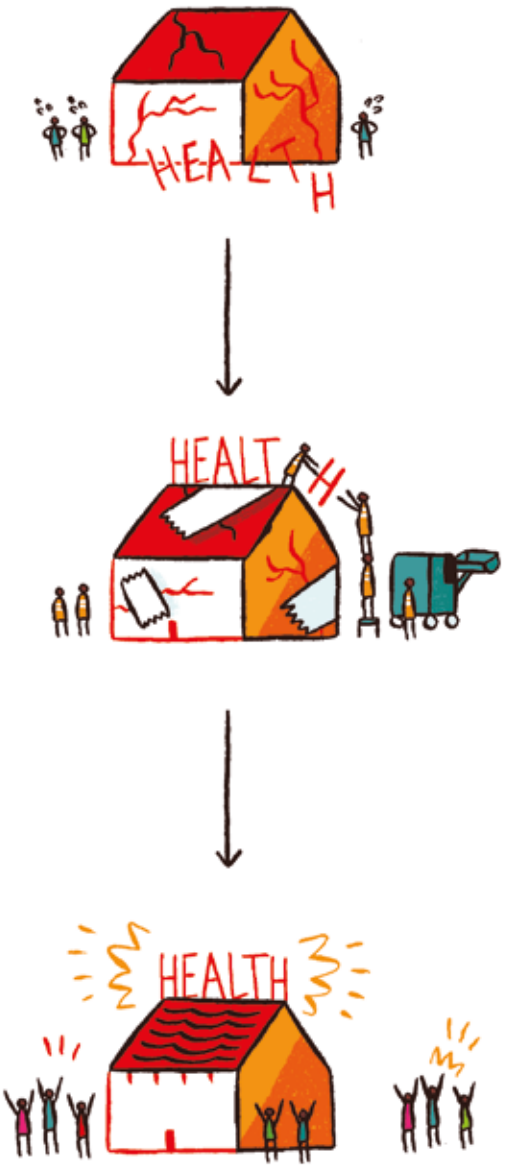
1 Positioning:

Observatories are located within the health system and provide a complementary alternative to institutional information systems

Observatories, which are sometimes seen as a system for checks and balances or as alternative mechanisms, have a central role within health systems. The need to maintain independence does not prevent them from positioning themselves as fully-fledged actors at the interface between all stakeholders in the healthcare pyramid. They exist to ensure the proper application of public policies and make reference to legal frameworks. As observatories produce original data and participate in good governance, they are at the heart of Universal Health Coverage, which promotes equitable access to quality health services and financial protection.

2 Mission:

Observatories aim to improve health systems, from local practices to public policies, by highlighting the accountability of each actor.



An observatory's mission is ultimately to contribute to positive and lasting changes in the health system. The effects can be immediate through improvements to the structure of a health service or through resolving a critical situation, and even relating to a specific user's situation. The actions of an observatory also have an impact on public policies because they create spaces for exchange and consultation through which challenges and blockages encountered by health programs are raised. By highlighting the individual and collective responsibilities of different stakeholders, the participatory dynamics of an observatory can identify solutions and strategies to achieve them. Regular meetings and reviewing commitments forces everyone to be accountable.

How it works:

Observatories aim to sound the alarm on problems and to collect information on the state of access and the quality of health services.

By listening to users, an observatory is able to see and hear how health services are doing and flag any issues and access problems encountered. Whether they alert on emergencies in real time or produce reports periodically on the level of access to health care, observatories serve as feedback channels.

Observatories produce validated data that is disseminated at various different levels.

Observatories are based at local level and are part of the daily life of health facilities. They contribute to evaluation processes by providing a snapshot of a specific point in time of the state of a health service. Data are compiled periodically and presented in order to show trends and developments: they serve as analysis tool. Validation is mandatory and can be done internally or by involving other stakeholders.

Observatories use data and information to establish dialogue between the actors concerned and feed advocacy at all levels of the healthcare pyramid.

Observatories do not merely disseminate data, they encourage exchange, awareness and decision-making by stakeholders. Reporting is a major part of the role and stakeholders are invited to react to observations made by the observatory: for cross-analysis of the causes behind problems observed, to find immediate solutions or to develop an advocacy strategy to influence decisions. At each level of the healthcare pyramid, reporting challenges differ with, at the local level, the involvement of health providers and users, and for regional or national levels, the participation of public institutions, technical partners and financial institutions and representatives of civil society.

4 Involvement:

Observatories are based on community, local and citizen involvement

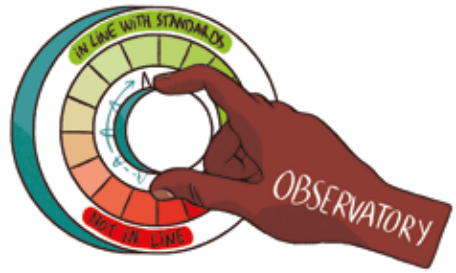
The community of users at health centers is at the heart of observatories; they thrive on the information they provide on quality and service access. Local level involvement is therefore of major importance: a monitoring approach that is cascaded from the ground up to decision makers, unlike a top-down mechanism. Mobilizing users — who respond to surveys or raise issues themselves — means ensuring they are aware of their rights, duties, and policies and regulations in effect.

Feedback from the learning workshop: a committed citizen approach

Observatories are:

- **Dynamic**
  They can be **pro-active** by anticipating situations; and **flexible** by being able to adapt to changes depending on their context and needs. They are "dynamic" tools that are part of an approach based on "anticipation" and "innovation". They are also "a change process that is changing", adapted to their specific context.

- **Participatory**
  They are tools for "citizen participation" for "better governance", and are considered a "sustainable community watchdog tool". They are "inclusive", "citizen-centered", "community", "collective", "mobilizing" because they involve various stakeholders in the broadest possible way.



- **A thermostat more than a thermometer**
  Observatories do not only measure the temperature, they mostly seek to regulate a situation, to correct things that aren't working, and to reach a state that is in line with the standards. An observatory's role is based on the key principles of "monitoring" and "warning". Moreover, far from being "unsettling", they aim to "guide" and "shape" things — two terms used to emphasize their will to transform the health system. Observatories are "a contribution to quality healthcare" and a tool for "strengthening health systems".

Observatory slogans

PART 01

At the root of these differences: different trajectories, contexts, choices and compromises

Although all observatories have the same foundations, each one of them is different, particularly in terms of its history. The origins of an observatory determines its resources, its intervention strategy and how it is positioned in the health system.

The forerunners

Several observatories emerged spontaneously from the context of the 2000s, which was characterized by difficulties in accessing HIV treatment and by the discrimination experienced by people living with HIV (PLHIV) in health centers. As a result, processes to gather, report and document stock-outs — carried out by patient organizations or locally established NGOs — sometimes existed before it was described as "observation" as it is today.

TESTIMONY

LOUIS TSAMO,
Secretary General of Positive Generation (Cameroon)

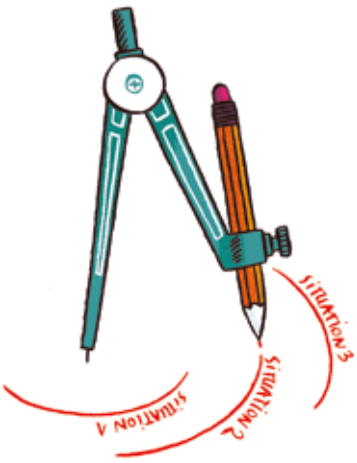
Activity began in 2008, in a context where people experienced disrupted care. You had to pay for treatment and it wasn't always available, there was a high prevalence rate and high levels of stigma. Patients had to navigate testing and accepting the disease, and then tackle treatment. Many did not accept the disease: for us, it was unacceptable that people who did accept it faced treatment stock-outs and/or additional charges [...]. We then began to document the first cases of stock-outs in hospitals. It started to annoy people and we were asked where the proof is? But at the same time people were telling us "do not say that it was me who said that". This is where the idea of an observatory to collect information in a structured way came from. The idea was there, but we didn't have the resources to pay people to collect at specific times. **We identified people who were likely to have information and we got them to contribute: users, support group members, the community health workers and the caregivers** [...] Given the lack of financial resources to pay informants, we opted for a simple, flexible, inclusive mechanism that empowered patients to monitor their access to care.

This historical background, which is characterized by a certain degree of militancy and the existence of an already structured civil society, contributed to making voluntary citizen mobilization the foundation of this type of observatory. Based on these successful experiences, several observatories provided methodological benchmarks and shared models with other interested organizations: the Positive Generation model was replicated in Central Africa and later in Chad; the model implemented by RAME in Burkina Faso also served as a starting point for two PLHIV organizations in Niger and Guinea. Sharing a model then gives rise to the creation of "platforms" of observatories often supported by donors, such as the 5% Initiative: creating networks can also foster the emergence of regional or even international advocacy, homogenizing observed practices and indicators.

Taking ownership of a model and applying it to the local context

An initial model can exist and be a source of inspiration and learning, but each organization reinvents their own depending on the resources at their disposal and their specific context. For example, depending on the type of lead organization — local NGO specializing in advocacy, patient organization, community-based organization… —, the network of people that can be mobilized will differ.

Like a compass that adapts to fit a given situation, an observatory must be able to regulate itself and reinvent a mechanism adapted to the specific nature of the health system, the relationship between civil society and health authorities, and the democratic context.



EXAMPLES

Positive Generation (PG) is a Cameroonian PLHIV organization established more than twenty years ago, which mobilizes patients and healthcare providers anonymously. ANJFAS is a Central African organization of women living with HIV: the observatory they developed mobilizes peer educators working with health services. PG's citizen approach is difficult to replicate in the Central African Republic, where civil society is still poorly structured and poverty makes it necessary to pay information gatherers a minimum wage. In line with their capacity, ANJFAS chose to simplify the data analysis procedures used by PG and produces monthly rather than weekly bulletins.

The observatory established in Niger is inspired by the model led by RAME (Access to Essential Medicines network, Réseau accès aux médicaments essentiels in French) in Burkina Faso, using funds from its lead organization, RENIP +. As Global Fund Sub-Recipient (SR) for PLHIV social support, RENIP + runs a psychosocial counseling center, which also informed OCASS (Community Observatory on Access to Health Services).

FROM EVALUATION TO LEARNING...

During the evaluation of observatory projects in Benin and Niger carried out by the organization CeRADIS, the evaluators set out three areas where it is necessary to be vigilant when replicating a model in another country to avoid delays, or the mechanism being weakened or abandoned:

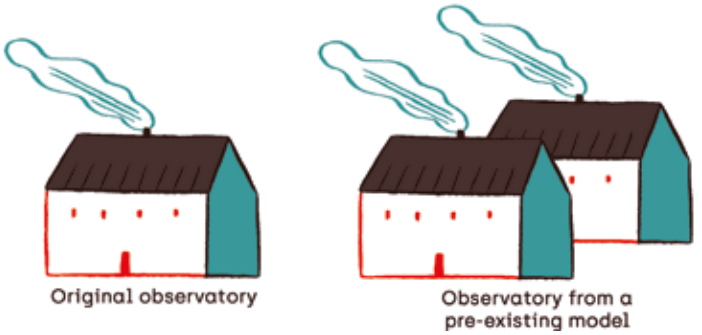
- When recruiting the teams to run the observatory, profiles, criteria and wages may vary from one country to another. Calls for applications must therefore be reworked to reflect the local context. The same is true for budgets and allowances given to data collectors, which must be aligned with national practices, especially if there is another observatory already established in the country.
- It is necessary to ensure that communication materials designed to promote an observatory in a specific country are well understood in your own country.
- Depending on national contexts, advocacy activities may evolve: in one country, media releases may be organize to attract the attention of public authorities, while in another, such a strategy may anger the authorities and seriously undermine the establishment of the observatory.

TAKEAWAY POINT

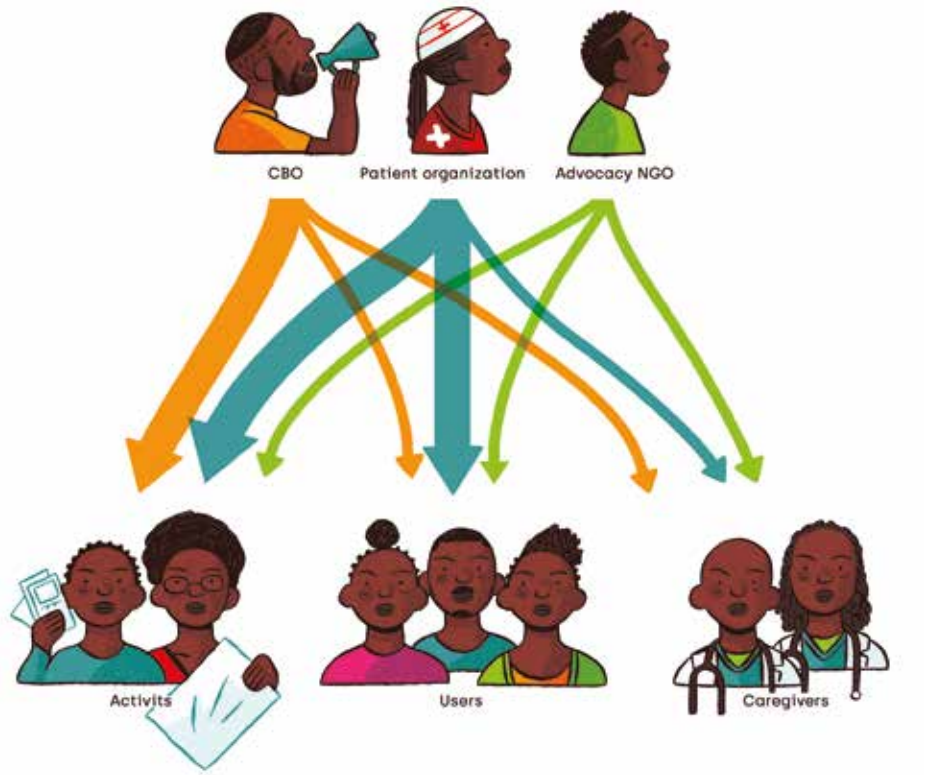
Among the conditions of establishing an observatory, the most crucial factors seem to be related to:

- **The funding model** (project-type resources or no specific resources);

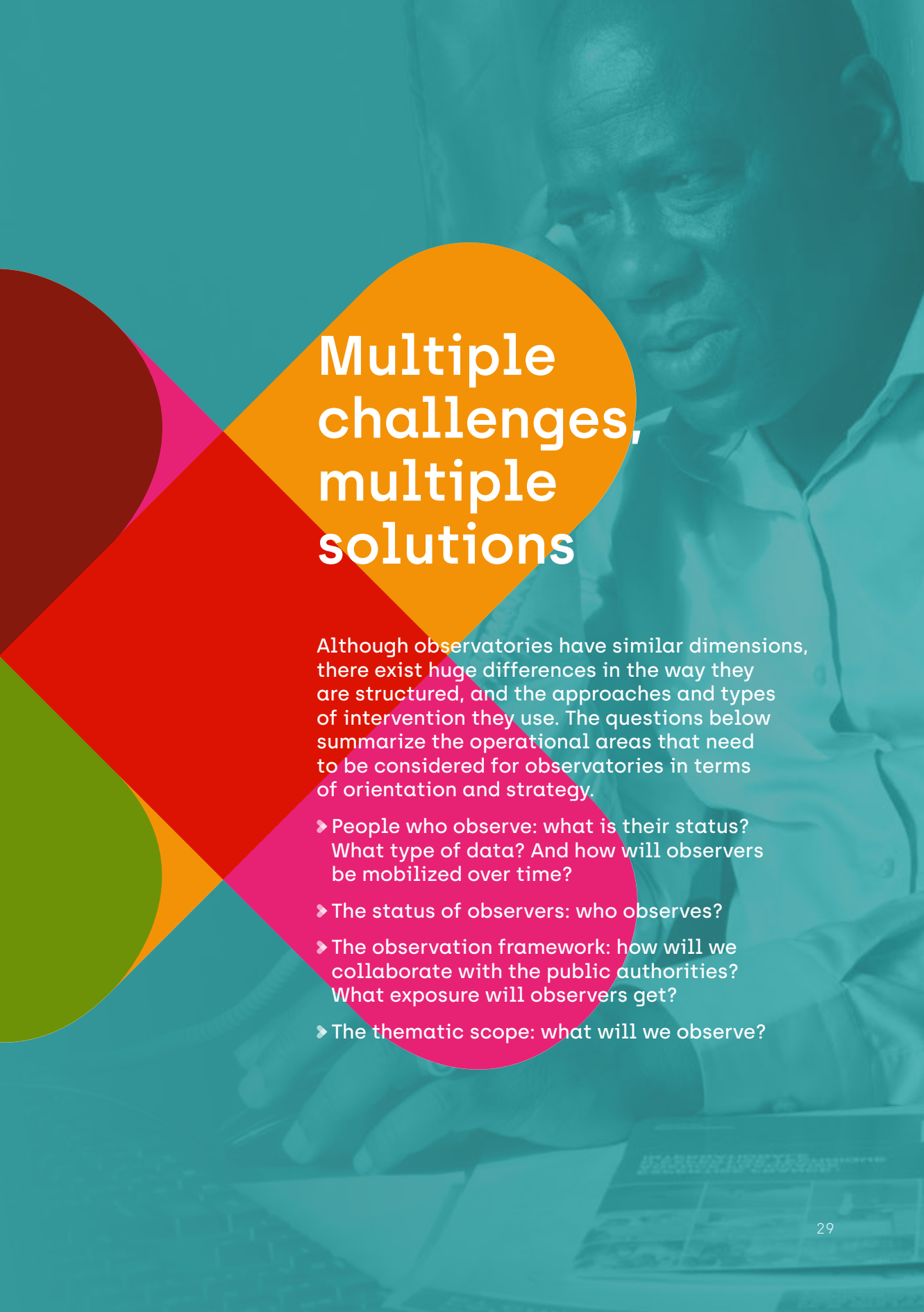
- **Methodology** (if a model is proposed by a lead organization or not);



- **Type of lead organization** (community based organization, patient organization, advocacy NGO) **and its related network.**



PART 02



Multiple challenges, multiple solutions

Although observatories have similar dimensions, there exist huge differences in the way they are structured, and the approaches and types of intervention they use. The questions below summarize the operational areas that need to be considered for observatories in terms of orientation and strategy.

- People who observe: what is their status? What type of data? And how will observers be mobilized over time?
- The status of observers: who observes?
- The observation framework: how will we collaborate with the public authorities? What exposure will observers get?
- The thematic scope: what will we observe?

People observing: what is their status? What type of data? How will observers be mobilized in the long term?

All observatories are based on community involvement that takes different forms. Some rely on citizen monitoring at as wider scale as possible, while others rely on investigators often from civil society actors who have experience in certain technical areas.

1 The status of people providing the information: monitors, data collectors, whistleblowers

Observing and sending information to the observatory — is this role given to people with the relevant mandate and are trained to play such a role; or is it a citizen act performed by people working in the health system or users?

There are 2 types of observatories: those that use “monitors”, and those that use “data collectors”.

- **Monitors,** also known as *sentinelles*, are citizens — usually users or community health workers — who are asked to make observations through their contact with health services. They come together voluntarily and act in the location where they are.

They have been made aware of their rights and duties in terms of health and return their observations via a toll-free number, a smartphone application or during discussions with the observatory’s facilitators. The greater the target numbers to be mobilized, the more flexible the selection criteria for monitors. The motto being: access to quality health is everyone’s business!

EXAMPLE

In Burkina Faso and Niger, patients and their families can directly contact psychosocial counselors who are present in health centers to report an issue. The counselors are the contact point who in turn alert the organization leading the observatory.

TESTIMONY

FROM A *SENTINELLE* IN CAMEROON

My daily reality is being a *sentinelle* and I wear it like a glove! Each day, I communicate life with a smile on my face. As an HIV activist, anything that is an obstacle to my daily life, I immediately spot it to get back on track. Being a sentinelle even helps me achieve my goal!

HEARING FROM THOSE INVOLVED

The image of a stethoscope represents data collectors, who must know how to "collect information at the source and to listen". We must "convince patients to express themselves freely, without fear or holding back," while obtaining "responses [that] are usable and do not distort the data collected."

- **Data collectors** are people selected and trained by the observatory to carry out data collection. This assignment can be given to community health workers or members of organizations who collect information as part of their professional or organizational activities. Data collectors are paid or remunerated and are identified based on established criteria: they are given specific training and receive regular supervision of their work. They may be from outside the health center (such as community leaders) or integrated within it (such as psychosocial counselors).

A STRATEGY OF OPENNESS: WORKING WITH BOTH DATA COLLECTORS AND MONITORS

In Madagascar, the observatory works with peer interviewers from the community and with voluntary caregivers who are asked to question their patients on the quality of care they receive: "the investigator, who is part of the medical staff, contributes to building a climate of trust between themselves and the patient, who is more likely to open up to someone who knows their HIV status. "

In Cameroon, the observatory led by PG also used a multi-source collection approach: information comes from users, organizations supporting people on treatment, community health workers, and caregivers. This multi-pronged approach enables the triangulation of data while offering a holistic and representative view of access to health services. To complement this, observers trained in social science research techniques, and who are volunteers but are paid for travel, go to health facilities every quarter to conduct qualitative surveys and to clarify what led the reported issues to occur.

2

Type of data collected

Depending on who observes, user-observer or paid investigator, the information reported will differ both in nature and frequency.

- Some observatories focus on early reporting of issues and finding short-term solutions. For example, a patient who experiences a break in access to treatment requires an immediate response from the observatory, which then will directly alert the health services. The data reported by monitors and whistleblowers are very varied (stock-outs, discrimination cases, etc.), and the timeframe differs according to the urgency of a given situation.
- Several observatories produce reports based on a set of standard data, based on pre-established indicators, recorded at regular intervals in one or more health centers and operate at regional or national level. Collection is then carried by people who are specifically trained and equipped, and a set protocol is followed. Monitoring and evaluation officers or data managers check the quality of the data before processing.

EXAMPLE

In Burkina Faso, RAME contacted two other organizations, REN-LAC (National Anti-Corruption Network/ Réseau national de lutte anti-corruption), which is composed of lawyers, and AFAFSI (Association of African Women Against AIDS/ Association des femmes africaines face au sida), which already had its own toll-free telephone line. These two organizations now share issues raised by users with RAME and they integrate them into their data collection mechanism.

HEARING FROM THOSE INVOLVED

"I am at the top of the control tower but I also have to check if the data is of good quality": magnifying glass, computer screen, and tension regulator — this symbolizes the role of a monitoring and evaluation officer.

They play a crucial role and their purpose is similar to that of a conductor who directs, corrects and controls the flow of information and data from collectors or monitors. They regulate data feedback and extract steady, understandable, quality outputs.

TAKEAWAY POINT

Behind the scenes, this is an emerging issue: how to reconcile the ambition to conduct research and produce data with being integrated in the community? Producing consistent data assumes standardized protocols, with specific tools that require a certain technical knowledge. It differs from work based on mobilizing a critical mass of observers who are very present on the ground, which generates an increase in abundant mixed information through interactions between citizens and the health system.

In addition, observatories that work with data collectors face specific issues related to their sustainability as they have to cover specific costs for recruitment, training, and supervision. How can the observatory ensure its survival, beyond the timeframe of the project?

EXAMPLE

In Guinea, the observatory works with trained and supervised investigators whose pay has been increased in order to limit turnover.

Various compromises have been made here and there: collection can be multi-source, with different types of monitors and data collectors. Protocols can also be simplified to allow people with less technical experience to participate in collection.

EXAMPLE

In Madagascar, Médecins du Monde and its partners have greatly simplified their collection protocol at the end of the first phases of the survey, in order to make it more accessible to community-based collectors rooted in the community, and who are among the key populations. One challenge is to adapt observation tools and channels to the profiles of observers, whether they are watchmen or collectors.

Relationship with the authorities: finding a balance between the need to establish a dialogue and the need for independence

The observatories question the health authorities about their responsibility in the event of malfunctions. The existence of a culture of consultation or a climate of mistrust is therefore decisive.

Is it necessary to have a framework agreement with the government? Should observation remain anonymous to guarantee its complete independence from the authorities, or should it be carried out "openly" by data collectors who have been registered duly before the health authorities? The answer differs for each observatory, depending on where they are positioned between the two options.

- For some, seeking approval from the authorities is incompatible with the checks and balances and whistleblower role of observatories — as it is the case for citizen initiatives working on human rights issues. This relationship of distance and independence from decision-makers often goes hand in hand with conducting anonymous data collection: "given the environment in which we are operating, it was necessary to maintain the anonymity of people who draw out the information. If people reveal their identity, they will experience reprisals. In such a situation, it is therefore crucial to ensure the safety of those who observe, although anonymous observation may create initial mistrust among health care providers and authorities."

HEARING FROM THOSE INVOLVED

As a coordinator, I have to protect the observatory — working like an umbrella — in a sometimes hostile environment that challenges its legitimacy

- For others, creating an open and formal consultation framework with the authorities is essential to change health policies and services. This is called “non-anonymous” observation: people known to health facilities and clearly identified as observers. While avoiding unsatisfactory and pointless complaints and ineffectual games of “attack/ defense”, this approach may run the risk of complacency from observers with regard to the health authorities to avoid undermining a good agreement, and ultimately lead to a loss of legitimacy of the observatory.

EXAMPLE

In Niger, when RENIP + launched its observatory they decided to seek authorization from the Ministry of Health before starting the collection process in 30 health facilities. Obtaining this authorization and approving the collection protocol enabled the introduction and legitimization of data collectors to site managers and also allowed for a permanent reporting framework to be established with the health authorities. The CCM uses and recognizes the value of the observatory. It sees the mechanism as “a third eye that allows us to see better what is happening around the latest threats of stock-outs, especially in relation to anti-tuberculosis drugs — they alerted us more than two months in advance. They are the first to warn about issues with reagents”, says the Niger CCM Chair.

Therefore, what some see as a risk (loss of independence), others see as an opportunity (recognition by the health system, observatories considered legitimate to submit proposals to develop them further). Making concessions is very dependent on national contexts.

TAKEAWAY POINT

There is certainly middle ground between risking the loss of freedom of speech and the opportunity for recognition. We have identified three situations: observatories asking public authorities to allow them to intervene (authorization); observatories coming to an agreement with the authorities that sets out the terms of collaboration and action but is not an authorization as such (which could be withdrawn from them); observatories taking action without a framework agreement with the government.

While there are different options to consider, a common strategy has nevertheless emerged: it consists of operating legally and being clear that the observatory is not there to attack public policies. Indeed it is quite the opposite; observatories aim to strengthen policies and contribute to the standards and principles that guide them, by raising the voice of users. The relationship with the authorities is necessarily built on educating and explaining the role of observatories.

The Thematic Scope: specialized or multisectoral observatories?

Although historically the first health surveillance observatories emerged from the response to the HIV epidemic and recurrent ARV stock-outs, most have progressively opened up to other conditions and thematic areas. Some people, however, consider they should have a specific focus, given that we cannot observe everything.

A natural expansion process, based on realities on the ground

The integration of other fields of observation is a natural process, particularly for observatories that are anchored in the daily life of health facilities and that will focus on the quality of services and reception.

EXAMPLE

In Burkina Faso, many users reported problems related to stock-outs of anti-venom serum . This was not initially an area the observatory worked on, but in the spirit of flexibility and adaptability, it was considered, and alerts were launched.

At a more general level, many observatories ensure that free healthcare is respected for relevant conditions and as part of maternal and child welfare (MCW). The issue of people being wrongly invoiced for services has been flagged and corruption attempts have been attributed largely to human resource management issues. Observatories can quickly widen their scope from focusing on a single health condition to addressing structural issues.

Some observatories have progressively broadened their focus to look at the health system as a whole, at a wider national level.

EXAMPLE

In Cameroon, various focus areas have developed: one observatory monitors human rights violations, another focuses on monitoring budgetary health policies. In addition, a community organization working to defend the rights of LGBT people monitors rights and access to care according to sexual orientation, and produces tailored reports, as part of a partnership with Affirmative Action.

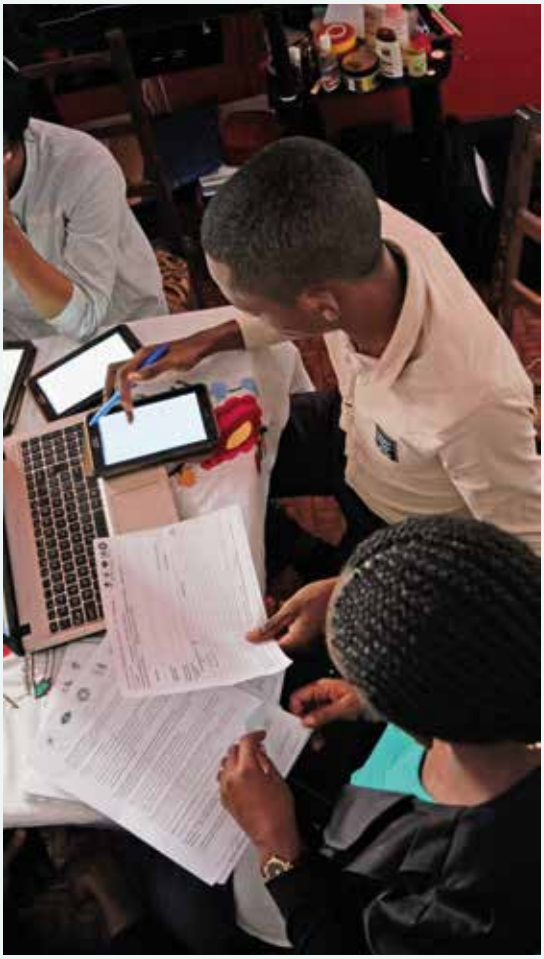
TESTIMONY

FROM A *SENTINELLE* IN CAMEROON

In 2017, a teacher was discriminated against. The story is linked to ARV stock-outs that forced her to go to the dispensing center every day. Her absences were noticed and she had to justify herself to the school management. So she told them about her status. After she disclosed, the director decided to get rid of her because she was suspected of transmitting HIV to children. After she was dismissed they refused her request to provide proof of employment. Faced with so many injustices, she confided in me and I immediately shared the information with PG. She has since received support from the legal service's lawyer who has managed to obtain compensation for wrongful dismissal.

This panoramic vision is intended to be both sectoral (the health sector), multisectoral (health but also human rights and discrimination) and spatial, with a wide national coverage. Zoom and wide angle are complex to handle simultaneously: the challenge is to combine a near vision focused on a pandemic and/or a particular problem and a panoramic vision at the scale of the health system.

The daily work of an observatory: the case of Médecins du Monde in Madagascar



A peer interviewer gathers the opinion of Jessica, a transgendered personne from Majunga. The HIV Observatory in Madagascar made it possible for this interviewer to get in touch with many MSM and key populations.

With his team of interviewers and supervisors, the focal point from Tamatave checks the field reports; a crucial activity for quality control. It's a tedious task as he has to check about ten tablets every week.

A sex worker, who just got an HIV test, receives pretest counselling. The interviewer watches and records indicators related to the patient's care in her tablet.

The data collector interviews a MSM who talks about his experience of stigmatisation and his fear of the HIV test. A bond of trust has established between the interviewer, also a MSM, and the man.

PART 03

A converging effect: moving towards an "observatory culture" at all levels?

For all the people mobilized by the observatory, it is a source of transformation, at an individual level as well as at a more structural and collective level. Far from being mere relays. The role gives them renewed commitment in their professional practice or as a user who is involved because they want access to health. Can we therefore talk of an emerging "observatory culture"?

Empowering citizens to express their rights to health

In parallel with collection activities, sensitization sessions and other educational talks, provided by psychosocial counselors or educators for the benefit of users contribute to improving their knowledge on their rights and duties in the field of health. Using other awareness channels, such as radio, can also help reach a wider audience.

Users who are informed are able to demand that the law be respected: vigilance about the fact that certain medical procedures are free is a good example of users having more power and being aware of things being falsely charged.

TESTIMONY

FROM A *SENTINELLE* IN BURKINA FASO

Being able to resolve a situation in 2016 made me happy. Several pregnant women attending a health center outside my area told me about a case where HIV testing was charged at 500 CFA. I reminded them that pregnant women receive free care and I went with them to the health center to report this issue to officials. The issue came about due to the lack of knowledge of a trainee about free services. Even though I wasn't involved with this center, I had the courage to face them thanks to RAME. The community has a voice that it can use. For the welfare of the community, we will not limit the areas of intervention. We will always be there for them.

Through these trainings, citizens are also encouraged to get involved in the observation mechanism, by raising their own issues, for example via a toll-free telephone number. A culture is growing due to a sense of accountability of the health authorities, dialogue between providers and patients and compliance with health legislation. Empowerment generates empowerment: “Knowing my rights has allowed me to help others,” said a user at the Regional hospital center, in Burkina Faso.

A new professional commitment for healthcare providers

Several observatory models — such as TAW or OCASS — rely on the day-to-day involvement of health workers: psychosocial counselors, nurses, midwives, etc. For these professionals, the link between the job and the role of observer is clear. Their close link to patients and support they provide them over time means they are informed about various issues that could compromise compliance: lack of order, legal issues...

"It was in this same office that a woman was tested and was given her ARVs. If she has a problem, she always comes back to me," says a sentinelle in Cameroon.

The observer role also gives them a special position and responsibility with the patient community. Many testimonials from psychosocial counselors highlight this: *"I am the eyes of those who cannot see"; "My role is to help people express themselves. I get information and I can raise the issue to find a solution. I can carry a message for the community."*

While professional commitment and activism can go hand in hand, speaking about it can be sensitive. Discrimination alerts can result in observers coming into conflict with their line management and the support of organizations leading the observatory is crucial to protect people and find solutions.

HEARING FROM THOSE INVOLVED

In 2016, I experienced something that brought me to tears! One morning, a nurse made this announcement: HIV-positive women who come to give birth must come with a bowl and bleach if they want to be seen [supposedly to limit the risk of contamination]. This news totally destroyed me. What had been announced was like telling patients to get out! I put my work at stake: it was out of the question that they should come with a bowl; it is discrimination. If it is necessary to do it, then the center should buy bowls!

My boss told me that I shouldn't oppose the decision of the administration. I even received a warning. I presented my arguments to explain why I was against it. I said I was ready to fight to the end, to stop my work: I who defend PLWHA, I could not accept such an injustice!

I called Positive Generation to report what was going on. The PG team went into the center, advised me to stay calm. These practices have since been banned. My boss told me that he never wanted to see these discriminatory practices again in his center.

A sense of accountability among health facility managers

If, at first, the presence of an observatory can frighten the staff of a health structure and generate mistrust among managers, it quickly becomes recognized and demanded for its usefulness.

EXAMPLE

In Cameroon, knowing that *sentinelles* and observers were operating in their services raised some concerns among health care providers. However, in the long term opinions have changed and the observatory has been gradually accepted and recognized by the health authorities. These are the words of a *sentinelle*: "The people in charge are aware of the work of Positive Generation, some of them share information themselves. Although in the early days, the issues that were raised caused disruption, now our leaders use this information to produce reports and wait for follow-up".

The observatory creates a sense of responsibility within teams that become more aware of the damage caused by negligence. The observatory puts on the table, makes visible situations that compel all stakeholders to get involved and find appropriate solutions.

TESTIMONY

FROM A MEMBER OF THE DIRECTION RÉGIONALE DE LA SANTÉ IN BURKINA FASO

There are many problems within health centers, for example the transition to free services was not well prepared, and it led to an increase in attendance at health centers and stock-outs. We pointed it out but politicians do not listen to us, but they are afraid of civil society. The work of the observatory helps us, we rely on it.

For such a culture of dialogue to spread, a first work of pedagogy and communication is essential to make the observatory understandable, to show that it is not a gendarme who would control the work of health workers but on the contrary, a partner to improve the quality and access to care.

Observatories find their legitimacy based around three central pillars: respect for the law by highlighting the importance of having public policies applied; its direct role in resolving flagged issues; its openness to all actors in the health system, from patients to health facility managers, through a culture of dialogue.

FROM EVALUATION TO COLLECTIVE LEARNING...

OCASS, which was subject to an evaluation in November 2017, has contributed to improving the accessibility and quality of care services: thanks to educational talks, improved patient experience (patients queues have decreased in all three countries); the supply of inputs and drugs has improved (the number of input stock-outs has decreased); as has the equipment available to caregivers (replacement or repaired CD4 machines, for example). Evaluators also observed that changes in health care provider behaviors are more visible when there are regular exchanges between these agents, the data collectors and users, to share and validate collected data.

Conclusion: key questions to guide observatories

When selecting the right model for an observatory, there are several questions identified as key questions for operationalization. They are sorted by theme below:

Objectives and changes envisaged

- At what level(s) does the observatory want to help change things? Is it primarily about solving local problems or influencing national or even international public policies?
- What do we want to produce? Are the outputs expected from the observatory raw observations or rather analyzed data? Do we only want to identify issues or do we also want to be able to explain them by identifying what caused them? Do we anticipate scientific outputs requiring a standard data collection protocol?

Being able to work: linking with the authorities

- How do we remain independent of the health authorities to preserve freedom of speech and freedom to make complaints while having access to the reality on the ground and being able to observe it?
- How do we create a framework for dialogue with the health authorities to discuss findings and analysis, and then develop solutions together to improve the situation?

Being able to work in the long term: community integration and sustainability

- How will citizens participate in the observatory and what will be the purpose? What scale of citizen participation is envisaged (quantity), type ("contributory" participation only or working together), at what level (citizen contribution to observation, integration of civil society in use of data to put pressure on authorities)?
- How will we ensure the sustainability of the observatory, especially when there is no project-specific funding?

Ensuring the quality of data produced

- How will we collect quality data? What mechanisms will be put in place for operational collection (protocols, recruitment, training and monitoring data collectors...), ensuring the effectiveness of investigations, quality control of data?
- How will data be validated? Do we want to opt for internal validation enabled by the design and the rigor of the protocol, triangulation of information, or external validation, through resources external to the observatory?

The answers to these questions do not necessarily match a given model but these are all questions that we must ask ourselves in order to work out the type of observatory model we are aiming for. We will come back to these questions, how to ask them and how to respond to them, in the practical guides.

A final word from... Eric Fleutelot, Director of the 5% Initiative

The 5% Initiative — France's indirect contribution to the Global Fund — aims to improve access to Global Fund financing in eligible countries and to increase the impact of Global Fund grants.

Very quickly, it became a priority to support civil society and the community because their interventions are valuable for the effectiveness of aid provided to countries, but also because, beyond funding, it is necessary to change practices and policies.

Identifying current issues or shortcomings has been a core principle in the community approach to health, along with a desire to regain power over one's own destiny by becoming fully involved in one's own health, the health of one's family and community.

We no longer question whether observatories are relevant or not, but there is still a question on how they should be funded. To ensure that their activities are sustainable, it certainly feels relevant for a tiny part of Global Fund grants to be allocated to observatories. They are dynamic mechanisms, which are increasingly having an impact beyond the response to the three diseases. It is up to each country to decide whether or not to do this.

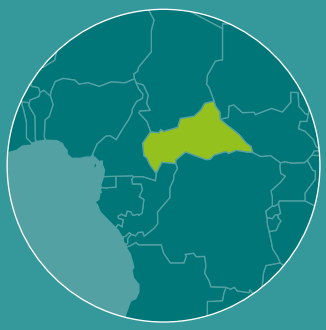
However, this may run the risk of observatories losing their independence. There is therefore not necessarily one simple solution to ensure sustainability, but rather appropriate solutions depending on the country and on the specific observatory.

Finally, this capitalization work, of which this booklet is a step and a tool, shows that efficiency and relevance are potentially at stake when one accepts to have no certainty and when one constantly question oneself.

Through this learning exercise, the 5% Initiative also has a role to play in sharing the results of observatories to further improve the impact of the Global Fund, by bringing these issues to the Fund's strategy and governance discussions. The 5% Initiative is demanding when it comes to impact. We also carried out this reflective learning exercise to better understand the influence that this type of funding could have on the trajectory of observatories to better prevent the pitfalls of instrumentalization. At the heart of this document, the local, civic and participatory anchoring of the observatories remains the cornerstone on which their legitimacy and sustainability can be based.

Who are we talking about?

Organizations that have contributed and shared learning



"TREATMENT ACCESS WATCH"

CENTRAL AFRICAN REPUBLIC

YEAR ESTABLISHED
2016

HOW IT CAME ABOUT
Project funded by the 5% Initiative, model inspired by TAW Cameroon

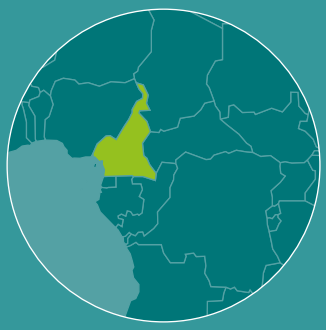
LEAD ORGANIZATION
Association nationale des jeunes femmes actives pour la solidarité (ANJFAS)

SCALE OF MECHANISM
14 health facilities in Bangui

SCOPE OF OBSERVATION
HIV/AIDS, malaria and tuberculosis

COLLECTION METHODOLOGY
- Feedback through monitors / sentinelles
- Face-to-face collection undertaken by peer educators, selected on criteria
- Supervision mechanism

RELATIONSHIP WITH THE AUTHORITIES
Authorization from the Ministry of Health obtained after the launch of the observatory



"TREATMENT ACCESS WATCH"

CAMEROON

YEAR ESTABLISHED
2009

HOW IT CAME ABOUT
Spontaneously through documenting issues based on user testimonials

LEAD ORGANIZATION
Positive Generation

SCALE OF MECHANISM
76 health facilities throughout the country

SCOPE OF OBSERVATION
HIV/AIDS, malaria and tuberculosis

COLLECTION METHODOLOGY
Anonymous large-scale and multi-source collection:
- Monitors: citizens mobilized during educational talks and caregivers
- Members of partner organizations supporting people on treatment, community health workers in hospitals who call the observatory to report issues
- Observers: volunteers who go out to the field to conduct investigations, especially in where there are contradictory sources

RELATIONSHIP WITH THE AUTHORITIES
Informal recognition after the launch of the observatory, made possible by support from technical and financial partners and the proven reliability of the data provided

"TREATMENT ACCESS WATCH"

CHAD

YEAR ESTABLISHED
2018

HOW IT CAME ABOUT
Project funded by the 5% Initiative, model inspired by TAW Cameroon

LEAD ORGANIZATION
Association Djenandoum Naasson (ADN)

SCALE OF MECHANISM
Logone Occidental province - 4 health districts - 56 health facilities

SCOPE OF OBSERVATION
HIV/AIDS, malaria and tuberculosis

COLLECTION METHODOLOGY
Mobilizing monitors and data collectors (psycho-social counselors, health workers, peer educators)

RELATIONSHIP WITH THE AUTHORITIES
Informal contact during the launch of the observatory

OBSERVATOIRE COMMUNAUTAIRE SUR L'ACCÈS AUX SERVICES DE SANTÉ (OCASS)

BURKINA FASO

YEAR ESTABLISHED
2012

HOW IT CAME ABOUT
Spontaneously documenting issues based on user testimonials in 2003, with the support of MSF; model inspired by the Treatment Action Campaign movement in South-Africa and by the TAW in Cameroon

LEAD ORGANIZATION
Réseau Accès aux Médicaments Essentiels (RAME)

SCALE OF MECHANISM
Nearly 2,000 health facilities

SCOPE OF OBSERVATION
HIV/AIDS, tuberculosis, malaria, procurement and supply chain management, MNCH

COLLECTION METHODOLOGY
Mobilization of monitors (users and care providers) and data collectors (psychosocial counselors, providers and users).

RELATIONSHIP WITH THE AUTHORITIES
Authorization from the Ministry of Health via approval of the collection protocol by the Comité d'éthique et de recherche en santé (CERS), after launching the observatory. Cooperation agreements are being finalized with the Ministry of Health.

OBSERVATOIRE COMMUNAUTAIRE SUR L'ACCÈS AUX SERVICES DE SANTÉ (OCASS)

GUINEA

YEAR ESTABLISHED
2014

HOW IT CAME ABOUT
Project funded by the 5% Initiative

LEAD ORGANIZATION
Réseau Guinéen des Associations des Personnes vivant avec le VIH (REGAP+) and Coalition des femmes leaders de Guinée (COFEL)

SCALE OF MECHANISM
54 health facilities in 8 regions

SCOPE OF OBSERVATION
HIV/AIDS, malaria, tuberculosis, primary health care, maternal and child health, and soon budget monitoring and health system governance

COLLECTION METHODOLOGY
Mobilization of monitors (users of health services) and data collectors (from CSOs and degree-holders or with BTS qualification)

Supervision mechanism quarterly

RELATIONSHIP WITH THE AUTHORITIES
Made contact before launching the observatory, which led to an information letter written by the Direction des Grandes Endémies, to facilitate the relationship between the mechanism and health facility officials

OBSERVATOIRE COMMUNAUTAIRE SUR L'ACCÈS AUX SERVICES DE SANTÉ (OCASS)

NIGER

YEAR ESTABLISHED
2014

HOW IT CAME ABOUT
Project funded by the 5% Initiative

LEAD ORGANIZATION
Réseau Nigérien des Personnes vivant avec le VIH (RENIP+)

SCALE OF MECHANISM
40 health centers in 8 regions

SCOPE OF OBSERVATION
HIV/AIDS, malaria and tuberculosis

COLLECTION METHODOLOGY
Collection undertaken by psycho-social counselors with training

RELATIONSHIP WITH THE AUTHORITIES
Authorization of the ethics committee at the Ministry of Health before launching the observatory

OBSERVATOIRE DE L'ACCÈS AUX SOINS VIH POUR LES POPULATIONS CLÉS

MADAGASCAR

YEAR ESTABLISHED
2017

HOW IT CAME ABOUT
Project funded by the 5% Initiative

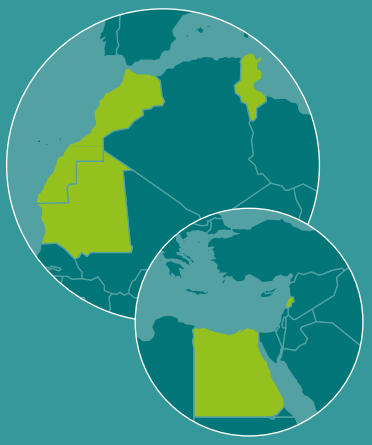
LEAD ORGANIZATION
Médecins du Monde France

SCALE OF MECHANISM
5 cities (Antananarivo, Tamatave, Diego, Mahajanga, Tulear), 44 health facilities

SCOPE OF OBSERVATION
HIV/AIDS

COLLECTION METHODOLOGY
- Regular face-to-face surveys conducted by peers from partner organizations using tablets in locations where key populations meet
- Supervision mechanism

RELATIONSHIP WITH THE AUTHORITIES
Authorization from the Ministry of Health via the Comité d'Ethique et de Recherche biomédicale (CERM) before the launch of the observatory



PROGRAMME FORSS : FORMER, SUIVRE, SOUTENIR

EGYPT, LEBANON, MOROCCO, TUNISIA, MAURITANIA

YEAR ESTABLISHED
2018 (still being established)

HOW IT CAME ABOUT
Joint initiative by Solidarité Sida and ITPC-MENA, funded by the 5% Initiative

LEAD ORGANIZATION
Solidarité sida

PARTNERS
ITPC-MENA, AGD, Al Shehab, ATP+, M-Coalition, RDR-Maroc

SCALE OF MECHANISM
15 collection sites

SCOPE OF OBSERVATION
HIV/AIDS

COLLECTION METHODOLOGY
Field surveys conducted by collectors from partner organizations, using a smartphone application

RELATIONSHIP WITH THE AUTHORITIES
Authorization of the authorities of the five countries before the launch of the observatory

The 5% Initiative support to observatories

9 projects funded

Country	Lead	Partners	Date	Funding
Cameroon, Central African Republic	Positive Generation	ANJFAS	2014 - 2017	€776,892
Cameroon, Central African Republic, Chad	Positive Generation	ANJFAS, ADN	2018 - 2021	€846,698.20
Burkina Faso, Guinea, Niger	RAME	REGAP+, RENIP+	2014 - 2017	€900,000
Burkina Faso, Guinea, Niger	RAME	REGAP+, RENIP+	2018 - 2021	€1,498,835
Benin, Niger	CeRADIS	LASDEL, MVS	2014 - 2017	€770,000
Democratic Republic of Congo	Médecins du Monde	UCOP+, FOSI	2013 - 2015	€521,301
Madagascar	Médecins du Monde	AINGA/AIDES, MADAIDS, AFSA, Solidarité des MSM	2017 - 2019	€787,500
Egypt, Lebanon Morocco, Mauritania, Tunisia	Solidarité Sida / ITPC MENA	ITPC-MENA, RdR-Maroc, M-Coalition, ATP +, Al Shehab Institution for Compréhensive Developement, AGD	2018 - 2021	€1,878,234
Burkina Faso, Cameroon	CHMP	RAME, Positive Generation	2019 - 2022	€600,000

3 technical support assignments

Project title	Beneficiary	Days of expertise	Date	Financement
Support for capacity building of ANJFAS	Positive Generation	50	2017	€58,670
Support for re-design and re-planning of the second phase of the Treatment Access Watch (TAW) project	Positive Generation	24	2018	€39,329
Support for RAME Observatory replanning workshops	RAME	28	2018	€25,785

Acronyms

AFAFSI: Association des femmes africaines face au sida

AGD: Association des Gestionnaires pour le Développement

ANJFAS: Association nationale des jeunes femmes actives en solidarité

ARV: Antiretrovirals

ATP+: Association tunisienne de prévention positive

CBO: Community-based organization

CCM: Country Coordination Mechanism

CeRADIS: Centre de réflexions et d'actions pour le développement intégré et la solidarité

CHMP: Centre humanitaire des métiers de la pharmacie

COFEL: Coalition des Femmes Leaders en Guinée

FOSI: Forum Sida

GF: Global Fund to Fight Aids, Tuberculosis and Malaria

HF: Health facilities

ITPC: International Treatment Preparedness Coalition

MCW: Maternal and Child Welfare

OCASS: Observatoire Communautaire sur l'accès aux services de santé

PG: Positive Generation

PLHIV: People living with HIV

RDR-Maroc: Réduction des risques Maroc

REN-LAC: Réseau national de lutte anti-corruption

RAME: Réseau Accès Médicaments Essentiels

REGAP+: Réseau guinéen des personnes affectées avec le VIH

RENIP+: Réseau nigérien des personnes vivant avec le VIH

TAC: Treatment Action Campaign

TAW: Treatment Access Watch

UCOP+: Union Congolaise des Organisations de Personnes vivant avec le VIH

UHC: Universal Health Coverage

UNAIDS: Joint United Nations Programme on HIV/AIDS

WHO: World Health Organization

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The Ink Link / Héloïse Chochois

Contributing organizations:
ADN, AFSA, Ainga Aides, ANJFAS, CDN, CHMP, COFEL, ITPC MENA, Mad'Aids, Médecins du Monde, PG, RAME, RENIP+, REGAP+, Réseau Madagascar Solidarité des LGBT, Solidarité Sida.

The learning process

2013

The 5% Initiative launches a call for projects on the theme of "Governance", after which four projects to launch or strengthen observatories are selected: the TAW observatory, in Cameroon, Central African Republic and Chad; observation of CeRADIS in Benin and Niger; OCASS in Niger, Guinea and Burkina Faso and finally an observatory led by Médecins du Monde in the Democratic Republic of Congo.

2016

Following a call for projects on the theme "marginalized populations", the 5% Initiative funds an observatory focusing on access to HIV care for key populations in Madagascar.

2017

A cross-cutting evaluation of the experiences of observatory projects carried out by PG, RAME and CeRADIS; Selection of two new observatory launch projects, supported by Solidarité Sida / ITPC and the CHMP following a call for proposals on strengthening health systems.

April 2018

Launch workshop for the learning exercise from which several common issues were identified, in Bordeaux, during the AFRAVIH conference.

September 2018 - March 2019

Field assignments in Burkina Faso, Cameroon and Madagascar to gather the experiences of people in the field working with observatories on a daily basis.

April 2019

Learning workshop in Paris bringing together about thirty participants representing 9 older and more recent observatories, at the end of which around fifteen experience documents were produced.

This learning document is the result of a collective process, bringing together more than thirty actors in the field, the 5% Initiative team and Expertise France Health Department's Pôle d'Appui technique et transversal and the project evaluators (Cabinet COTA). It has been coordinated and written by Perrine Duroyaume, Hélène Gombert and Jean-Eudes Beuret.

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