



GUNDO-SO: THE CHAMBER OF CONFIDENTIALITY

**A community-based project
dealing with the issue
of disclosing one's HIV status
among women living
with HIV in Mali**

ARCAD - SIDA Mali

Association de Recherche de Communication
et d'Accompagnement à Domicile des Personnes
Vivant avec le VIH et le SIDA



Membre de la Coalition Internationale Sida



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This brochure was created by Fatou Gaye, intern at Coalition PLUS as part of her Master's degree in Public Health.

To gain a better understanding of the capitalisation of the Gundo-So project and create the brochure, a review of the relevant literature was carried out and an assignment in the field was conducted to do a qualitative study including interviews, focus groups and field observation.



TABLE OF ACRONYMS

AFAS

Women's association supporting AIDS widows and orphans

AFD

French Development Agency

AIDS

Acquired Immune Deficiency Syndrome

AMAS

Assistance and support association for people living with HIV/AIDS in Mali

ARCAD-SIDA

Research, Communication and home-based care for people living with HIV/AIDS in Mali

ARV

Antiretroviral

CESAC

Care, facilitation and counselling centre for people living with HIV/AIDS

CIHR

Canadian Institutes of Health Research

CReCES

Canada Research Chair in Health Education

DERSP/UB

Education and Public Health Research Department of Bamako University

FDL

Fondation de France

HIV

Human Immunodeficiency Virus

PLHIV

People Living with HIV

USAC

Care, Support and Advice Unit

USAID

United States Agency for International Development

UQAM

Quebec University in Montreal

WLHIV

Women Living with HIV

WHO

World Health Organisation

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Dr Dembélé Bintou Keita

Director of ARCAD-SIDA

Gundo-So came into being because women living with HIV on the African continent and specifically in Mali had a very definite need.

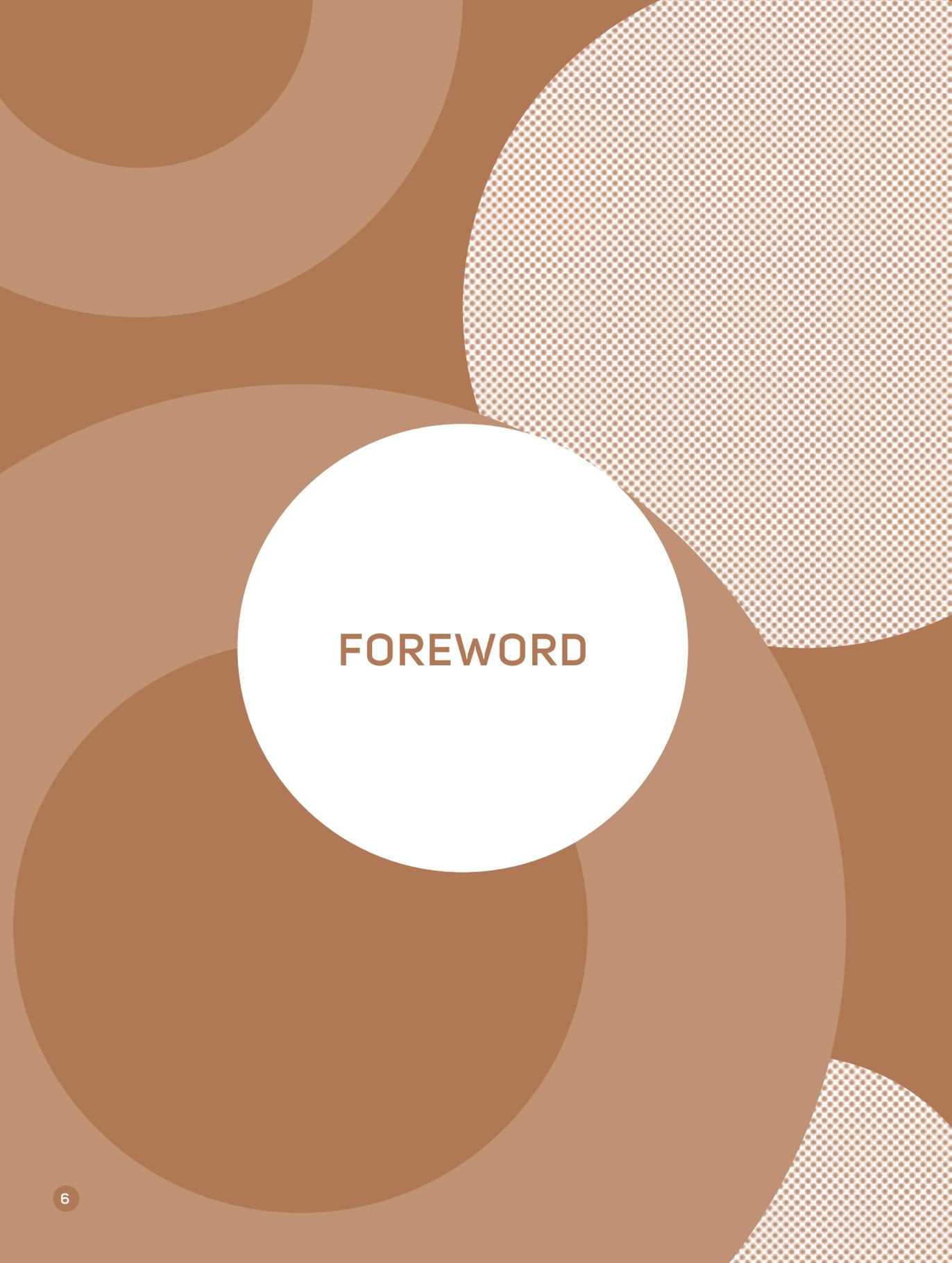
In Mali, cultural and social constraints are harder on women than men, and these are exacerbated if the woman is HIV positive. For these women, resources are limited because of stigma, discrimination and especially repudiation. Therefore, choosing to disclose one's HIV status is a fundamental issue for women and their children.

In order to face these challenges, they need support and empowerment. This is why the Gundo-So programme was set up. It responds to women's needs and also service providers' needs on the issue of disclosure. The programme enables women to recover their self-esteem and make decisions for themselves.

A woman who feels good in her mind feels good in her body.

Today, it is important for care providers, like us, to get closer to our users and help them in their daily lives.

Discover this wonderful and rewarding project which we have created together, with and for women.



FOREWORD

What is this brochure about?

This brochure is a presentation of the Gundo-So project: its implementation, its adjustment and capitalisation processes.

The word capitalisation has several different meanings depending on the context. The definition which probably fits best is the one by Pierre de Zutter (1994) which states that capitalisation is “the shift from experience to shared knowledge”.

The main objective is to see what lessons can be learned, identify best practices and draw full benefit from them. Therefore it is a procurement, collection, organization and analytical process of collecting the know-how utilised during the project.

Capitalising on experience is therefore essential if we want to improve the quality, efficacy, efficiency, sustainability and relevance of the tasks carried out by the organisations.

Using this procedure, practices can be improved on and eventually be extended to and incorporated by others. This procedure also allows for critical thinking in order to avoid repeating the same things or making the same mistakes twice.

« Know-how is fine but knowing how to say what we do and how we do it is better. »

Emilie Henry

Community-based research manager at Coalition PLUS until April 2014

What is the use of capitalising Gundo-So?

The reasons for capitalising Gundo-So:

- The desire to incorporate it into ARCAD-SIDA's quality system.
- The desire to share this experience which came from a leading HIV/AIDS organisation in West Africa.

« If we capitalise Gundo-So, we can disseminate the programme on a local level to ARCAD-SIDA's other sites outside Bamako, integrate it in the psychosocial support package and then at a sub-regional level as a member of Coalition PLUS and the Afrique 2000 network. It is an opportunity to transfer skills to other organisations which is consistent with the programme Transfer ¹ led by AIDES, member of Coalition PLUS and funded by the French Development Agency (AFD). »

Dr Dembélé Bintou Keita
Director of ARCAD-SIDA

« In line with its operational logic, Coalition PLUS puts great value on sharing experience and pooling together strengths to optimise the results of work carried out in the field. That is why it supports capitalising the Gundo-So project, an excellent programme on disclosing one's HIV status, which members and partners can acquire and take ownership of. »

Emmanuel Trénado
Permanent secretary of Coalition PLUS

¹ Project Transfer: “Assistance in setting up and empowering 4 regional platforms providing support to HIV/AIDS organisations in North, West, Central and East Africa and in the Indian Ocean”.



Membre de la Coalition Internationale Sida



Presentation of ARCAD-SIDA

ARCAD-SIDA (Research, Communication and home-based care for people living with HIV), founding member of Coalition PLUS in 2008, is the biggest HIV/AIDS organization in Mali. It was set up in 1994, and is actively involved with the Health Ministry in access to care for people living with HIV (PLHIV).

Its purpose is to facilitate access to care and psychosocial support for infected and affected individuals, using outpatient treatment sites and a community-based approach.

ARCAD-SIDA also cares for vulnerable groups such as men who have sex with men, sex workers, handicapped people and those who are deprived of liberty.

One of the characteristics of this organisation is the involvement of infected and affected people in all decision-making processes.

Its principles are based on four essential points:

- Focus on access to testing and counselling, medical care and psychosocial support, including home-based interventions, for people living with HIV and their families.
- Ethical and equal access to treatment including antiretrovirals (ARVs) for all.
- Respect for people's rights.
- Involvement and cooperation with people living with HIV.

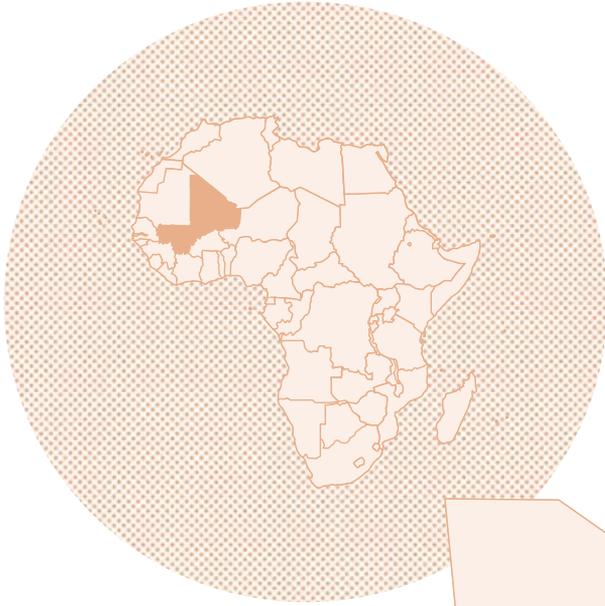
ARCAD-SIDA IS ALSO ²:

16

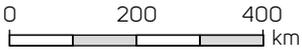
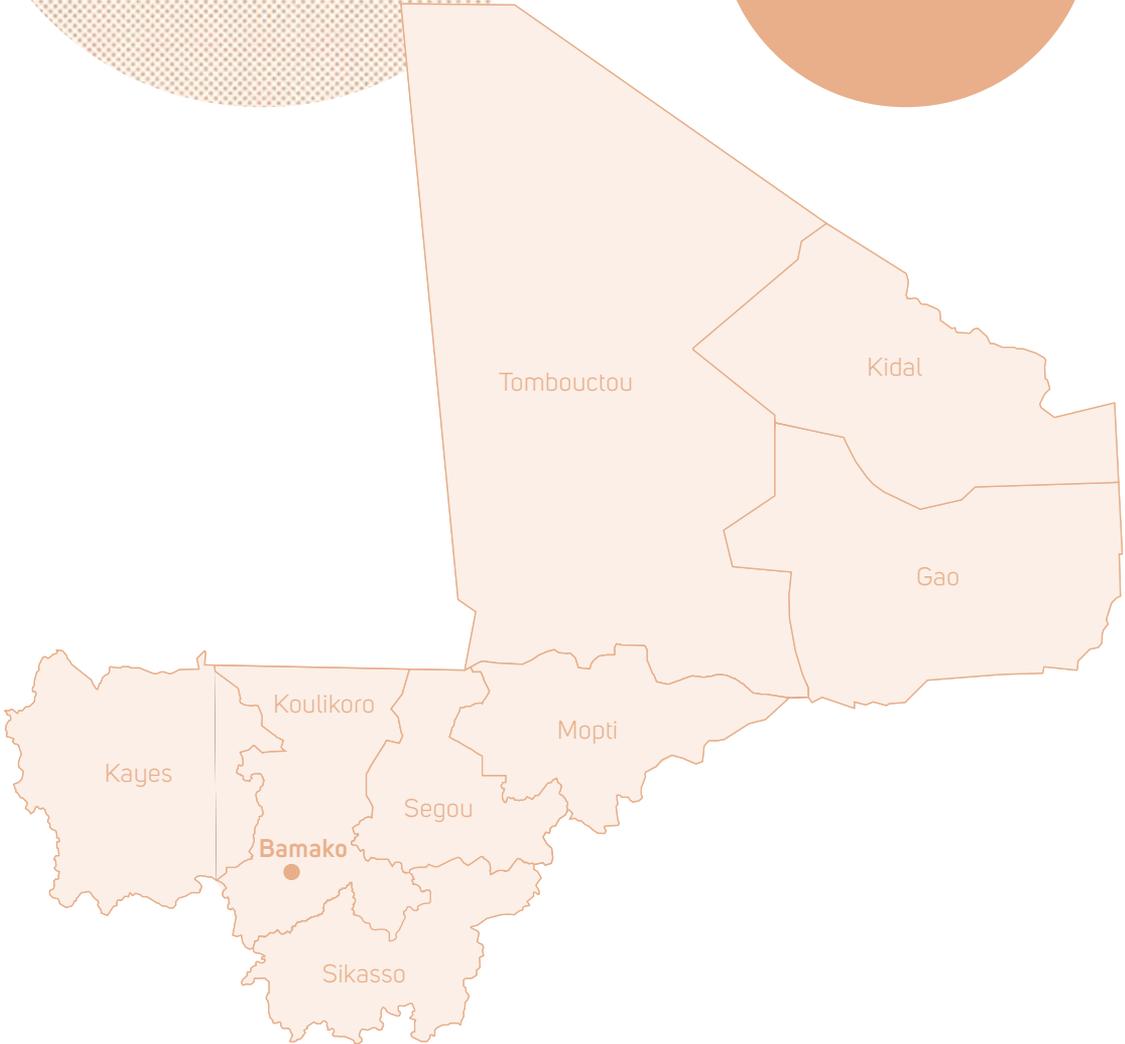
care and treatment sites
including one night clinic.

More than 14 500

patients receiving ARV treatment,
i.e. 50%
of the country's AIDS patients.



Map of Mali



I

INTRODUCTION

In 2010, ARCAD-SIDA set up the Gundo-So project, a programme to improve the provision of proper tools for women living with HIV on the issue of disclosure, with the aim of improving their quality of life.

« I was very excited about Gundo-So, for me it's more than just a programme, it responds to the fundamental needs of women living with HIV. »

Dr Dembélé Bintou Keita
Director of ARCAD-SIDA

Gundo-So was inspired by a similar programme developed in Quebec known as "Sharing Together... for life" (PP/PP). It is a community-based programme of sharing, with, by and for women living with HIV (WLHIV). Its purpose is to promote reflection and dialogue between women on the issue of disclosure and the burden of secrecy, and to help them develop coping strategies.

Warning!!!

Gundo-So does not promote either disclosing one's status nor keeping it secret, but aims to provide women with the proper tools for being able to make an informed decision according to the different contexts in their lives.

The name Gundo-So is an expression from the traditional language of Mali, Bambara. "Gundo" means confidentiality and "So" means a chamber or hut. The name was chosen by those who took part in the programme, who, long before the beginning of the project, used to meet in a hut to discuss HIV related issues.

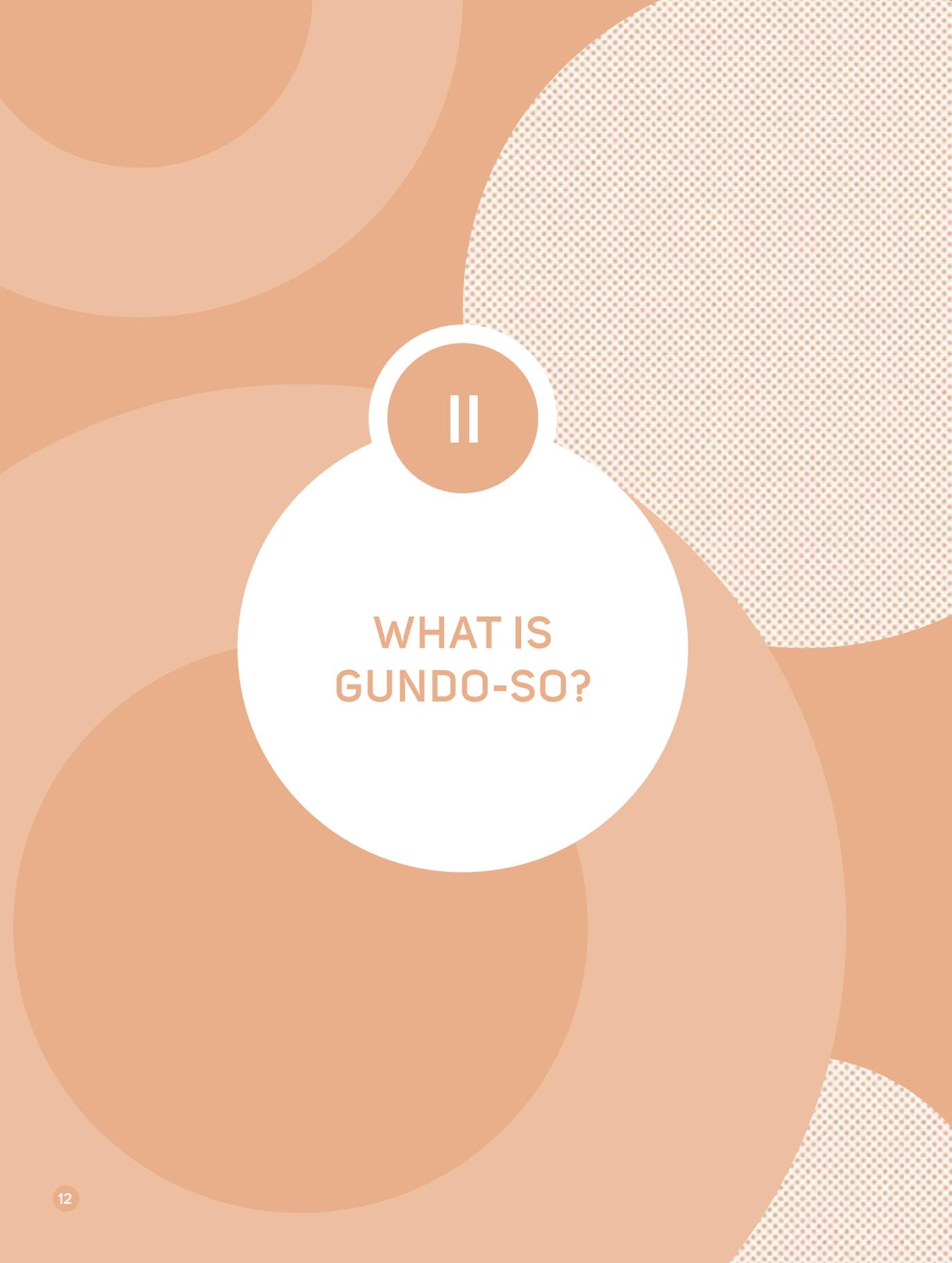


« The chamber represents a safe place where they can open up and talk about all their worries. »

Dr Adam Yattassaye
Programme manager at ARCAD-SIDA

THE COMMUNITY-BASED APPROACH

We speak of a community-based approach to health when the members of a community-geographically or socially speaking- come together to reflect on their health problems, voice their needs and priorities, and take an active part in implementing and operating appropriate activities responding to these priorities.

The background features several overlapping circles in various shades of orange. A large circle in the upper right quadrant is filled with a fine halftone dot pattern. In the center, a white circle contains the text 'WHAT IS GUNDO-SO?'. Above this white circle is a smaller orange circle with a white border, containing two vertical bars.

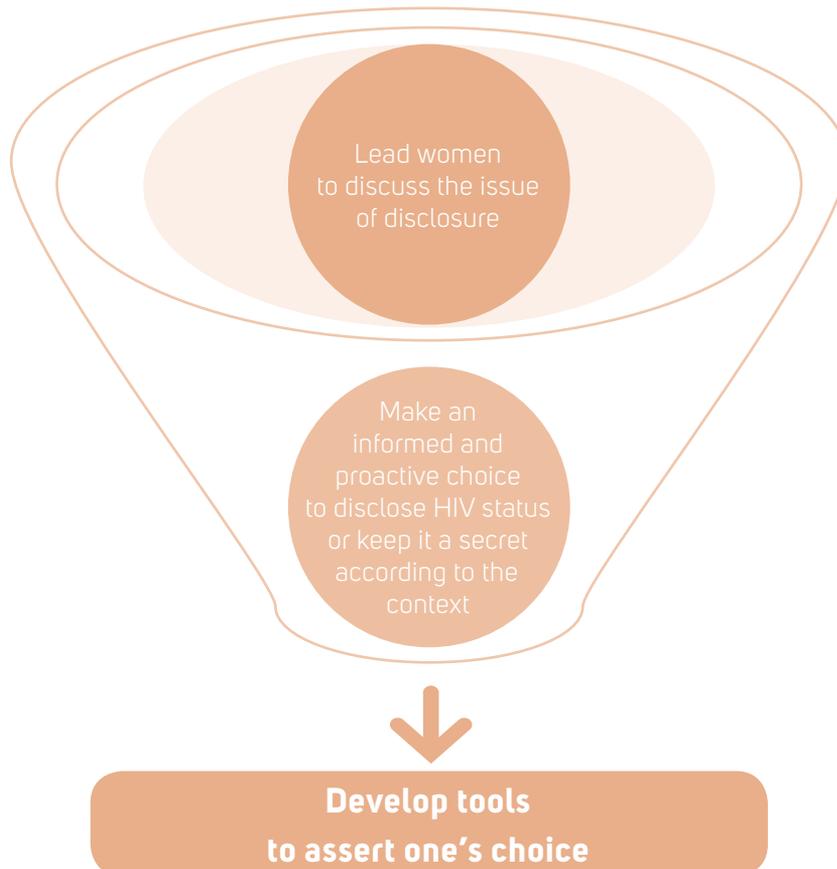
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**WHAT IS
GUNDO-SO?**

Gundo-So: an empowerment ³ programme to help WLHIV make informed and deliberate choices

Gundo-So: an innovative programme consistent with the reality and diversity of situations WLHIV encounter, giving them the choice of whether to disclose their HIV status or not.

The objectives of Gundo-So:



« Gundo-So is one of the few projects whose aim is to enter deeply into the issue of disclosure, contrary to the questions we usually have, where healthcare personnel order women to disclose their status. »

Karine Pouchain

Head of the Health Promotion and support for patients department at the Fondation de France (FDF)

³ The WHO definition of empowerment refers to the level of choice, decision, influence and control that users can exercise over events in their lives.

Gundo-So includes 1 individual assessment meeting, 10 weekly group meetings and 1 optional group meeting, including activities and tools

specially designed for the Malian culture and easily understood by the women. Each meeting lasts 2 hours.

The meetings are organised in 5 phases:

WELCOME

« Commitment to the programme and personal assessment before the programme »



MEETINGS 1, 2 AND 3

« Explore the overall background of the issue of disclosure »



MEETINGS 4, 5 AND 6

« Make the decision to keep one's HIV status to oneself and plan how to keep it secret »



MEETINGS 7, 8 AND 9

« Make the decision to disclose and plan how to do it »



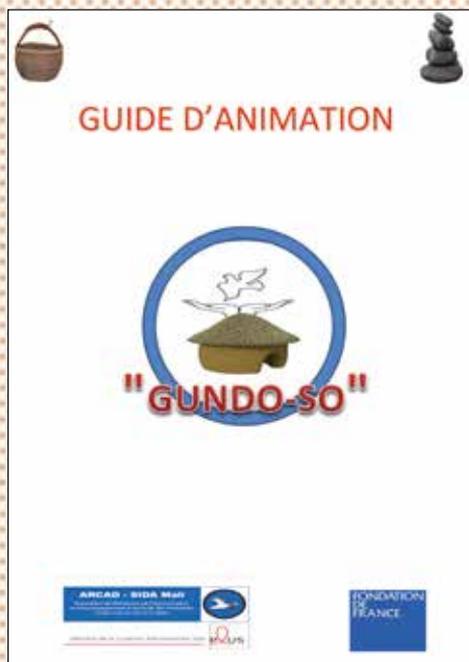
MEETINGS 10, 11 AND 12

« Assess achievements and share within the community »



Inclusion criteria for women are:

- Willingness to discuss HIV status with other WLHIV.
- Being available to attend the 10 meetings.
- Being emotionally strong (women should be over the crisis period immediately following a positive test result, i.e. on average six months.).
- Compliance to programme rules and conditions : confidentiality, non-judgment, respect for others and so on.



For further information on programme contents

Contact: **Dr Dembélé Bintou Keita**

Director of ARCAD-SIDA

Email: arcadsida@arcadsida.org

Tel: 00 223 20 23 72 59 • Fax: 00 223 20 22 49 13



WHY GUNDO-SO?

1. A real need for WLHIV to tackle the issue of disclosing their HIV status

In Mali, medical care for people living with HIV has been free since 2004. However, apart from the medical aspect, taking the psychosocial dimension into account is crucial if we want to improve quality of life. This observation is even more pronounced among WLHIV because of their lack of financial independence and their low level of decision making power (condom use and family planning for instance).



« Psychological care underpins medical care; it is difficult to take medication if psychological or social problems get in the way. It is the idea that health is an overall state of wellbeing as stated by WHO. »

Emilie Henry

Community-based research manager at Coalition PLUS until April 2014

Women make up 63% of patients cared for at ARCAD-SIDA, 80% of whom are housewives and/or do small income generating activities.

Gender concerns lead women to be particularly exposed to stigma, divorce, and repudiation, having their children taken away or being abandoned.

To help them cope with these difficulties, ARCAD-SIDA offers them psychological care activities such as a fashion show with HIV positive women, choral singing, chamber of secrets, home visits, cooking workshops and so on.



Some initiatives like individual counselling sessions and focus groups were set up but there was no formal programme to follow up this capacity-building process.

« They are in the best position to know what's right for them. This is the very notion of empowerment which is expressed through the acknowledgment that people have a right to take part in decision-making processes that concern them directly by developing or strengthening their capacity to find solutions to their own problems. »

Pr Joanne Otis

Chair of CReCES, UQAM

The need for a programme on the issue of disclosure was identified on several different occasions including:

- Focus groups with WLHIV organised by ARCAD-SIDA.
- Activity reports and feedback from local HIV/AIDS organisations in Mali.
- Consultations with doctors, psychosocial helpers and social workers.

These experiences and field surveys helped WLHIV to talk about the huge difficulties they have to face. The burden of secrecy and the issue of disclosing their HIV status with their partners, parents, children and others around them are at the heart of their concerns.

« Emotionally I wasn't feeling too good and I was afraid of talking about my HIV to others. Before the programme, I was anxious, stressed and withdrawn. I was also suffering from insomnia. »

WLHIV, divorced, 36



This need also came up in 2010 in the exploratory study of the multi-country research project called "PARTAGES", carried out by Coalition PLUS on the issue of disclosing HIV status. Within the context of this study, interviews were conducted with various HIV care stakeholders and PLHIV. The issue of disclosure arose as a major concern for both stakeholders and PLHIV.



Front page of PARTAGES brochure.
To download the research brochure, visit:
<http://www.coalitionplus.org>

« The “PARTAGES” project helped to reveal the burden that disclosing one’s HIV status embodies both for PLHIV and for medical and psychosocial staff. Thus, it was decided to tackle the issue from a research point of view in order to get insight into individual, psychosocial and contextual determinants of disclosing, and from a concrete point of view with the implementation of Gundo-So. This joint action between research and action worked very well and the two projects enhanced one another. »

Adeline Bernier

Community-based research officer at Coalition PLUS

It was in light of all these needs that Gundo-So was set up, to contribute to improving quality of life among women living with HIV.

2. « Sharing Together... for life » (PP/PP), from Quebec to Mali

ARCAD-SIDA took inspiration from a pilot project called “Sharing Together...for life” (PP/PP), initially conducted in Quebec in 2006 by community-based organisations leading actions for WLHIV in Montreal in collaboration with the Canada Research Chair in Health Education (CReCES) and the Quebec University in Montreal (UQAM).

« This participatory research enables knowledge and practice to meet in order to understand better the real lives of WLHIV. This greater understanding has given rise to new knowledge which has been subsequently turned into concrete action which

in turn has improved living conditions, health and well-being for the women concerned. »

Lyne Massie

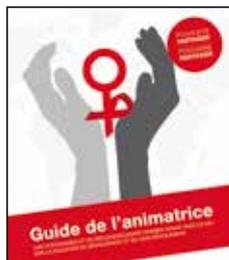
Coordinator of “Sharing Together...for life” (PP/PP), CReCES, UQAM

As part of a partnership with community-based organisations in Quebec, the CReCES developed an intervention aiming to provide WLHIV with better tools to deal with the issue of disclosing their HIV status in different life contexts, with the idea of empowerment and informed choice behind this decision. Consequently, with the partners UQAM and Coalition PLUS, the “Sharing Together...for life” (PP/PP) project was adapted to suit Malian culture and got off the ground in Mali.

« “Sharing Together...for life” (PP/PP) is the baby of WLHIV and facilitators from Quebec, including some from Africa, Haïti and other parts of the world. So we are very proud to know that our thinking and courage are useful for other women and that this baby we have brought into the world will grow and be shared with other women throughout the world. It is in this spirit that we perceive the very essence of “Sharing Together...for life”. »

Pr Joanne Otis

Chair of CReCES, UQAM



To download the PP/PP facilitators guide, visit: <http://www.pouvoirpartager.uqam.ca/>

IV

HOW WAS GUNDO-SO SET UP?

1. Pre-conditions

How Gundo-So came into being

It all started during an assignment for the "PARTAGES" project, when the director of CReCES presented the "Sharing Together... for Life" (PP/PP) project which the members of ARCAD-SIDA immediately took an interest in, as this project seemed to respond in every way to the issues which were coming up for them.

Thus, after a second meeting in Casablanca, the director of CReCES and the community-based research manager in Coalition PLUS, carried out an exploratory assignment in Mali to study the feasibility of the project with the staff of ARCAD-SIDA and its local associates. The latter are leaders of partner organisations (AFAS and AMAS) and an anthropologist from the Education and Public Health Research Department of Bamako University.

This exploratory assignment in Mali enabled those involved to identify these needs and to observe a favorable context for carrying out this project:

- Real needs based on conclusive data.
- Factors within ARCAD-SIDA such as the organisational capacity to carry out the project:
 - Strong commitment from the management, especially the director of ARCAD-SIDA
 - Staff motivation
 - Enough staff to implement the project
 - The DONYA training centre
 - Community-based approach: community-based activities, strong involvement of WLHIV and NGO leaders, presence of HIV positive people on the organisation's staff
 - Understanding of the logic behind the "Sharing Together... for Life" (PP/PP) guide
- Support from partners: backing from decision-makers and potential supporters.

Before Gundo-So was put into action, a focus group that the women called "The Chamber of Secrets" was set up by ARCAD-SIDA staff to respond to the women's needs. The aim was to enable them to talk about their sexual (and other) problems as women living with HIV/AIDS. These conversations not only brought to light all the difficulties these women have to face on the issue of disclosure but also the difficulties faced by the facilitators who, despite their experience in group and individual counselling, often felt ill-equipped to offer structured support to these women.

Observations in the field demonstrated that ARCAD-SIDA staff were used to facilitating focus groups and had the required skills to implement the project.

Even if such a project had never been carried out by ARCAD-SIDA, the staff, in proportion to

their resources, had experience in their daily tasks (using a community-based approach) of practices and insights into how to assist WLHIV on the issue of disclosure.

2. Cultural adaptation and implementation

a. Guiding principles

Four fundamental concerns guided the development of the Gundo-So project:

- Find culturally appropriate tools and activities which have meaning in the country context of Mali.
- Develop activities which take Malian WL-HIV's comprehension into account.
- Remain true to the fundamental elements of the initial "Sharing Together... for Life" (PP/PP) programme.
- Develop an evaluation process of the quality of this tailor-made model.

b. A partnership between academics and NGO stakeholders

One of the major assets of the Gundo-So project was the solid partnership between Coalition PLUS research staff, CReCES, ARCAD-SIDA and local associates.



« There were some very interesting and rewarding exchanges between CReCES and ARCAD-SIDA which helped us revisit and re-experience our own culture. »

Dr Dembélé Bintou Keita
Director of ARCAD-SIDA

« The strong point of this partnership is what we have in common; we all have a community-based approach and our main concern is to respond to needs and improve quality of life for our target population. »

Dr Adam Yattassaye

Programme manager at ARCAD-SIDA

« It is clear that the strong commitment and deep conviction of women living with HIV/AIDS, the community-based stakeholders working with these women as well as the researchers and decision-makers had a huge role to play in the implementation and success of this study. »

Pr Joanne Otis

Chair of CReCES, UQAM



« The strong partnership in this project is different from the North to South partnerships we are used to seeing; there were equal exchanges between the North and the South, making it an effective partnership and not only on paper when the project was written up. »

Karine Pouchain

Head of the Health Promotion and support for patients department, Fondation de France

Roles and contributions from each partner

- ARCAD-SIDA, Gundo-So project initiator, is a founding member of Coalition PLUS and takes an active part in community-based research actions. The ARCAD-SIDA team managed the project implementation through participatory engagement in collaboration with local organisation leaders and an anthropology professor from the Education and Research department at Bamako University.
- Coalition PLUS, as an international HIV/AIDS union with partner organisations located in Europe, America and Africa and whose members put the community-based approach at the heart of their action, has played a prime role in this project. Its support has been technical and financial.

Coalition PLUS used its own financial resources to fund 15% of the project to fulfill the various assignments in France, Montreal and Bamako.

« As well as granting financial resources to Gundo-So, Coalition PLUS has also acted as a catalyst in facilitating and supporting the project. »

Dr Adam Yattassaye

Programme manager at ARCAD-SIDA

- The CReCES at Quebec University in Montreal (UQAM) is involved in the project through its partnership with the COCQ-SIDA, member of Coalition PLUS. The CReCES which initiated the project played an essential role in its implementation.

Its support was crucial in adapting “Sharing Together... for life” (PP/PP) to the Malian culture. Staff at CReCES actively supported ARCAD-SIDA’s team in developing the facilitation and training guides so that they were in line with the “Sharing together... for life” framework for intervention. The CReCES used their own financial resources to fund 15% of the Gundo-So cultural adaptation process

and evaluation. Moreover, a grant of 30% of the budget was awarded by the Canadian Institutes of Health Research (CIHR) for transferring expertise of the research-action project “Sharing together... for Life” to Mali. These funds covered the costs of salaries and travel expenses for CReCES staff as well as gratuities for the knowledge translators (see P25).

- The Fondation de France (FDF) funded 40% of the project as part of its “Gender and HIV” programme.



The reasons why FDF supported this project:

« The Gundo-So project includes several items that prompted the Fondation de France to provide funding:

- The project’s innovativeness.
- The link between research and action. The alliance of these two entities is not often visible in other projects and FDF wants to encourage this type of venture in “Gender and HIV” calls for proposals. The idea is that projects funded for research can further action on the ground.
- A deep understanding of the gender approach.
- The notion of empowerment, participatory approach and coproduction with WLHIV.
- The support of ARCAD-SIDA which is recognized for the high quality of its activities and its reliability.

Karine Pouchain

Head of the Health Promotion and support for patients department, FDF

- After the success of the project's pilot phase, USAID, as part of its Positive Health, Dignity and Prevention project funded an extension of the programme in 7 health care sites.



c. Organisational capital

1. ESTABLISHMENT OF COMMITTEES

Three committees were set up.

A steering committee made up of members of ARCAD-SIDA's management, the CReCES team and Coalition PLUS research staff. Its role was to provide the general framework of the intervention and guarantee the monitoring and control of the other committees while complying with the logical framework.

A technical committee made up of the director of ARCAD-SIDA, an anthropologist from the Education and Research Department of Bamako University, the coordinator of the training centre, facilitators of the pilot phase and test phase, and ARCAD-SIDA's programme manager. Its role was to adapt the contents of the workshops and tools to Malian culture.

A scientific committee made up of an anthropologist from the Education and Research Department of Bamako University, ARCAD-SIDA's programme manager, the coordinator of CESAC (Care, facilitation and counselling centre for people living with HIV/AIDS), CReCES staff members, the community-based research manager of Coalition PLUS and the coordinator of the DONYA training centre. Its role was to work on the cultural adaptation documentation and especially to facilitate follow-up and evaluation work. It also produced the follow-up and evaluation tools and process documentation.

2. OPERATIONALISATION

Operationalising the various meetings was facilitated by the implementation of a commission, made up of 4 facilitators who had been involved in the project since its beginning, the director and the programme manager.

The four facilitators worked on:

- Workshop follow-up.
- Writing up monthly reports with details on how the workshops were progressing.
- Supporting the women during the process (difficulties, constraints).
- Support in case of difficulty.
- Purchase of materials for the meetings.

ARCAD-SIDA's programme manager and director supervised the programme through regular meetings with the four facilitators and participation in the last meetings at the end of the programme for each group.

This commission was in close collaboration with the financial department to make assessments on budget and spending.

3. FACILITATORS/KNOWLEDGE TRANSLATORS

The facilitators are psychosocial counsellors who also include WLHIV and HIV/AIDS organisation leaders who work at ARCAD-SIDA. Some WLHIV were also recruited during the test phase of the project.



The knowledge translators involved in this project are medical students who were working on this issue as part of their theses. They had taken part in a training course on ethics in research and they speak Bambara. Their role was to support facilitators in:

- Observing, taking notes and writing up minutes of the various meetings.
- Gaining a better understanding of the facilitator's guide by translating some of the terms into Bambara.
- Preparing the meetings one or two days in advance.
- Filling in various documents: log book, support sheets and questionnaires.

4. THE WAY WOMEN ORGANISE THEMSELVE

The women chose a metaphor to describe their group: the village of peace "Hèrèbougou" or the village of happiness "Lafiabougou", and a village chief "Dogoutigui" who was elected by the group. Each woman chose a nickname like youngest child "Laguarè" to name the youngest one in the group; the eldest was called Tanty, a sign of respect in African culture.

The aim was to create a context or framework which was particular to them with a specific operating model, rules and sanctions: e.g. if someone is late, they have to tell a funny story to make the others laugh.





« Between the women and us, we are a family, we are friends. »
Facilitator, WLHIV, married, 40

There were some strong emotions in the group, some cried when others told their stories and experiences; during the stone exercise for example.



« Before joining the programme, I used to cry all the time, now I don't, because I found people I could say everything to, people I could trust not to reject me. »
WLHIV, widow, 45

Women were singing during or at the end of the workshops. It liberated them and helped them to “unload” their feelings.

« I really like the song at the end. It was very important for me because it showed that we were relieved and there was solidarity between us. »
WLHIV, married, 46

5. REVIEW MEETINGS

With the partners

Discussions between the partners were decisive while the project was being set up.

Over twenty conferences and video conferences were organised to talk about how the project was progressing and make updates on its implementation; various meetings were organised including 2 in Quebec and 3 in Bamako.

With the team

Within ARCAD-SIDA, the technical team also organised and took part in informal encounters and several validation meetings, as well as about twenty formal meetings.

d. Stages

Setting up Gundo-So was preceded by an exploratory assignment that helped to:

- Analyse the feasibility of the project on the ground.
- Draw up a cultural adaptation and implantation pilot project in Bamako.
- Work on grant applications at the Fondation de France and Canadian Institutes of Health Research (CIHR).

Implementing the programme meant that the tools and techniques of the facilitation guide, the training guide and a special training course for trainers needed to be culturally adapted. The involvement of knowledge translators was also fundamental. This was done in several stages: a test phase, a pilot phase and an extension phase.

STEP 1:

TEST PHASE: ADAPT, TEST THE TOOLS AND PRODUCE AN INTERMEDIATE FACILITATOR'S GUIDE

Adapting the tools



Organise and implement 2 groups of 10 WLHIV, mediated by the facilitators of focus groups on two sites / discussion workshops



Follow-up meetings with the technical committee to use the feedback from discussion workshops and produce an intermediate facilitator's guide



Assignment to share changes made to « Sharing together... for life” and incorporate them into the intermediate facilitator's guide with partners from Montreal

STEP 2:

PILOT PHASE: TRY OUT TOOLS AND VALIDATE FACILITATOR'S GUIDE

Develop training guide in Bamako



Training for 16 facilitators and validate training guide



Involvement of 6 knowledge translators



Implement 12 groups of 8 WLHIV on 6 sites to try out the tools



Assessment workshop with facilitators, CReCES and Coalition PLUS staff in Bamako to validate the facilitator's guide

STEP 3:

ASSESSING THE PILOT PHASE

STEP 4:

EXTENDING THE PROGRAMME: SCALE UP (7 SITES)

Organising 10 groups of 8 women and instigating the initial model among 50 women living with HIV

1. Step 1: Test phase

Adapting the tools > Produce an intermediate facilitator's guide

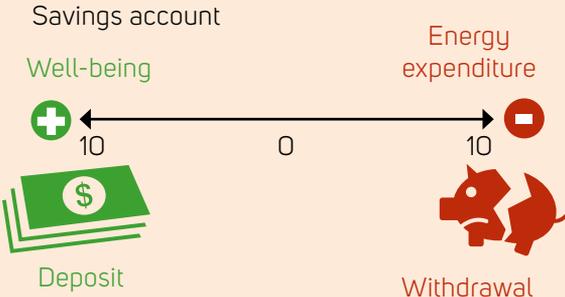
THE BIGGEST CHALLENGE OF SETTING UP GUNDO-SO: ITS CULTURAL ADAPTATION

Cooperation between the various committees enabled the organisers to single out the irrelevant activities in the "Sharing together ...for life" (PP/PP) programme which were difficult to adapt to the realities of Malian culture. Therefore, tools which were inspired by Malian customs and values were proposed.

The first obstacle was the language barrier and the literacy level of the women the programme was addressed to (most of them cannot read or write).

The team's experience in community-based activities was used and harnessed to the full. The strategy was to role-play "Sharing together...for life" situations by organising workshops with WLHIV, set up focus groups by facilitators to re-adapt the "Sharing together.... for life" guide to the realities of Malian culture and contribute to reflection on producing the facilitator's guide.

For the cultural adaptation of the project, the number of gatherings was increased from 7 in the "Sharing together.... for life" to 10 for Gundo-So.

Objective of the tool	The Quebec model
<p>Measure the weight of the burden of secrecy with regard to HIV</p>	<p>Weighing scales</p> 
<p>Analyse and assess the pros and cons of a decision taken</p>	<p>Savings account</p> <p>Well-being</p>  <p>Deposit</p> <p>Withdrawal</p>

SOME EXAMPLES OF THE TOOLS WHICH WERE ADAPTED TO MALIAN CULTURE

During the programme, participants possessed a tool which was used for collecting and stocking their productions and their own assumptions about the various activities.

In the "Sharing together.... for life" guide, the tool used is a personal diary that each participant writes in for the duration of the programme.

In the Gundo-So version, as most of the participants couldn't read or write, this tool could not be used. The tool used was a shopping basket that Malian women use to go to the market every day. They

put their food in it but also their little women's secrets. For instance, they can also make a stop at the medical centre to get their medication.



The Malian model

Stones of different sizes representing the weight of secrecy, the choice of each stone is explained



Meaning in the appropriate social context

When daughters leave their homes to go and live with their husbands, fathers give their daughters a black stone "gabakuru" with these words: "My daughter, this stone is your ally and most trusted confidant. If you want to get something off your chest and you tell somebody about it, you should know that the secret no longer belongs to you, you will belong to the secret as you belong to the person you confided in. But if you confide in this stone, it will never betray you".

Sticks of different sizes

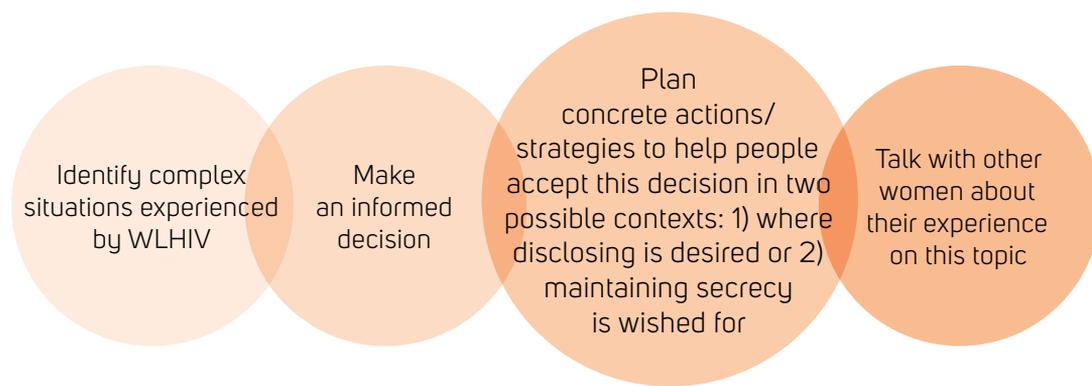


The sticks are learning tools used in Malian primary schools to teach arithmetic ("jate" in Bambara), shapes and dimensions. The women use them to do their tontine accounts.

These tools were tested during the activities of the 2 groups of 10 WLHIV in 2 ARCAD-SIDA centres. These sessions had two purposes: the participating WLHIV actively took part in the programme's design and dynamic while benefitting from the session; besides, what the group produced was

food for thought for the various stakeholders on how to adapt the programme to the Malian culture.

The facilitation of these 2 groups was based on the objectives of the "Sharing together....for life" programme following this pattern:



At the end of the test phase, an assessment workshop with facilitators and the follow-up technical committee was organised to talk about the various gatherings and incorporate changes.

• **Assignment to share the changes made to "Sharing together...for life" and incorporate them into the intermediate facilitator's guide with partners in Montreal.**

The purpose of this assignment was:

- To provide an overview of how the cultural adaptation was coming along since the beginning of the project.
- To collectively incorporate the changes suggested by ARCAD-SIDA.

- To think about the development of a training guide and training courses for facilitators.

« The thing that struck me most was this woman who was hiding her HIV positive status from her husband and the husband was hiding his too. During the programme, the woman decided to let her husband know by leaving her prescriptions around for him to see. From then on, things changed between them and got better, their relationship became more stable. »
Facilitator, WLHIV, married, 46

2. Step 2: pilot phase

The pilot phase was conducted on the basis of the intermediate facilitator's guide. The information collected during this phase helped to readjust and finalise the latter in order to end up with an operational facilitator's guide. During this phase, the training guide for trainers was finalised and their training was carried out. In addition, the knowledge translators were involved and also trained.

In chronological order, this pilot phase was conducted in the following way:

- **CReCES and Coalition PLUS provided a support mission**

The purpose of this mission was to support ARCAD-SIDA staff in validating the training guide, in training the facilitators and validating the facilitator's guide on the basis of the gatherings during the pilot phase.

- **Training for facilitators was needed to lead the project: training for 16 facilitators and validation of training guide**

The training guide was created at the same time as the training for facilitators was carried out. It was conducted by the technical committee which includes the educational committee from the DONYA

training centre (see box), the facilitators of the pilot phase and CReCES staff members.

Several studies have shown that training the facilitators is a key element in the success of a project. That is why training was such an important part of this project. It helped the facilitators to understand the various components of the programme, to understand the logic behind it, and to master the contents of the activities to be able to put them into practice. This project allowed the facilitators to make suggestions and give their opinion on the contents of the training.

The community-based approach was used, as it was for producing the intermediate training guide.

The training course was offered to 16 facilitators for 4 days, during which the three trainers used the facilitator's guide to formulate, test, adjust and produce the training guide. The facilitators who were chosen are psychosocial counsellors working for ARCAD-SIDA, who facilitate community-based actions or who are leaders of HIV/AIDS organisations in Mali. This group of facilitators also includes the WLHIV who participated in the test phase and were picked out for their listening and leadership skills.



The Donya training centre was set up in 2003, with the aim of upscaling access to HIV treatment by training stakeholders involved in the fight against HIV/AIDS. It came into being thanks to the conjoined efforts of AIDES and ARCAD-SIDA.

The DONYA centre has:

- A large training room that can seat 35 people.
- A smaller room with a seating capacity of 22.
- A documentation room.
- A terrace for meals and relaxation.

- **Involvement of knowledge translators**

The commitment and involvement of knowledge translators was crucial in this project.

There were 6 of them and at the beginning of the test phase they benefitted from a training course on the facilitator's guide, the expected outcomes of the project, confidentiality and non-judgment rules and also on their roles in the project.

« The thing I liked most about Gundo-So was the atmosphere of trust within the gathering, we were a cohesive group. There was no difference between knowledge translators, facilitators and users, and this made the women feel comfortable. Also the fact that there was a doctor there but not wearing a white coat reassured them. »

Dr Ténin Diawara

Knowledge translator

- **12 groups of 8 WLHIV on 6 sites were facilitated**

After the facilitators and knowledge translators were trained, 12 groups of 8 WLHIV benefitted from the programme on 6 ARCAD-SIDA sites (2 groups per site) to try out the tools.

- **Assessment workshop with facilitators, UQAM and Coalition PLUS in Bamako to validate the facilitator's guide**

At the end of the pilot phase, an assessment workshop was organised to take greater account of feedback on the tools and to make changes in the facilitator's guide. This workshop included CReCES staff, the community-based research manager at Coalition PLUS, the director of ARCAD-SIDA and the programme manager.



3. Step 3: Assessing the pilot phase

The pilot phase was assessed using quantitative data collected through pre- and post-intervention questionnaires (35 questions) which were given out by the facilitators before and after the programme. In addition, qualitative data were collected at each meeting (through log books) reflecting each participants particular thought process (progression, development). These data also include feedback from participants and facilitators during plenary sessions.

Criteria included in the evaluation were:

- The burden of secrecy.
- Decision-making / self-esteem.
- Being able to plan and implement strategies for keeping status secret.
- Being able to plan and implement strategies for disclosing.
- Support from the other women in the group.
- Perception of being able to control one's life.

The results of this pilot phase showed positive and conclusive effects. That is why the programme was enlarged to accommodate a greater number of WLHIV and to extend it to other ARCAD-SIDA locations.

4. Stage 4: Extension

The programme was carried out with 12 groups of 8 WLHIV in 6 locations where ARCAD-SIDA has care facilities in Bamako and one location in the region of Kayes.

This phase was evaluated using the same data collection tools and the same evaluation criteria as for the pilot phase.

USING THE DATA

The data were analysed by CReCES staff. Quantitative data were processed using statistical analysis software (SPSS). Descriptive statistics were produced (frequency, proportion, average and standard deviation) to describe socio-demographic and behavioral characteristics of the sample.

Assessment of the effects of Gundo-So was made by comparing averages obtained during pre- and post-intervention for each evaluation criteria using statistical techniques appropriate to these kinds of data (matched samples).

As for the qualitative data collected in the log books and questionnaires, they were processed using qualitative data analysis and research software (ATLAS.ti) by analysing thematic content.



V

**RESULTS
OF PROGRAMME
EVALUATION**

The Gundo-So project was approved by the ethical committee of the National Institute of Research in Public Health in Bamako which decreed that the programme was consistent with human rights ethics.

The effects of the programme

The results of the programme's effects include those of the pilot and extension phases. In total, 190 WLHIV benefitted from the programme between 2012 and 2014. Mean age for women was 35. Women had been aware of their HIV status for 3.7 years on average.

Results ⁴ show that WLHIV who benefitted from the programme feel:

- Less overwhelmed by the burden of secrecy.
- Better able to make a clear and informed decision about disclosing their HIV status or keeping it a secret.
- Better able to plan and implement strategies to keep their status a secret.
- Better able to plan and implement strategies to disclose their status.
- More supported by other women.
- Better able to have a strong feeling of control over their lives.

« With Gundo-So, we reach the heart of the difficulties faced by WLHIV in my country. »

Dr Dembélé Bintou Keita
Director of ARCAD-SIDA

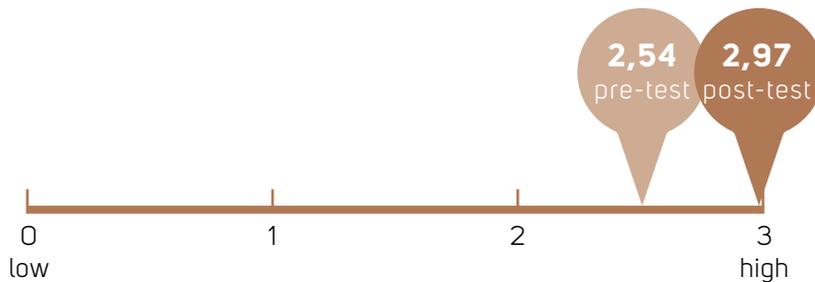


« Gundo-So provides psychological relief for these women. As a HIV doctor, this project seems to me to be essential for people living with HIV/AIDS. »

Dr Mamadou Cissé
Doctor at CESAC in Bamako

⁴ Average score on multi-item scales

Perception of support from other women



« Taking part in the programme brought about changes in women's relationships with each other. They are less anxious and realise that they can live in society without worrying about their status. »

Facilitator, WLHIV, widow, 34

« The women formed a group and kept in touch even outside the programme. A bit like sisters. They give each other advice and encourage each other to take their treatment. »

Facilitator, WLHIV, widow, 34



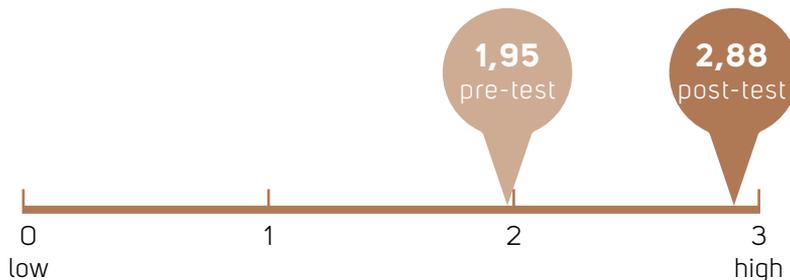
« What struck me most about the programme is the fact that we were able to chat with the others without fear of being rejected or discriminated against. »

WLHIV, married, 44

« The strong point of the programme is that we are with other women. We even made a tontine, got to know one another and kept in touch even if we are not in the same area. »

WLHIV, widow, 34

Being able to make a clear and informed decision about disclosing status or keeping it a secret



« Before, I used to tell them that they had to disclose, but with the programme, I understood that it's preferable to help them pinpoint the advantages and disadvantages in each situation and let them decide for themselves. »

Facilitator, WLHIV, 56

« After the programme, I realised that some revelations are not worthwhile. For instance, disclosing to someone who cannot help you in any way (morally or financially). However, some revelations are useful if they are with someone who can support you and keep your secret. »

Facilitator, WLHIV, widow, 34

« I understood that disclosing one's HIV status is not always the solution and that we can keep it a secret without it being a burden. »

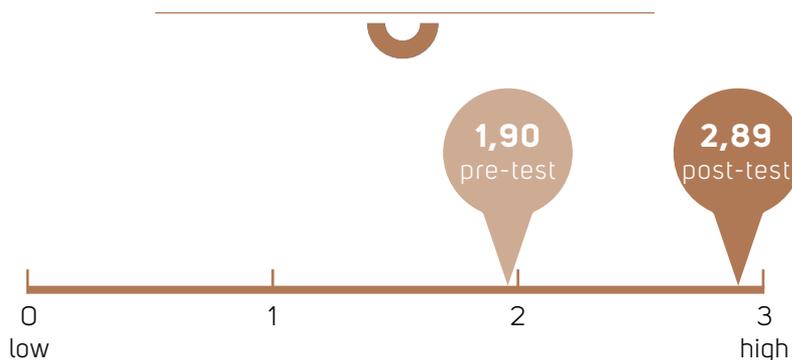
Facilitator, WLHIV, married, 40

« We used to tell women to tell their husbands and we never gave them a choice about that. Because of this pressure, some women stopped going to the treatment site. After the programme, we realised that this wasn't the right way of doing things and we needed to give them time and let each woman choose what they want to do with their own strategies. »

Opinion of several focus group facilitators



Feeling of self-efficiency with regard to planning and implementing strategies for keeping HIV status a secret

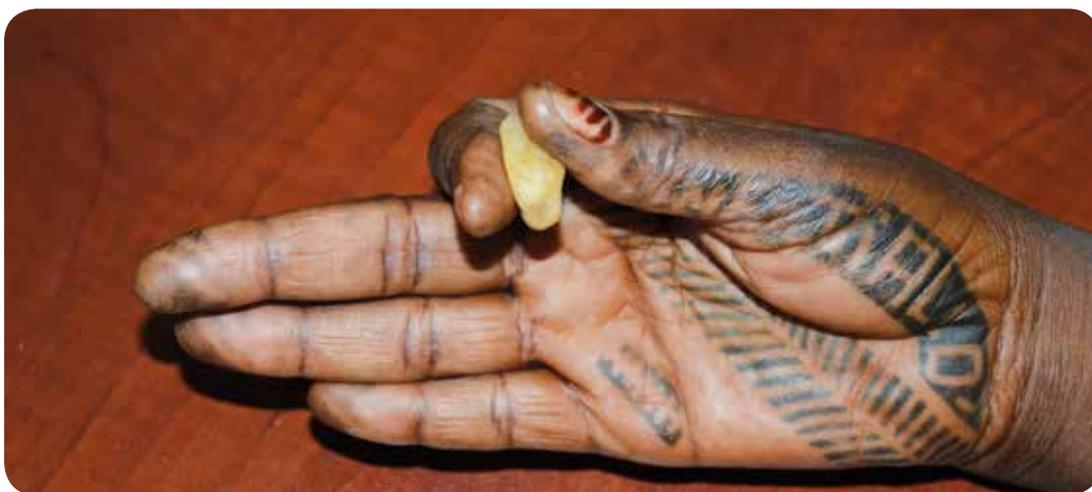


« Before joining the programme, I was going to tell my brother but now I realise that I don't need to anymore. There are people here who support me and it's better if I tell them than my brother.

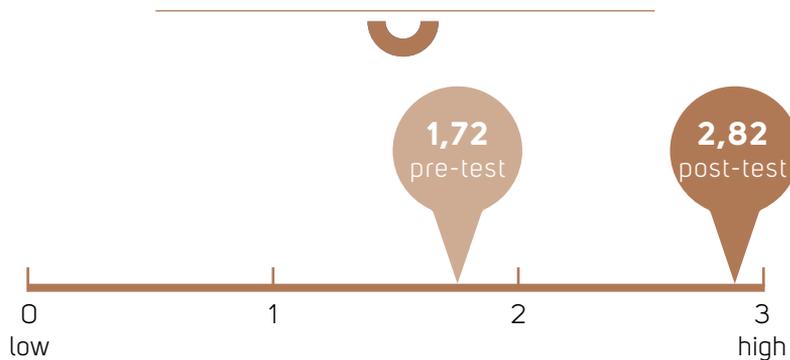
»
WLHIV, widow, 45

« Before joining the programme, I was isolated from others, I kept my distance and was very withdrawn. Thanks to the programme, I can now talk to other people and I also found a way to keep my HIV status and medication to myself.

»
WLHIV, married, 34



Feeling of self-efficiency with regard to planning and implementing strategies for disclosure



« During the programme, I got some strategies to help me disclose my HIV status to my father, and it worked really well. »
WLHIV, widow, 45

« I got some strategies to help me disclose to my son. »
WLHIV, married, 55

« The programme helped me disclose to my mother who took it very well. »
WLHIV, divorced, 34

« I have an older brother I wanted to talk to about my HIV infection but I wasn't sure I was able. With the help of the programme, I did it and it worked. »
WLHIV, widow, 34

« I got a lot out of the programme. I didn't want to disclose my status to my children but in the end I decided to tell my daughter and it went very well. »
WLHIV, married, 46

« The programme gave me peace of mind. I was able to talk about it to my brother and his son and also my own daughter. »
WLHIV, widow, 48

Feeling of having control over one's life

2,02
pre-test

2,62
post-test

« The programme comforted me and helped me feel like living again. »

WLHIV, widow, 45

« I was very satisfied with the programme, I felt more stable afterwards and I feel so much better. »

WLHIV, married, 55

« After the programme, I felt more emotionally stable and felt like living again. Whereas before, I thought I could never have a normal life again. »

WLHIV, married, 34,
two HIV negative children

« Through the programme, I discovered that I could get married and have healthy children. »

WLHIV, single, 35

« "Since I took part in the programme, I'm less shy and I feel better. I had stopped having tea with my family but now I've started again, even with my children. I've recovered a taste for life. »

WLHIV, married, 39

« The women are less stressed, get closer to the others and look after each other. »

Facilitator, WLHIV, married, 46

« What struck me the most about the programme is that it enabled me to get back into society, to be more self-assured and this helped me to take my medication properly and regularly. »

WLHIV, single, 35

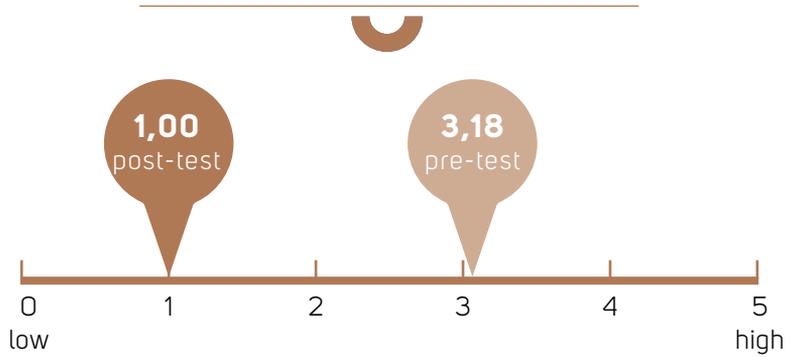
« Because of the programme, I feel calm, and I can talk to my kids easily without telling them that I'm going to die soon. I look after myself, and I still sell red palm oil and peanut paste like I used to. »

WLHIV, married, 44

« I feel more emotionally stable since I joined the programme. »

WLHIV, divorced, 34

Feeling of being overwhelmed by the burden of secrecy



« Gundo-So relieves you from the burden of this illness. »
 WLHIV, widow, 45

« To sum up, the programme made me feel like living again despite all the trouble I had with my illness, my divorce, losing a child, and the burden all this left me with. »
 WLHIV, divorced, 34

« The programme arrived at a moment in my life where I was feeling very down, very anxious; I didn't want to live anymore and I didn't know how to talk about it with my loved-ones. »
 WLHIV, married, 34

« I feel so much better. I have forgotten about the illness and I take my medication carefully. »
 WLHIV, widow, 34



« The women who took part in Gundo-So have become more open, there are no more barriers between us. »
Dr Khadidia
 Doctor at CESAC



VI

LIMITS
OF THE PROJECT

Despite the undisputable success of the project, as the evaluation showed, several limits regarding availability of time and money should be taken into consideration when reflecting on the feasibility of the project.

For the women



- Some women found it difficult to take the time to come to all ten meetings and find excuses for doing so
- Delays caused by people arriving late can make the meetings go on too long

For the facilitators (psychosocial counsellors)



- Extra work load caused by conducting the ten meetings
 - Not enough time to fill out the evaluation documents
 - Meetings are highly-charged emotionally

For the organisation



- Time
- Overall cost of project

VII

GUNDO-SO'S CONTRIBUTIONS AND NEXT STEPS

ARCAD - SIDA Mali

Association de Recherche de Communication
et d'Accompagnement à Domicile des Personnes
Vivant avec le VIH et le SIDA



Membre de la Coalition Internationale Sida



Benefits for ARCAD-SIDA

As Dr Dembélé Bintou Keita has pointed out, "Before, we used to support PLHIV to help them die, now we help them live".

Nowadays, care for PLHIV should go beyond medical treatment and this is confirmed by the Gundo-So project.

Gundo-So is a solution for our service providers

to help PLHIV to live with their illness in a better way and improve their quality of life.

This programme has strengthened the community-based approach within ARCAD-SIDA and this philosophy has become part and parcel of the psychosocial counsellors' everyday life in each ARCAD-SIDA location.



Benefits for CReCES

Apart from the fact that “Sharing together...for life” (PP/PP) and Gundo-So share the same logic model, it turns out that a large proportion of WLHIV in Canada are from African communities themselves. Therefore, as regards the results of the Gundo-So evaluation,

it has some external value and in the light of knowledge sharing, Gundo-So’s cultural adaptation also enabled the CReCES staff to improve their training and facilitation manual for the “Sharing together...for life” (PP/PP) programme.



Next steps

Gundo-So is a mobile and dynamic project enabling people to reflect on practices and ways of doing things.

As Karine Pouchain, Head of the Health Promotion and support for patients department at the Fondation de France, points out "The logic of this project can help organisations be more open to other activities in the future".

- This project has led to other projects on sexual and reproductive health, aiming to improve sexual and emotional well-being among WLHIV.
- Today, ARCAD-SIDA's goal is to decentralize Gundo-So throughout Mali and to develop it so that other organisations in the sub-region can benefit from it. The issue of disclosure is also difficult for men. Staff from ARCAD-SIDA carried out a survey among 46 men living with HIV which showed the relevance of supporting men on this issue. Today, staff are working on a Gundo-So which would be adapted to men living with HIV in Mali.



« *Gundo-So is a tool, an instrument adapted to cultural and social settings. It guarantees confidentiality and acknowledges the ethics and dignity of all. And this is what will help men take the first step, to reveal themselves*

without prejudice, judgment or ostracism and talk about their HIV, their lives and be accepted for who they are.

Dr Aliou Sylla
President of ARCAD-SIDA



« *I feel there is a need there... they really need to have someone to talk to for their emotional stability. I think Gundo-So could work for men, there are no secrets between men and this is a huge advantage.*

The opinion of a psychosocial counsellor working at ARCAD-SIDA on the issue of men living with HIV

« *I think it would be a good thing to do the same for men because they hassle their wives and if they understood, things would go better.*

WLHIV, married, 44

VIII

ADVICE
TO SET UP
GUNDO-SO
SUCCESSFULLY

Criteria for successfully implementing Gundo-So

Principles

- Have an in-depth understanding of the intervention.
- Respect the process and the various steps of the programme.

Community-based approach

- Pay attention to the by and for (by WLHIV and for WLHIV).
- Co-construction with WLHIV and healthcare personnel is indispensable to increase ownership and facilitate implementation in the field.
- The team must play an active role right from the beginning ; they must be involved and committed.
- Include emotionally stable WLHIV (those who have known about their HIV positive status for more than six months).

- Make sure the women are available to come to all gatherings: check the dates and times with them.
- Ensure confidentiality.
- Build capacity:
 - Provide training for facilitators
 - Support facilitators who, during the whole process, carry a heavy weight emotionally
 - Organize a “burn out” meeting to release emotions
- Have at least two facilitators in each group.

Culturally appropriate tools

- Readapt the programme so that the tools are chosen according to customs and culture with concepts that women and other professionals understand and make sure everything is understood.

Criteria to successfully evaluate Gundo-So

- Plan an assessment of the efficacy of chosen tools.
- Make sure there's not too much paper work; filling in documents takes up a lot of the facilitators' time.
- Plan an anticipated and thorough programme evaluation.
- The knowledge translators can facilitate the evaluation process. In this case, make sure they are involved right from the beginning of the programme and train them at the same time as the facilitators.

« I would like the programme to be extended to others so that all women can take part in it. »
WLHIV, married, 44

As the Bambara saying goes

*"You cannot pick up a stone with one finger!"
"Boloden n'goni kélé tè gabarkuru tâ!"*

Which means: In unity there is strength!





Coalition Internationale Sida, PLUS
Siège social : Tour Essor – 14 rue Scandicci
93508 Pantin Cedex – France
Tél : + 33 1 77 93 97 10 – Fax : +33 1 77 93 97 09
E-Mail: coalitionplus@coalitionplus.org
www.coalitionplus.org

