

Mobilize

Train

Collect

Position


Report back

Influence

COLLECTIVE LEARNING

Community health observatories

Practical Guides



The 5% Initiative was launched in 2011 and is France's indirect contribution to the Global Fund. Its mission: to support eligible countries – francophone countries in particular – to develop and implement Global Fund-supported programs. The 5% Initiative's work takes three forms.

By mobilizing qualified experts for short-term assignments, the program is able 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.

The 5% Initiative also funds 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 policy and/or 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 implementation of the 5% Initiative is led by Expertise France, the French public agency for international technical assistance.

COLLECTIVE LEARNING

Establishing and running a community health observatory

Practical Guides



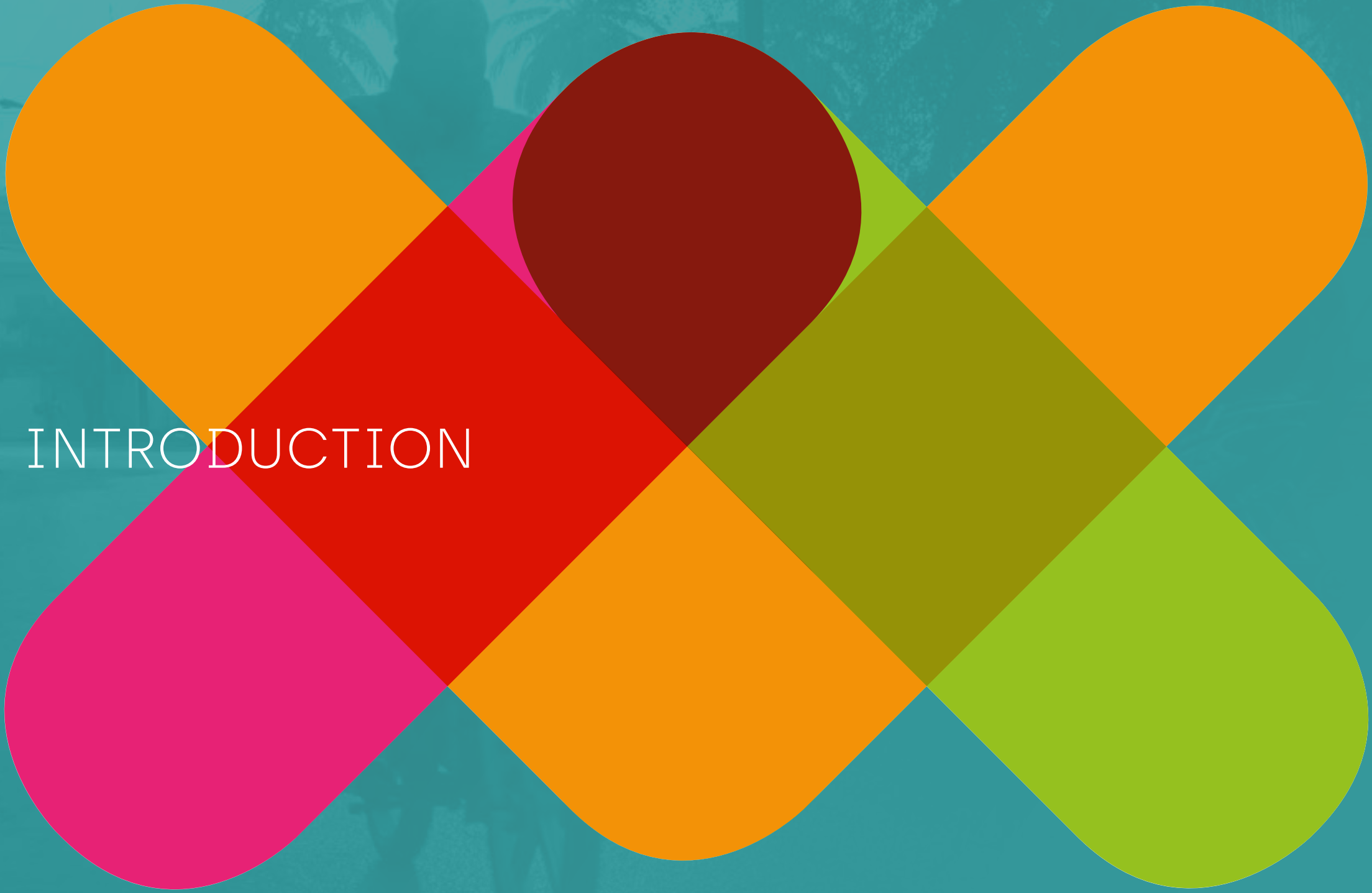
COLLECTIVE LEARNING

Establishing and running a community health observatory

**Practical
Guides**

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INTRODUCTION

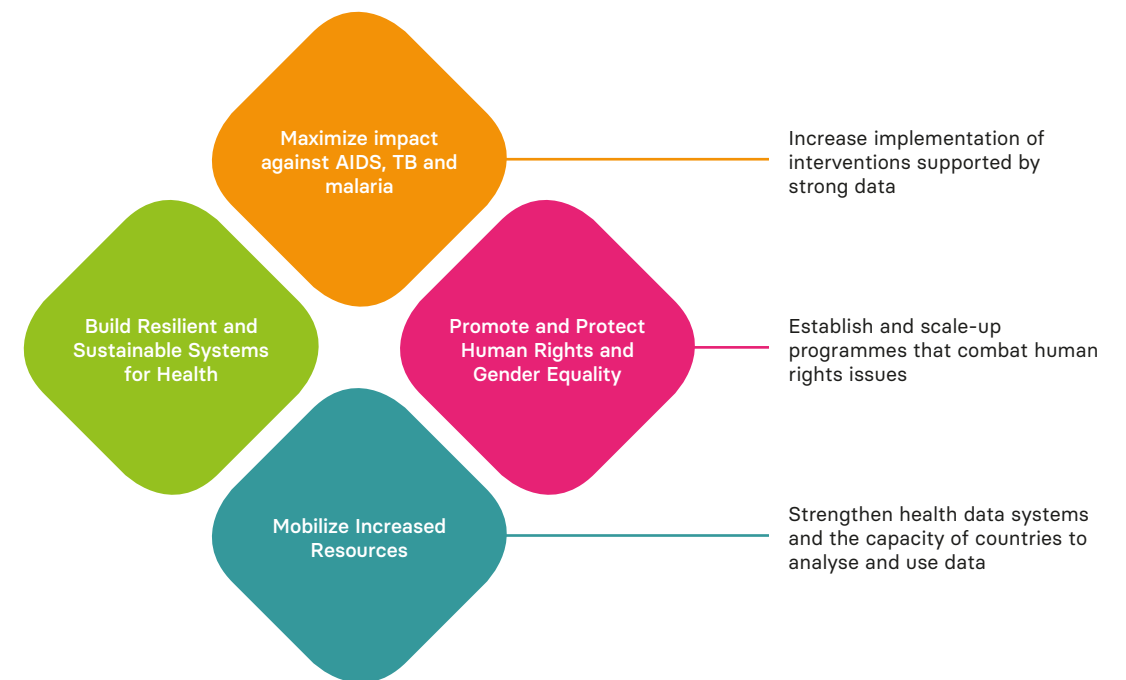
Observatories at the crossroad of strategic health system challenges

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.

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

Global Fund strategy



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.



➤ 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.

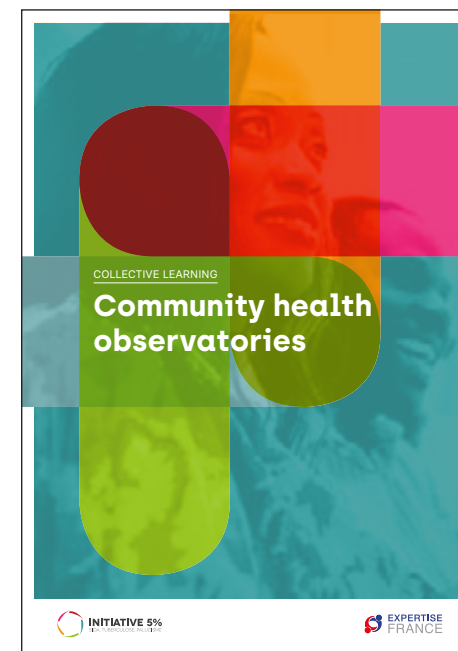


"OUR DIFFERENCES ARE OUR RESOURCE"!

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 document for? What does it contain?

Learning means placing key actors at the center 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 provides a critical objective 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 collection of six practical guides provides those interested in setting up an observatory with concrete benchmarks around data collection, training, mobilization, reporting, positioning and advocacy.
- There is also a booklet that accompanies these guides, which provides an understanding of observatories, their differences, the things they have in common and how they operate. It is aimed at a broad readership, for people that would like to understand the essentials of these innovative mechanisms in just a few pages. This document is the result of a collective learning exercise and combines definitions with insights from those involved in running observatories on a daily basis.

GUIDE 01 MOBILIZE

Observatories are essentially a product of citizen mobilization, to defend the rights of people who use health systems. Users and health service staff are fundamental cogs in this wheel. Even when data collection is carried out by trained and / or paid data collectors, users play a key role reporting things that aren't working well.

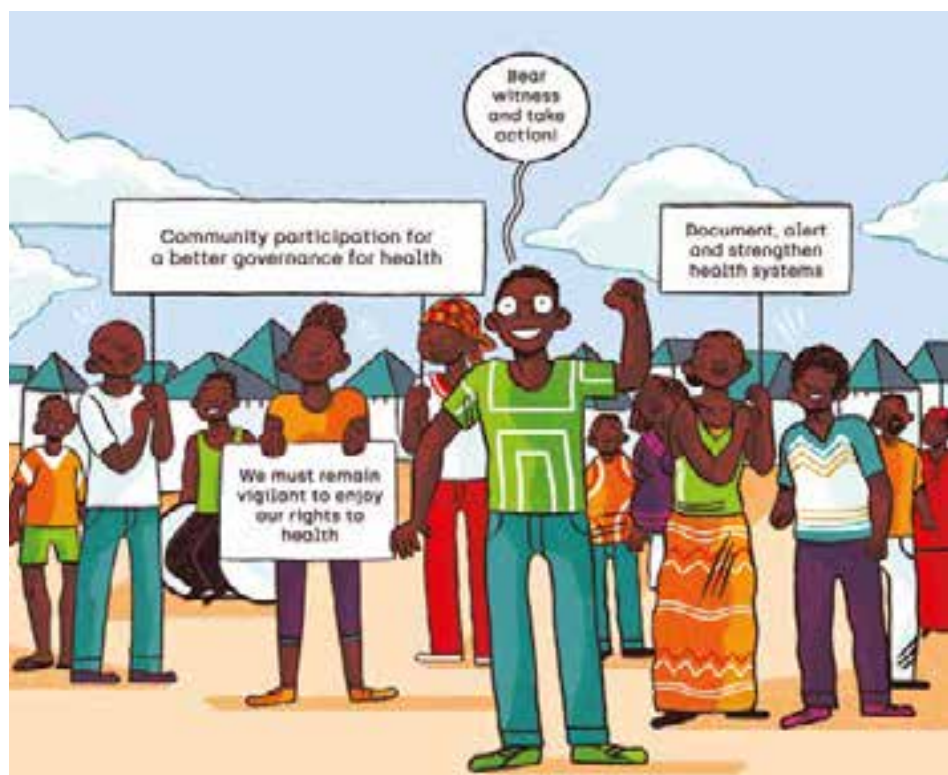
It is therefore necessary to stimulate mobilization, so that this watchdog approach is ubiquitous and continues for as long as possible, in different locations over time. Working with users who self-mobilize also makes it possible to reduce the observatory's dependence on external funding. It is important to also note that feedback mechanisms for citizens - such as toll-free telephone lines, apps... - will be ineffective if people are not informed that they exist. It is therefore a question of creating both a culture of observing and sharing information among citizens and a culture of accountability among the public services.

How to mobilize? Which audiences to target, in what locations and when? What materials and tools to use?

01

How can citizens be involved as widely as possible in an observatory's mission?

In all observatories, citizen mobilization is focused primarily on defending the rights of people who use health systems. Once users are aware of their own rights and of the fact that health services are obliged to be accountable, they are better able to defend their rights and take on an observer role. However, this requires awareness and training. Many different methods and opportunities are harnessed to mobilize people: the experience from Cameroon below demonstrates some of these.



TREATMENT ACCESS WATCH IN CAMEROON: VARIOUS DIFFERENT WAYS OF MOBILIZING CITIZENS

In Cameroon, TAW (led by Positive Generation – PG) works with three types of actors: *sentinelles* (health workers engaged to provide feedback), users of health services who approach the observatory directly and observers, who are sent out quarterly by the observatory to validate the information reported. Mobilization efforts relate primarily to the first two categories: the challenge is to mobilize as many people as possible.

METHODOLOGY

Various different methods are used to mobilize and recruit people:

- Calls for applications - for data collector positions or to work as an observer - posted in hospitals, in markets, in places where people meet;
- At the observatory: people approach PG of their own accord to become observers, because they have heard about the observatory in the media;
- Improvised meetings in the field, around health centers and in places where people gather: "we find a group of people and we start a discussion. Then we begin to explain";
- Educational talks: providing information at the end about the right to health and existing norms.

SUCCESS FACTORS

It can be useful for observatories and / or the organizations that runs them to be in the media. Through campaigning and media activity, PG promotes its work to users, who come to speak to the organization of their own accord. However, it is also necessary to meet users in the field, outside of the hospital, where people gather. Mobilizing people in this way requires an all-round approach and its effectiveness depends on using various different complementary methods.

To learn more about TAW's multi-source data collection approach, read the « **Collect** » guide.



02

Observatories and the media: what are the potential partnerships and to what effect?

Visibility is a major challenge for observatories: they need to integrate themselves into health systems, but they can only play their role as a key point of contact and coordination if they prove themselves in the eyes of healthcare providers, patients, users and the authorities as a legitimate and essential actor. In this way, engaging the media, whether it is in print, online, via radio or through social networks, may be a relevant approach.

In addition to using the media for visibility and communication purposes, observatories can also use it as an awareness-raising channel for citizens. Several observatories have used radio to mobilize citizens as "monitors", particularly where conflicting information exists, or citizens are not informed about the measures that are deemed to facilitate their healthcare access.



BURKINA FASO: RECORDING A RADIO PROGRAM TO SENSITIZE USERS

In Burkina Faso, the authorities introduced free healthcare in 2016 for children under five and pregnant women. However, users were unaware of which medication, services and age groups this change related to. In addition, some health workers took advantage of the lack of clarity and were charging for free services: "placing a stone in your file" was the expression used to describe health staff taking under the table payments. To address this tangible lack of information, RAME (Réseau d'Accès aux Médicaments Essentiels) recorded a radio program to discuss free healthcare, among other things, and also to present the observatory's work.

METHODOLOGY

The observatory made sure that health staff were involved: a health center manager took part in the show, along with three members of the observatory (RAME focal person, RAME program manager and a data collector). They also used the program as an opportunity to promote a toll-free telephone line for users to report violations of their rights. The program consisted of an interview between the radio host and the guests. One single broadcast was planned initially on the most popular local radio station, but the program was in fact broadcasted several times, in the local dialect, including during peak hours.

IMPACT

A health center manager noted an increase in attendance and observed improved relations between users and care providers, with fewer complaints from users and a decrease in the number of poorly referred people (i.e. referrals to services that did not fit their needs or experiences of interrupted care). There was a real need for information because the radio show decided to rebroadcast the program various times over several months, which was not initially requested by RAME.

SUCCESS FACTORS

In order for radio awareness-raising to be successful, it is necessary to:

- ▶ Consider the target population and tailor the content of the message;
- ▶ Involve the health authorities in the process;
- ▶ Have multiple broadcasts, with different terms and / or formats. i.e. don't just share the message once;
- ▶ Combine this activity with others, plan multi-channel interventions (radio, toll-free telephone line, etc.). The radio program will inform people, but this is not sufficient: it needs to be combined with giving people access to a toll-free telephone line, so that any issues can be reported.

A strong argument for using radio is that it is efficient: educational talks are expensive, especially when participants ask for expenses. Using radio to broadcast awareness messages, for issues such as access to free care, requires relationships of trust to be established to convince listeners: it is necessary to lay the foundations by going to meet users or organizing meetings and opportunities to share.

The stakes are high as this type of program can really leverage recognition for the observatory and establish a link and a framework for dialogue with the authorities. For example, in the Central African Republic, ANJFAS (Association nationale des jeunes femmes actives en solidarité) spoke out on the radio to inform people about free medication funded by the Global Fund. Following this, the Prime Minister asked the observatory for information to go directly to him rather than publicly announcing things that aren't working on the radio, which made it possible to quickly obtain an appointment high up in government. This was an unexpected effect, which was very useful for the observatory's recognition, and which saved valuable time in terms of advocacy.



TAKEAWAY POINTS

- ▶ **Work with local media** to increase visibility and encourage spontaneous mobilization of users
- ▶ **Make use of all spaces** where citizens meet to engage in discussion to build citizen confidence
- ▶ **Inform and educate citizens** on the existence of legal norms that frame health systems to enable them to gain autonomy in demanding that their rights are respected
- ▶ **Use radio** to regularly broadcast awareness messages and present the observatory's work
- ▶ **Use various mobilization channels** to reach as many people as possible (toll-free telephone line, educational talks, posters, leaflets...)



GUIDE 02 TRAIN

As we know, there are many different actors working with observatories - data collectors, monitors, supervisors, etc. - and each group requires a different kind of training. The trend towards these roles becoming more professionalized or technical also raises questions: do we risk moving away from the initial spirit in which observatories were created to involve citizens and users of health services as being central to evaluating and improving delivery of care? It is therefore necessary to look at the training methods and how we select the different actors.

01

Going from being a user to a stakeholder making demands: training citizens

Observatories that rely on spontaneous feedback from users of health services must consider crucial questions around training and awareness-raising of users: what messages do they need to convey? In which language? Where should they conduct talks for the greatest impact?



POSITIVE GENERATION IN CAMEROON: COMBINING TRAINING AND MOBILIZATION

The PG observatory has often been cited as a model of citizen mobilization: it is primarily users of health services that contact the observatory to provide information on the services they have received (as part of a program called "feedback"), as well as people working in the health system (called "sentinelles"). This monitoring function is supplemented by quarterly observations carried out by people with a higher level of training, who validate the data received by cross-referencing the data sources and dig deeper into the reasons why the issues reported occurred.

METHODOLOGY

User training is combined with pre-existing educational talks: for example, a condom awareness session will end with a section on the right to health. Particular emphasis is placed on knowledge about the legal framework that sets out citizens' rights: PG photocopies documents and distributes them to encourage users to independently demand that their rights are respected and demand accountability.

IMPACT

"It was at a time when there were fewer stock-outs, but still extra costs were being charged to patients and treatment was being provided without the necessary consultations. One day, a patient living with HIV was billed 2,500 FCFA for a CD4 test, although the law sets the cost at 1,000 FCFA. Based on what is stipulated in legal documentation, the patient refused to pay this price despite staff and the director of the hospital being inflexible. The rates were subsequently changed, and a new director was selected because of the bravery of this user. This gentleman embodies our vision! »



Mobilizing users of health services requires designing training and awareness programs adapted to local contexts: it is necessary to take into account the level of literacy, the local language or languages and collective semantic codes to ensure the messages shared by trainers are well received and understood. These citizen awareness programs also need to be flexible and adapt to both positive and negative feedback from people who receive training.



RAME IN BURKINA FASO: DESIGNING ADAPTED TRAINING MATERIALS

In Burkina Faso, OCASS (Observatoire communautaire sur l'accès aux services de santé) mobilizes psychosocial counselors who conduct systematic data collection and also build the knowledge of users around their rights and duties. In order to do this, RAME decided to use a specific tool adapted to the low literacy level of users: an image box.

METHODOLOGY

The image box was developed based on the National Charter of Health Service Users, which is not translated into local languages and has not been widely disseminated. In collaboration with the DPS (Directorate of Health Promotion), RAME adapted the content of the charter into images to make it understandable for all. The image box is accompanied by a user guide and was used during educational talks on the rights and duties of users, which mainly took place in health facilities. The health facility managers supported the process by getting involved in programming the talks and the health workers helped to mobilize users.

IMPACT

According to health workers, these sessions improved communication and relationships with patients and care providers. The data collectors found interviews with users easier and found they were more reactive when answering questions and they reported their own observations more readily. In Bobo Dioulasso, the focal point (REVS+) had to request more image boxes to meet the needs of healthcare providers and facilitators who wanted more sessions in health facilities.

SUCCESS FACTORS

The fact that a national reference document (the users' charter) was used helped the observatory's activities to be accepted by the health authorities. Involving health care providers also provided the awareness sessions with scientific backing, adding legitimacy. Repetition of the messages shared - the image box was available in form of posters displayed in health facilities - and the fact that they were translated into local languages contributed to strong ownership among users of their rights and duties in matters of health.



The talks were key to create a relationship of trust between the health authorities and the observatory. For OCASS, they are an opportunity to discuss 5 priority issues: the right to access health services, the right to good service experience, the duty to respect the facility's operating rules, the duty to be courteous to health staff and the duty to ensure the premises are kept clean. In other words, there was a significant focus on the duties of users, which was appreciated by health workers. In Burkina Faso and Niger, talks are facilitated by two psychosocial counselors and a health worker.

There are two underlying issues to be mindful of in terms of user awareness, regardless of the format or the materials used. Firstly, assessing the effect of training remains a challenge (assessing changes in perception and behavior is a long and often costly process). Secondly, training for psychosocial counselors responsible for leading the talks should not be neglected: if they do not have a good grasp of the knowledge they are supposed to disseminate, the awareness session may not be successful.



02

Training data collectors: who to train and how?

Recruitment

Among observatories that both mobilize users and use data collectors, whether they are paid or receive expenses, training seems to be a way of ensuring that the data collected is of good quality. The profile of data collectors differs from one observatory to another: each sets different recruitment criteria according to the expected technical level. For some, a minimum level of education is not required, as people who are willing to engage may be excluded (the need for a diploma is seen as the "the nail in the coffin of citizen engagement"). For others, data collectors must have a minimum level of education because their role is not only to collect data but also to take steps to resolve the issues raised.



DATA COLLECTORS AT COFEL IN GUINEA: RECRUITMENT CRITERIA, A STEERING COMMITTEE AND A CHARTER

After the first phase of implementation, COFEL (Coalition des femmes leaders de Guinée) drew out crucial lessons to improve the recruitment and training of data collectors. Those selected previously sometimes lived too far from activity sites, which delayed or jeopardized data collection; some did not have a high enough literacy level to initiate the process of resolving issues raised.

WHO TO RECRUIT?

Now a set of criteria is used: to be a resident, to have experience in psychosocial support, to be able to ensure confidentiality of the data provided to them, to be comfortable speaking, to be fluent in national and local languages, to have completed high school. In addition, it was recommended to involve peer educators from key population groups in the collection process. 80% of data collectors are women and the majority were people living with HIV (PLHIV).

HOW TO RECRUIT?

A steering committee has been set up to ensure transparency in the recruitment process. It is composed of civil society organizations (CSOs) and technical and financial partners who are observer members. The steering committee approves recruitment adverts and meets to review the applications received. Direct links for CSOs who are both members of the steering committee and providers of data collectors have been formalized to avoid conflicts of interest. A charter is also in place to protect data collectors: it is a contract between the collector, the organization they belong to and the observatory, which gives right of scrutiny to the observatory in case of difficulties.

Representation of key populations as data collectors is also crucial to understand any discriminatory practices that may exist. In Madagascar, the observatory trains peer educators from vulnerable population groups. They are selected based on terms of reference drawn up in consultation with all partners: he or she must have a direct proven link with key populations (sex workers (SW), injecting drug users (IDU), men who have sex with men (MSM) and PLHIV) and be able to guarantee the confidentiality and privacy of the people surveyed and the safety of equipment. A certain compromise must therefore be found between representation requirements among the data collectors (PLHIV for an HIV collection) and requirements for quality data.

Training

Depending on the time and resources devoted to training data collectors, they may be trained in the use of data collection forms, facilitating talks or to look more in-depth at issues relating to ethics and confidentiality. Involving supervisors, beyond the initial training, can make it possible to evaluate the work of data collectors, to continue their training and to adapt the activities of the observatory to the reality on the ground.



GUINEA - ADAPTING TRAINING THROUGH SUPERVISION

Data collectors selected by COFEL were trained for five days. This initial training was supposed to focus on understanding the observatory's work, collection forms, educational talks, the rights and duties of users and gender. However, the time allocated meant that not all these themes could be covered, and priority had to be given to understanding how the observatory works and to the data collection tools.

PROVIDING ONGOING TRAINING: REFRESHER TRAINING AND TRAINING SUPERVISION

Refresher training is planned once during the three-year project and support and supervision assignments are planned each semester. A supervisor was therefore able to observe that the data collectors

had not understood the frequency of data collection and each month they provided data that had to be collected each quarter. Data collectors were also able to point out to their supervisors that the frequency of educational talks, which were supposed to take place once a quarter, was not sufficient given the needs reported by users and health providers.

There are limitations in this example in terms of training for supervisors. The training cascade (who trains who?) needs to be planned taking account of each person's abilities. Providing supervision involves a significant cost that not all observatories can take on.



BURKINA FASO - SKILLS TRANSFER BETWEEN OLD AND NEW DATA COLLECTORS

RAME is responsible for around a hundred data collectors, working in nearly 2,000 health facilities - three times the number compared to when the observatory was created - and has had to tackle the issue of how to train them with limited resources. Transferring experience between new and old data collectors has emerged as an effective and efficient solution.

METHODOLOGY

RAME created an experience transfer form that had to be completed by the old data collectors: it included questions around their motivation for collecting,

successful experiences and things that hadn't gone well, as well as practical advice based on their experience. Four days were devoted to training new data collectors. They were first given a



presentation on the collection process and went on a field visit and following this there was time for sharing and discussion between old and new data collectors. At the end of this workshop, a practical document was put together and was distributed to all the data collectors. Thirteen of the old data collectors were also selected to provide ongoing supervision.

IMPACT

This training method has proved particularly useful to reassure new data collectors. Benefits have also been observed for the old data collectors, who appreciated the opportunity to express themselves, they felt valued and took greater ownership of their observatory role. The turnover of data collectors has decreased.



TAKEAWAY POINTS

- **Continue user awareness activities**, even if data collection is carried out by data collectors: "what you don't know can't hurt you!"
- **Ensure that the messages shared are well understood by recipients**, in terms of language, level of literacy and their practices
- **Involve the health authorities during talks**, in order to create a relationship of trust between the observatory, the health centers and decision-makers
- **Set up a system for skills transfer** and experience sharing between old and new data collectors, where there is a high turnover of collectors
- **Make sure you have a plan in place to adapt the training provided**, where necessary – supervision training, refresher training or feedback forms - whether training citizens or data collectors
- **Find a compromise** between the representation requirement for data collectors in terms of the target group (peer-investigator) and the level of training expected: if the data collectors are not peers, it is necessary to make sure that the experiences of vulnerable groups are integrated in another way (e.g. through partnerships with organizations representing vulnerable populations).
- **Introduce a "data collector charter"** to protect data collectors from possible tensions with the organizations they belong to.

GUIDE 03 COLLECT

Data quality and usefulness is a priority for observatories, as it is both the basis of their legitimacy and lays the foundation for advocacy and behavior change.

How to undertake data collection while ensuring the safety of collectors? What data validation or verification mechanisms should be put in place? What tools should be used?

01

Implementing a data collection process and defining a methodology and tools to use

Survey-based or multi-source data collection?

- There are two ways for observatories to define their source (or sources) of information, which are dependent on the human and financial capital they have available and on their relationship with the authorities:
- Multi-source collection**, based on multiple informants, with different profiles: users, patients, health workers, psychosocial counselors, etc. Having multiple points of view will allow for the triangulation of the data.



- Data collection based on field surveys** by data collectors. Data collectors make visits to health facilities and conduct interviews using pre-determined collection forms to enable monitoring of specific indicators that represent a health facility's status. This is the approach used in the Central African Republic and Madagascar, for example.



USING MULTI-SOURCE DATA COLLECTION: CASE STUDY ON TAW IN CAMEROON

The approach used is to mobilize a large number of citizens and health workers, known as "*sentinelles*".

METHODOLOGY

PG began by sensitizing members of patient support groups to use a helpline to identify problems encountered around care, treatment or the way people are treated at health facilities. Psychosocial counselors, who regularly interact with people who have recently been tested at these organizations, were also involved. Finally, users were also approached during sessions

that provide information and citizen education on the right to health. In addition to being multi-source, data collection is also anonymous. As it is not possible to verify the information directly from the sources, it is all the more important to use multi-source data collection to ensure data is reliable by checking it through triangulation: it is the consistency of information provided by several independent sources that validate the information.

Anonymous observation or non-anonymous data collection

Some observatories prioritize protecting their sources, for example in hostile political contexts. Non-anonymous data collection can create problems for people who openly report issues. In Cameroon, after the observatory reported issues to the National AIDS Council, certain health care providers began contacting the observatory. Treatment Access Watch (TAW) tried out a feedback mechanism that guaranteed the anonymity of people raising issues. The preferred feedback channels were helplines or radio programs, where listeners can participate.





THE EXPERIENCE OF NON-ANONYMOUS DATA COLLECTION IN THE CENTRAL AFRICAN REPUBLIC

ANJFAS works with observers who operate openly in health facilities. They must know how to read and speak French, have a minimum level of schooling of up to 9th grade and have experience of one of the three pandemics. Most of them are peer educators. They are supervised by TAW and where issues arise they check the information. Since 2018, the observatory has also worked with *sentinelles*, who observe through their work (at health facilities) and are also non-anonymous.

METHODOLOGY

During on-site visits observers introduce themselves, they explain how they work and show their authorization from the Ministry of Health. They visit each department and ask health care providers about the availability of drugs, inputs, staff presence, and so on. They then survey users to gather their points of view. If the responses of health workers and users differ, the observer will try to confront the issue through questioning or by soliciting a third point of view. During field visits observers display the regulations about free or paid services at the health facilities. Visits last approximately two hours per facility.

IMPACT

Non-anonymous data collection has advantages for ANJFAS, because it allows them to return to the source

if there are questions and to directly speak to users and health staff if there is a discordance. It gives users confidence and it allows observers to do more than simply collect data; they directly tackle issues where they can.

NECESSARY CONDITIONS

The viability of non-anonymous data collection is based on the existence of a legal collaboration framework with the Ministry of Health, and their involvement before the project starts up. According to ANJFAS, if this is followed there may be problems with some health facility officials, but not with the Ministry. Data collection is also often carried out by peer educators who are already known to health personnel.

See the "Train" guide in relation to recruiting data collectors

Where non-anonymous data collection is carried out by someone sent by the observatory, using survey forms, also called collection forms, is crucial for interviews to be conducted properly and for data to later be analyzed.



MADAGASCAR - CREATING A QUESTIONNAIRE ADAPTED TO PEER INVESTIGATORS AND TARGET GROUPS

METHODOLOGY

Developing the questionnaire gave rise to many debates about the appropriate words to use and the relevance of each question. Co-developing the tool is essential. Several validation and revision processes were then carried out (by the ethics and biomedical research committee (CERBM), and by epidemiologists at Médecins du Monde (MdM) France), followed by a translation into Malagasy and a pretest

carried out over one month, which led to other modifications.

CHALLENGES ENCOUNTERED

As soon as the first surveys were launched, data collectors complained about the length of the questionnaires, difficulties in asking sensitive questions, and the fact that they did not manage to keep people who were used to receiving compensation for long - these issues were raised during



the first supervision visit. Most of the recommendations given and the techniques learned during training had not been applied. The question numbers and choice of answers were not understood by the interviewers. Some questions were badly rephrased, and others that were too sensitive, were not asked at all (transgender sex, monthly income, etc.). Many of the answers were in the "other" category, which complicated data processing. Finally, confusion was observed for some interviewers between the role of sensitizer (who influences the person they are speaking to) and investigator (who tries to gather answers as faithfully as possible).

Time is needed to test questionnaires and adapt them to the experiences of data collectors and vulnerable populations. It is also necessary to check the competence of data collectors, not in a theoretical way but through practically carrying out several questionnaires: at least three evaluation interviews in training per investigator is necessary to assess their ability. Data quality must take priority over quantity: questionnaires must be short and be adapted various times in line with feed-back from investigators and respondents.



A READJUSTMENT PHASE

As a result of these observations: the questionnaires were redesigned and the way changes are validated was improved; the size of the questionnaires was reduced; the role of supervisors was strengthened; training was given to tease out more around answers categorized as "other". This has improved the quality of data considerably.

Selecting your data collection tool: the example of using digital technology

Using digital technology (tablets and corresponding software) to carry out surveys and process data has certain advantages: data (alerts) is transmitted instantly, the questionnaires can be adapted into several languages and are available on the same device... However, it is necessary to be very attentive to certain issues such as the choice of IT equipment, the safety of investigators and the equipment and confidentiality around data.



USING TABLETS IN MADAGASCAR: OPERATIONAL PROBLEMS AND POTENTIAL SOLUTIONS

SELECTING YOUR TOOLS

The software that was selected to collect and aggregate survey data is called Kobo Toolbox¹, a free and relatively intuitive piece of software. However, the simplified interface was not fully adapted to the complexity of the questionnaires and the M&E officer had to learn to code for the tool to be fully operational. It is therefore necessary to take time to choose the right tools and software and to have financial flexibility to train someone or mobilize the necessary human resources.

ENSURING THE SAFETY OF PEOPLE AND EQUIPMENT

In order to limit the risk of attack or theft, there were negotiations with people who managed the places where the investigations took place (bars, nightclubs, etc.) and strict rules were imposed: restricted hours, working in pairs, immediately informing managers if threatened. In order to promote ownership of tablets and limit potential damage or misuse, peer investigators were allowed to use them outside of data collection: having a personal interest in owning them meant they

took better care of them. There were also rules relating to this: restrictions around the number and type of the applications installed, limited access to configuring the tablet, no access to modifying questionnaires once interviews were completed. No peer investigators were attacked during the two years of use and only 6 out of 52 purchased tablets were reported stolen.

RECONCILING DATA PROTECTION AND MONITORING

In order to protect the data, MdM made it impossible to review questionnaires once the interview was complete. However, after some questionnaires came back with nonsensical responses, it was deemed necessary for supervisors to have the right to inspect and check questionnaires: the procedure was modified to allow supervisors to check the data before sending it to the server.

1. <https://www.kobotoolbox.org/>

Here again we highlight the importance of having a process to make changes to the approach. In the Madagascar example, it was possible to make improvements by training staff and recruiting a dedicated data manager to verify the questionnaires and validate them. Sustainability beyond the project cycle of an approach of this kind, which is complex and requires flexibility in terms of staffing, is certainly an issue.

 **FOR MORE INFORMATION**

KoboToolBox is a free application that can be used to create online questionnaires. It is available in several languages and is relatively simple.

ODK Collect is an Android application, which is more powerful but less intuitive for users.



TAKEAWAY POINT	
Anonymous observation	Non-anonymous collection
Protects observers, whether they are users or health workers, in challenging contexts.	Assumes establishing a relationship of trust and a framework of collaboration with the authorities.
Is an inclusive approach, which empowers citizens, who become expert patients, and can operate with little dedicated funding.	Enables you to check your sources if there are contradictions and to go beyond pure data collection to identify solutions: observers direct issues and can also resolve some of them.
Multi-source observation	Technology-based systematic surveying
Mixed feedback from psychosocial counselors, health workers, users, etc. through a helpline, an app, a radio program...	Timely visits to health facilities by interviewers who conduct interviews with users and health workers, using digital or paper questionnaires.

Non-anonymous data collection and anonymous multi-source collection are often combined given their respective advantages, with one complementing the other.

 **02**
How to ensure the reliability of data?

Contextualizing and verifying information at the source: ANJFAS does not consider feedback from monitors alone to be sufficient. It is necessary to go on-site to verify the information and gain a greater understanding of the situation directly from the source. Data collectors are operating non-anonymously, they know who has raised an issue and can go back to them if they have questions.

Triangulating data: To ensure the production of quality data in an anonymous multi-source collection context, observatories triangulate data. This involves checking the consistency of information transmitted by several sources that are independent of each other. TAW in Cameroon sends data collectors on the ground every quarter to validate or invalidate information reported. Triangulation of information is also used in non-anonymous data collection, but it plays an absolutely central role in anonymous collection.



Creating a survey protocol: For systematic data collection, a survey protocol can be created to check the consistency of answers to the same question. This is another form of triangulation -internal in this case.

Digital data collection - checking if a survey is genuine: When data collection is done using digital tools, it is possible to use the geolocation data to ensure that the survey has been carried out in the place indicated. It is also possible to see how much time has been spent on each question: time milestones make it possible to check that the interview has taken place, by comparing the time spent on the questionnaire with an average. In Madagascar, Médecins du Monde and their partners realized that several answers to surveys had been fabricated, thanks to the location and duration of the survey being recorded.

Raising awareness among users about their rights and duties: During user awareness sessions, emphasis can be placed on the need to provide reliable information only, which can be verified by their own experiences. Some observatories feel it necessary to conduct an audit while others place their trust in users: "we shouldn't question the reliability of statements given by users; we believe in the user's point of view".

For more information on supervision, see the "Train" guide

Supervising data collection: Supervision may be necessary to check the reliability of data and to improve protocols, where required.

- In Madagascar, supervision made it possible to identify inconsistencies between the data sent by investigators and the health facility consultation registers. When it was necessary to replace a data collector urgently, the supervisor made sure that the investigation was completed and ensured that a new investigator was recruited and trained. Supervision has therefore been essential for monitoring but also to ensure that training continues along the way, which are two elements that contribute to the quality of data collected. In addition to data control and managing data collectors, supervisors also review survey protocols.
- ANJFAS also emphasizes the need for periodic debriefings with data collectors and monitors, for example to redefine terms such as "stock-out" or "unavailability", where they are interpreted differently by health staff and the observatory. Health staff sees a stock-out as being when a drug is no longer in stock, while the observatory sees a stock-out as being when the patient does not receive their medication. This is not the same thing and, therefore, it may challenge the validity of the transmitted data due to the lack of a common language. The terms must be clarified and the protocol adapted.



TAKEAWAY POINTS

- **Put in place** one or various mechanisms to ensure data quality
- **Plan several test phases** in order to arrive at a reliable collection methodology that is relevant and adapted to the practices of the interviewers and to the feelings of the groups surveyed
- If the situation requires a quick response from the observatory, **the data must be at a minimum triangulated.**
- **Put in place, if possible, a supervision mechanism**, which plays a key role in quality control, data collector management and ensuring ongoing improvements to survey protocols
- **Check the skills of recruited data collectors both** theoretically and practically based on scenarios or evaluation interviews
- If using a digital method, **use the monitoring functions** provided by this type of tool (geolocation of surveys, time-based checks of surveys)

GUIDE 04 POSITION

When observatories are created, they become part of a network of many different actors, including government bodies, patient organizations, health centers, etc. As their work depends entirely on the cooperation of these actors, observatories must establish their position by being clear about what they will do and by highlighting the synergies that exist or that need to be created. The challenge is twofold: positioning oneself at the interface between the local and national levels, and even international, in other words between the field and the decision-making powers (vertical positioning) and positioning oneself alongside other organizations supporting patients and health systems (horizontal positioning).

01

Horizontal positioning: the importance of partnership

Observatories are an innovative dynamic and can be perceived as disruptive competitors by existing stakeholders, which could lead them to fail. It may be necessary to hold discussions at various levels to demonstrate the absence of competition and promote the existence of shared benefits.

MADAGASCAR - RESPONDING TO MISCONCEPTIONS

BACKGROUND

In the context where MdM's observatory operates, competition is an issue: among the organizations working to respond to HIV are Global Fund sub-recipients, whose performance is measured, among other things, by the number of people from key population groups who are tested. If they do not meet their agreed targets, these organizations run the risk of being removed and replaced by other organizations. Surveys conducted for the observatory are carried out by peer-interviewers with key population groups, and they sometimes participate in or support testing. This has been perceived as a threat, an intrusion or even "client theft" by some peer educators from sub-recipient organizations. They failed to understand the observatory's aim and its work and saw it as being in competition, which particularly complicated its work.

THE OBSERVATORY'S RESPONSE

In order to reassure the organizations and make the observatory's mission clear, they organized visits to the field. A meeting took place first with the coordination mechanism of the key population organizations, but there was still some confusion. The officials of these organizations were still wary and asked for an official letter to be sent to clarify the observatory's rights, which MdM obtained. The observatory and its partners subsequently held information meetings on how the observatory operates and also invited all Global Fund sub-recipients to attend feedback sessions.

Establishing dialogue between sister organizations makes it possible to highlight common interests and to demonstrate the absence of competition. This is even more important for organizations responsible for collecting specific indicators for the observatory, who in the event of a disagreement may withhold information to put pressure on the observatory.

Establishing good relations enables successful horizontal positioning, but it is also valuable for advocacy. Each organization can take a report and present it at local level by contextualizing it. Consolidating partnerships contributes to observatories gaining recognition beyond the area where they are working, and can even spread the model to other regions.



02

Vertical positioning

"The best guarantee of an observatory's sustainability is it being endorsed by national pandemic program managers and international organizations," wrote OCASS evaluators in November 2017. How then can we establish a stable and quality working relationship with the authorities, without this relationship affecting the independence and freedom of speech of the observatory? Answers to this question differ radically and one is not necessarily better than another: they differ because of the diversity of contexts, the relationship between each organization and the government and each observatory's trajectory.



CENTRAL AFRICAN REPUBLIC: FROM UNDECLARED DATA COLLECTION TO THE CREATION OF A FRAMEWORK FOR DIALOGUE WITH THE AUTHORITIES

BACKGROUND

When it was established in 2016, the observatory did not inform the Ministry of its activities. When it published its first bulletin, the Ministry was surprised, and on the ground health facilities disagreed with the data presented. The bulletin mentioned cases of stock-outs and referred, without explanation, to situations where patients had not obtained their medication, whereas health facilities saw stock-outs as meaning no stocks of medication.

THE ANSWER

A dialogue process was initiated through a series of meetings: initially between the Ministry and health facility officials to discuss the data collected; and with the Director General of Health, during which the observatory was able to explain its approach from the users' point of view. Then later with the DG and health facility officials who questioned the data, which allowed the observatory to go over the data presented in its first bulletin point by point. The observatory then set up

meetings every three months, with all the stakeholders, to review published bulletins. A year later, the observatory took advantage of the international AFRAVIH conference to meet with the Central African Ministry of Health and request formalization of their collaboration through an official letter, which they obtained.

IMPACT

Once this framework was established, observers received a pass from the Ministry to visit health facilities to facilitate their data collection work and to prevent their work being perceived as "spying". This discussion process, which was initiated during the creation of the observatory, has laid a solid foundation for feedback: the framework for dialogue has expanded and an annual meeting has been set up with the Director-General to present the observatory's top-level results. The observatory itself has started awarding certain health facilities, which have demonstrated good practice and have shown willing, with a community "seal of approval".

The difficulties initially encountered in the Central African Republic demonstrate it is necessary to have a framework for dialogue between the observatory and the health authorities. The situation is the same in Cameroon, although the observatory is positioned differently: "in our relationship with the authorities, we do not want to have reports that are too formalized. An agreement would limit us. We base the legality of our work on our citizenship focus." In reality, the observatory has built its reputation over a long period based on action.





CAMEROON - GAINING RECOGNITION

BACKGROUND

In its twenty years of existence, PG has been built on a very strong activist identity: "we were known for saying things loudly that others were thinking in a low voice". Since the observatory was established, PG has encountered reluctance from the Ministry: "Demonstrating the quality of the data is not always easy. But we have always provided evidence that what we are presenting is true. Little by little, we have won their trust."

METHODOLOGY

Gaining ground in the healthcare landscape has been long and gradual:

- ▶ Speaking with other actors in the response to improve health systems: "We had to show what we were doing, our synergies, how we can work together in a dynamic collegial way. We are not enemies!"
- ▶ Working closely with technical and financial partners, to gain their recognition. For example, "the partnership with Médecins Sans Frontières (MSF) was a highlight: they came to us knowing we had some avenues to follow and proposals. The National Program has changed its perception of us as a result of this partnership."
- ▶ Presenting and championing the observatory's approach based on the mechanisms in place that make data trustworthy: "we have our principles that we stick by: if a patient does not have their medication, it is a stock-out. It is necessary to be sure of your concepts, have clear assumptions, and be uncompromising."

IMPACT

The transition from a situation of opposition and confrontation to one of dialogue has enhanced the observatory's recognition. However, recognition of the observatory by the authorities was not easy to obtain. "We had to fight and the support from technical and financial partners was important for us to be recognized."



While some observatories negotiate a collaboration framework with the authorities, others seek recognition in and through action, without a formal agreement: the reliability of the data provided, openness to dialogue, the quality of protocols, the provision of solutions to problems and support from technical and financial partners represent the basis of this recognition. In the case of the RAME observatory in Burkina Faso, it came about as part of a project (with staff, resources, duty of accountability) and was required to safeguard the funded activities so the observatory had to request authorization from the authorities.

Vertical and horizontal integration of observatories is mutually reinforcing. Being able to integrate into an operational environment is an asset to be recognized by the authorities, and vice versa. PG's experience demonstrates this, as does the FORSS project¹: a duplication risk with another observatory was identified and, according to the project lead, "we must be careful to work together and avoid any criticism": recognition by the authorities is dependent on this horizontal integration.

The FORSS (MENA region) project's recent experience of organizations that carry out the project starting to meet the with authorities is that they are not always welcoming. However, in Egypt, it would be inconceivable to work without the agreement of the ethics committee: "without agreement from the authorities, we would place data collectors in difficulty." The FORSS project has decided to follow the same path as ANJFAS, but recognizes that "in general, we will need different intervention strategies depending on the country".



TAKEAWAY POINTS

- ▶ **Maintain ongoing communication with actors from other organizations** to avoid blockages, misrepresentation of the nature of the observatory's work or its objectives
- ▶ **Make data quality a priority** because the observatory's recognition by initially reluctant or even suspicious authorities may depend on it.
- ▶ **Get support from technical and financial partners**, who can be of great help, especially when relations with the authorities are difficult.

1. The FORSS project, supported by Solidarité Sida and ITPC-MENA, started up in 2018 and aims to create community observatories on access to HIV care in five countries: Egypt, Lebanon Morocco, Tunisia and Mauritania.

GUIDE 05 REPORT BACK

Reporting back corresponds to a pivotal moment between data collection and moving changes forward among users, health workers or the authorities. In order to ensure that the observatory's voice is heard and that the issues raised are resolved and because the data presented are often problematic for the authorities, the feedback process must be planned in advance:

Who reports back? At what level(s)? In the presence of whom? How? How to direct feedback so that solutions emerge? And how to deal with attempts to de-legitimize the observatory and its data?

01

Where to report back? When? With whom and with what objective?

In most cases, reporting back takes place within a health facility. Since observatories operate at community level, its first point of action and discussion is at the local level, although the results can also be disseminated to national or international decision-makers. Reporting back can be done face-to-face through meetings organized with all or some of the stakeholders, and / or by distributing bulletins, reports, newsletters. It is sometimes necessary to move from local to national level where problems are the responsibility of the government, and health centers are not able to directly intervene.

The objective of reporting back is primarily to share the information. In some cases, the purpose is to validate data and in others it is to obtain the recognition and approval of data by all, or even to outline a strategy for action, a collective response or to engage in coercive action. The way that data is reported back and discussed is critical.

OCASS IN NIGER'S APPROACH TO REPORTING: COLLECTIVELY IDENTIFYING IMMEDIATE LOCAL SOLUTIONS

THE METHOD

The observatory led by RENIP + in Niger collects information and disseminates it to all actors at the health facility: pharmacists, laboratory technicians, radiologists, doctors, user representatives are all invited to get involved in reporting back data. These discussions are facilitated by the data collectors themselves, who are often psychosocial counselors, supported by the observatory team if

necessary. It involves being relatively comfortable speaking and being able to explain the observatory to a wide audience. To guide them, RENIP + has provided a feedback framework that data collectors can use to prepare their presentation: this template provides a framework, reminds people of the essential steps (introduce, present the framework and collection methodology, present the results, facilitate discussions, give a summary).

THE AIM

At this point, reporting back is therefore a means of presenting the results; analysis and interpretation of the data has not yet taken place. It is only after the feedback meetings that the collection forms are sent to RENIP + to feed into the reports that will be validated by the Steering Committee, which comprises health authorities, representatives of civil society and international partners (UNAIDS, Global Fund, etc.). The aim is also to collectively find solutions at the local level rather than systematically pushing the responsibility to higher levels.

IMPACT

Holding regular local feedback sessions to bring together all the actors concerned, makes it possible to solve certain problems quickly. Often, a lack of information at management level explains the persistence of certain problems, such as a lack drug input supplies or defective machines not being replaced. In addition to enabling the feedback of information, this process also creates dialogue at all levels of the health pyramid. The

regularity of these meetings creates a dynamic that is favorable for joint accountability from managers and health workers, who work together to improve the care provided to users.

The Niger example emphasizes the need to make reporting back an opportunity for horizontal exchange and not for accusation: seeking solutions through dialogue rather than reporting issues directly to the central level makes it possible to create a relationship of trust in accepting the work of data collectors and in driving change. In the same vein, OCASS in Niger refers both to findings relating to things that aren't working at health centers and to good practices observed among health staff in its feedback sessions.





CENTRAL AFRICAN REPUBLIC: REPORTING BACK – FINDING A BALANCE BETWEEN FULFILLING THE NEED TO INFORM OFFICIALS AND MAINTAINING A CERTAIN DISTANCE TO ENSURE THE INDEPENDENCE AND SECURITY OF OBSERVERS

Where a culture of dialogue does not pre-exist between the organization leading the observatory and the political authorities, it can be difficult to conceive of involving decision makers without worrying that the observatory will be compromised.

In May 2016, ANJFAS issued a bulletin highlighting major issues in ARV distribution in several health facilities covered by its observatory. "At first, as health facility management were not informed, there were negative reactions when TAW estimated that 25% of

health facilities had low levels of ARVs and that none of them had sufficient levels." It was necessary for the Director General of the response to endemic diseases to intervene and explain the role of the observatory and its interest for the management of ARV treatment centers in Bangui. In parallel with the publication of these reports, ANJFAS also initiated advocacy work with the managers. As a result of this joint intervention, patients stopped paying excessive consultation fees in the affected Bangui health facilities.

The ways in which observatories report back is therefore determined by the existence (or not) of a culture of dialogue between civil society and the political authorities. A climate of mistrust or insecurity will contribute to reducing the opportunities for discussion between data collectors and officials, to both preserve independence and ensure the security of representatives of the observatory. When reporting is not done by a person but is shared online, for example, the dissemination of results does not endanger the individuals who carry it out. Positive Generation in Cameroon uses this method and sends TAW bulletins to a mailing list, replacing the interactivity of an oral presentation with a meticulous visual presentation of the data.



From reporting to action: Creating favorable conditions - a good atmosphere, a relationship of trust

Several observatories report the difficulties they encountered at the outset, faced with health authorities who were defensive and attempting to delegitimize the observatory and its work. Although not inevitable, observatories must prepare for and anticipate this and try to create conditions that are conducive to dialogue.

The Médecins du Monde observatory was quick to understand the importance of the mood at feedback sessions, particularly when they were run by people that attendees already knew, people able to adopt "a positive, sincere and transparent attitude, and who did not fall into the trap of criticism or guilt and admitting weaknesses and who were able to mobilize."





MADAGASCAR: LEARNING FROM MISTAKES

FIRST FEEDBACK SESSION - JULY 2018

"The mood was rather mistrustful in terms of the data presented [...] They mostly disagreed about the very low testing rates and the participants did not understand them in relation to their idea of reality. We did not really have an answer to give them, we came out frustrated, dissatisfied. We did not have strong arguments to support it, and we ourselves did not trust our data... as if we had done it for nothing."

SECOND FEEDBACK SESSION - DECEMBER 2018

"We had gained confidence and knew how to defend our ideas, our results [...]. Despite questions about the reliability of the results [...] we explained our data from a qualitative point of view. We demonstrated the reliability of our data. And the meeting resulted in a decision [...] Participants had taken on board the results, had discussed them and understood that we are not afraid to speak the truth. Our results showed some courses of action."

FACTORS OF IMPROVEMENT

Several conditions were met to improve feedback sessions:

- Additional safeguards were put in place for data reliability, with an emphasis on monitoring the data collectors
- The trick questions had been anticipated, particularly from the point of view of the collection protocol: to specify how the results were developed, to know how to contextualize them, to identify the limitations, but also to have sketched out some solutions
- The observatory has gained confidence over time: "our observatory has matured".



TAKEAWAY POINTS

- Make sure, regardless of the method chosen, that the data collected is of quality and that the team that presents it can defend the data and present arguments about the methodology used.
- **Adapt the format of reporting issues to the type of issue reported:** some issues require early warning and immediate resolution outside the usual timeframe of meetings while others that are more structural can be presented during feedback sessions.
- **Involve data collectors in feedback sessions** to strengthen their advocacy skills and facilitate the dissemination of data by entrusting it to someone already known to managers and health workers. If the data collectors are entrusted with this activity, **plan training** sessions accordingly.
- Get health workers to validate the information collected to garner the support of all actors for the observatory's work.
- **Closely follow up decisions** taken at feedback sessions to ensure they are implemented.
- Get **people to run the feedback session who know local terms**, anecdotes, culture, sense of humor, to encourage dialogue and ownership of the presented results.



GUIDE 06 INFLUENCE

Some of the issues that observatories report can be resolved locally, especially through feedback meetings. However, other issues sometimes need to be raised at a higher level. How can you have a real influence with the decision-making authorities using the collected data? Although it comes at a later stage, advocacy is a crucial activity for observatories exploring different strategies in line with their capacity and the type of relationship they have with decision-makers.

Mobilize

Train

Collect

Position

Report back

Influence

01

Uniting to amplify the voice of the observatory: creating platforms

In several observatories, advocacy does not initially appear to be a priority, but becomes one when the authorities need to be called upon to deal with the issues reported. Although "technical" committees can be adapted to run an observatory, they are not effective advocacy tools. Collection teams also do not always have the skills to advocate. The formation of CSO coalitions of varying sizes is a relevant solution to this issue.



MADAGASCAR: A PLATFORM OF CIVIL SOCIETY ORGANIZATIONS

BACKGROUND

When setting up the observatory in 2017, launching the surveys took precedence over setting out an advocacy strategy and producing data on their use. However, the need to advocate to the authorities has become more urgent, due to issues such as input stock-outs.

METHODOLOGY

The five partners in charge of the observatory decided to set up an advocacy platform, that aimed to be a "palliative force to monitor and report problems in the response to HIV in Madagascar". It is based on the assumption that bringing together "all the CSOs working in the HIV response will be a decisive force to improve the implementation of national policy". Three stages were required:

- Write a charter, which the platform will be based on,
- Inform the authorities of the existence of the platform,
- Expand the platform by integrating other CSOs.

They were aware that the composition of the platform may face competition and tensions between organizations in the sector. In Madagascar, it was important to try to promote from the outset the idea of synergy between all the organizations by proactively encouraging their participation in the observatory's activities: it was a question of "throwing the doors wide open to avoid making it exclusive". It is preferable to do this from the early stages of the observatory.



NIGER - BREAKING DOWN THE BARRIERS OF HEALTH ADVOCACY

BACKGROUND

The same process was used in Niger. A technical steering committee composed of the three national planning bodies, UNAIDS, local and international partners involved in the response to the three diseases, already existed but its scale and composition did not meet the RENIP + requirements in terms of advocacy. Publishing reports validated by the steering committee was not enough to resolve certain recurring issues at a more macro level: supply of inputs, lack of human resources or significant turn-over.

IMPLEMENTATION

RENIP + enabled the creation of a large, open and inclusive platform that comprises around 20 organizations working in the field of health, including governance and health financing. In order to set up the platform, RENIP + used its network, as a member of the CCM in Niger, and with representation on various bodies including the CNLS (the national committee for the fight against AIDS) and the inputs supply

committee linked to the Ministry of Health. No organization has refused, although some are not proactive. An implementation protocol has been signed between the various organization and the quarterly reports are now validated by the platform before distribution.

IMPACT

In April 2019 the platform was invited to present the issues reported by OCASS to European parliamentarians for the Global Fund replenishment, in the presence of the First Lady of Niger. Opening the platform up to stakeholders not working on HIV also avoids the pitfalls of verticalization.



02

Working with influential people

Some observatories choose a different strategy: rather than creating coalitions, they mobilize nationally influential figures who can engage their network to promote the observatory's key messages.





GUINEA - "CHAMPIONS COMMITTEE"

BACKGROUND

The COFEL observatory works with the Global Fund team in Guinea to carry out its advocacy work. Despite the work carried out, there are still limitations. Two events made the issue of advocacy even more crucial. In 2017, a fire broke out at the central drug depot, a few months after the Global Fund estimated the stored drugs were worth \$3 million, and informed the health authorities that if the drugs expired, they would be held responsible and would have to refund the cost. The coordinator of the observatory expressed doubts as to the accidental nature of the accident and was threatened as a result. In July 2018, the country experienced a national stock-out of ARVs and despite immediate mobilization by the observatory who quickly produced a report, the situation has not been resolved.

ESTABLISHING THE CHAMPIONS COMMITTEE

COFEL created a champions committee to overcome these obstacles. It is not

made up of organizations but rather influential people: former ministers of health, chairs of partner organizations, senior UN officials, the order of pharmacists, lawyers and doctors. None of the people contacted refused to join the committee. The committee is chaired by former ministers - but the composition of the committee is fundamentally multisectoral and combines legal and health skills. The champions committee only gets involved in issues that the steering committee is unable to resolve: it produces documents that it is able to take to the highest level and communicate on networks, etc.

IMPACT

One of the direct effects of setting up this committee was that it strengthened the observatory's legitimacy. Not wishing to seek authorization from the Ministry of Health, the observatory nevertheless benefited from the support of the Minister, which facilitated its integration into the healthcare landscape.

Establishing a champions committee may create rivalries between the various influential people. The make-up of the committee should take this risk into account. COFEL's experience is not replicable everywhere: political instability could quickly make the composition of the committee obsolete and the scope of the "champions" voice would diminish. Mobilizing political leaders can pose a serious risk to the apolitical nature of observatories. It would then be necessary to find other types of "influencers", outside the political field.



TAKEAWAY POINTS

- **Pre-empt the need for an advocacy strategy**, as soon as the observatory is set up.
- **Discuss the possibility of building a coalition of CSOs to advocate**, and if this strategy is adopted, ensure that potential tensions and competitive relationships are addressed by adopting an inclusive approach from the outset explaining the synergies that exist.
- **Contact influential and respected people** to potentially form an advocacy committee and enable the observatory to gain the institutional recognition necessary for it to be integrated into the health ecosystem.
- **Focus your advocacy work on conclusions that have already been agreed by the various actors**, whether it is the local health authorities or neighbouring community organizations. The greater the ownership of advocacy issues, the greater the number of allies you will have, and the more sustainable mobilization will be.



CONCLUSION



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.

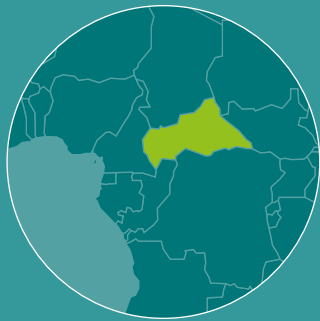
However, this may run the risk of observatories losing their independence. There is therefore not necessarily one simple solution to ensure sustainability, but rather appropriate solutions depending on the country and on the specific observatory.

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? How do they operate?

Observatories who have contributed to the learning exercise



"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

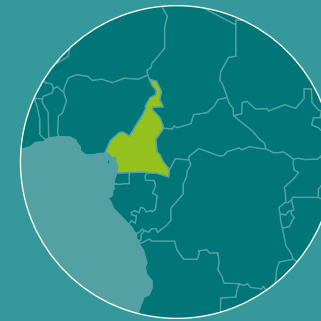
RELATIONSHIP WITH THE AUTHORITIES

Authorization from the Ministry of Health obtained after the launch of the observatory

HUMAN RESOURCES¹
5 employees: 1 coordinator; 1 Finance Manager; 1 Data Entry Officer; 1 M&E Officer; 1 Advocacy Manager

OFFICES:
Hosted at ANJFAS's offices

EQUIPMENT AVAILABLE
3 computers, 1 printer



"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 care providers
- 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

HUMAN RESOURCES
7 employees: 1 coordinator; 1 Quality Control Manager; 1 statistician; 1 Data Entry Officer; 1 person in charge of community mobilization; 1 Lawyer; 1 Paralegal

OFFICES
Hosted at PG's offices

EQUIPMENT AVAILABLE
3 video projectors; 3 printers; 7 computers

¹ People involved in the daily running of the observatory



"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 (psychosocial counselors, health workers, peer educators)

RELATIONSHIP WITH THE AUTHORITIES

Informal contact during the launch of the observatory

HUMAN RESOURCES

5 employees: 1 coordinator, 1 assistant, 3 supervisors

OFFICES

Hosted at ADN's offices

EQUIPMENT AVAILABLE

Freephone line; Data collection forms (paper)



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

BURKINA FASO

YEAR ESTABLISHED
2012

HOW IT CAME ABOUT

Spontaneously through documenting issues based on user testimonials

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

HUMAN RESOURCES

3 employees: 1 Accountant, 1 M&E Officer, 1 coordinator

OFFICES

Hosted at RAME's offices

EQUIPMENT AVAILABLE

1 freephone line looked after by another partner organization; 1 data management software: CS Pro



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

21 health districts - 54 health facilities

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

HUMAN RESOURCES

3 employees: 1 project manager, 1 accountant, 1 M&E Officer

OFFICES

Hosted by a consortium of NGOs

EQUIPMENT AVAILABLE

Freephone line, computer, 1 printer, tablets



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
30 health centers throughout the country

SCOPE OF OBSERVATION
HIV/AIDS, malaria and tuberculosis

COLLECTION METHODOLOGY
Collection undertaken by psychosocial counselors with training

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

HUMAN RESOURCES
4 employees: 1 Program Manager, 1 Accountant, 1 Communications Officer, 1 M&E Officer

OFFICES
Rental of an office at RENIP+ head offices

EQUIPMENT AVAILABLE
1 freephone line; 3 computers; 1 printer; 1 Facebook page; Excel; 1 server and 8 tablets in the process of being acquired



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

HUMAN RESOURCES
10 employees: 1 Program Coordinator, 1 M&E Manager, 1 Data Manager, 1 analyst, 1 Advocacy Officer, 5 focal persons (1 in each town)

OFFICES
1 office in the capital

EQUIPMENT AVAILABLE
52 tablets; 1 data entry and analysis software: KoboToolBox; 1 data analysis software (RStudios)



PROGRAMME FORSS : FORMER, SUIVRE, SOUTENIR

EGYPT, LEBANON, MOROCCO, TUNISIA, MAURITANIA

YEAR ESTABLISHED
2018 (still being established)

HOW IT CAME ABOUT
Project funded by the 5% Initiative

LEAD ORGANIZATION
Solidarité sida and ITPC

SCALE OF MECHANISM
15 collection sites

SCOPE OF OBSERVATION
HIV/AIDS

COLLECTION METHODOLOGY
Field surveys conducted in pairs comprising the focal point of the partner organization and a peer educator, 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's 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 Comprehensive Development, 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	Funding
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 of African Women Against AIDS (Association des femmes africaines face au sida)

AFRAVIH: Alliance francophone des Acteurs de santé contre le VIH et les hépatites

AGD: Association des Gestionnaires pour le Développement

ANJFAS: Association nationale des jeunes femmes actives en solidarité

ARV: Antiretrovirals

ATP+: Association tunisienne de prévention positive

CCM: Country Coordinating Mechanism

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

CHMP: Centre humanitaire des métiers de la pharmacie

CNLS: Conseil national de lutte contre le sida

COFEL: Coalition des Femmes Leaders en Guinée

FORSS: Former, suivre, soutenir

FOSI: Forum Sida

GF: Global Fund to Fight Aids, Tuberculosis and Malaria

HF: Health facilities

IDU: Injecting drug users

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

RAME: Réseau Accès Médicaments Essentiels

RDR-Maroc: Réduction des risques Maroc

REGAP+: Réseau guinéen des personnes affectées avec le VIH

RENIP+: Réseau nigérien des personnes vivant avec le VIH

REN-LAC: National Anti-Corruption Network (Réseau national de lutte anti-corruption)

SW: Sex workers

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

VP: Vulnerable populations

WHO: World Health Organization

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Contributing organizations:

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

The analysis and conclusions presented in this document are the responsibility of the authors. They do not necessarily reflect the official point of view of Expertise France.

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.



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 was produced by Perrine Duroyaume, Hélène Gombert and Jean-Eudes Beuret. It 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).



INITIATIVE 5%
SIDA, TUBERCULOSE, PALUDISME

Initiative 5% sida, tuberculose, paludisme

Expertise France
73, rue de Vaugirard
75006 Paris - France
01 70 82 70 82
www.initiative5pour100.fr



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The 5% Initiative was launched in 2011 and is France's indirect contribution to the Global Fund. Its mission: to support eligible countries – francophone countries in particular – to develop and implement Global Fund-supported programs. The 5% Initiative's work takes three forms.

By mobilizing qualified experts for short-term assignments, the program is able 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.

The 5% Initiative also funds 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 policy and/or 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 implementation of the 5% Initiative is led by Expertise France, the French public agency for international technical assistance.

