

S1: Presentation Page

Good afternoon everyone!

Thank you for your interest in “*Sharing Together For Life*”. Without further delay, we’re going to start presenting the “*Sharing Together For Life*” program, which was developed and evaluated as part of community research efforts carried out by the Canada Research Chair in Education and Health of the *Université du Québec à Montréal* (UQAM) and over 10 Quebec HIV/AIDS advocacy community organizations.

We should mention that the development, implementation and evaluation of “*Sharing Together For Life*” were supported by the CIHR’s HIV/AIDS Community-Based Research Program.

This presentation will be made by **Ginette Tremblay** and **Dada Bakombo**, co-founders and ambassadors of “*Sharing Together For Life*”.

Enjoy the webinar!

Our presenters



Ginette Tremblay

Ginette Tremblay has dedicated her life to helping people. During her 25-year nursing career, she completed a bachelor's degree in education, a bachelor's degree in psychosocial intervention models at Concordia University and rational emotive therapy studies.

Her work with the HIV/AIDS community started in 1992 when she began to facilitate grief support groups at the Pierre-Ainault centre in Montreal and became a volunteer support worker at the Centre for AIDS Services of Montreal--Women (CASM).

Ginette soon became a volunteer at AIDS Community Care Montreal (ACCM), where she facilitated support groups and later became a Case Manager. During this period, she moved to the Outaouais region for a year and a half to work at the Bureau régional d'Action Sida (BRAS) as a support coordinator.

Ginette has worked with the HIV/AIDS community for 20 years and was honoured for her contributions by the Farha Foundation in 2010.

Our Presenters



Dada Bakombo

Wife and mother, Dada Bakombo is a UQAM graduate in educational interventions in family and community settings. She is also working towards her degree in psychosocial interventions. After joining GAP-VIES in 2005, she worked as a facilitator in living environments, a coordinator for the African component of *"Pour une réponse interreligieuse au VIH/SIDA"* (an inter-religious response to HIV/AIDS program) and a care and volunteer action coordinator.



She has served as a coordinator for the Sharing Together For Life program and has worked as a research assistant on many research projects, including the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), the study on the impact of food safety on the health of people living with HIV/AIDS, the study on the emotional and sexual health of women living with HIV (*"Plurielles"*), and the second generation monitoring study of Anglophone African and Caribbean communities in Montreal. She continues to work with people living with HIV, providing them with the support they need in an atmosphere of respect and professionalism.

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Our presenters



Joanne Otis

Joanne Otis is a professor in the sexology department of UQAM. Her research work involves analyzing psychosocial and cultural factors related to sexual health, as well as the development, cultural validation, implementation, and evaluation of applied programs. She works with various populations: teens in schools, street youth, men who have sexual relations with other men, and people living with HIV. She is known for conducting participatory research projects in partnership with local HIV/AIDS groups located in Quebec, in Canada and abroad.

Our Presenters



Lyne Massie

Lyne Massie holds a Bachelor's degree and a Master's degree in sexology from UQAM. She has worked with local HIV/AIDS advocacy groups and currently works as a research coordinator in UQAM's sexology department. She has coordinated various research projects and has evaluated two programs to improve the quality of life of women living with HIV in Quebec and Mali: "Sharing Together For Life" and "*Plurielles*."



S6: Presentation of Partners

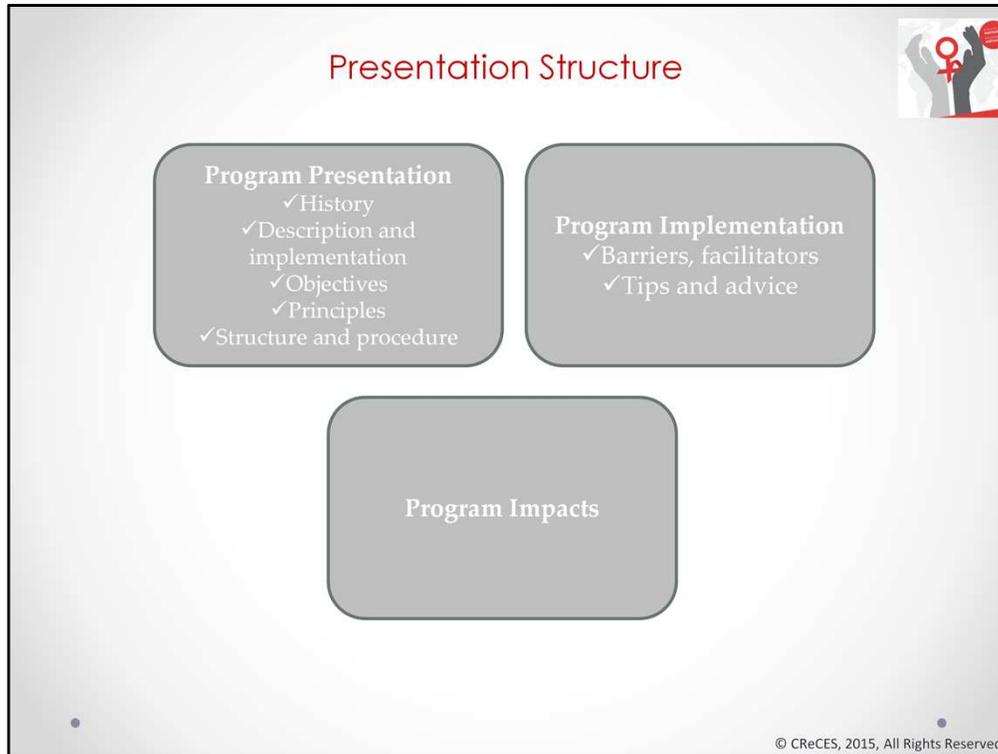
These are all the local and university partners from Quebec and elsewhere with whom we have developed a solid relationship, fueled by a common goal: improving the quality of life, health and well-being of Quebec women living with HIV (WLHIV).

We'd like to use this forum to express our **GRATITUDE** to them!

THANK YOU for believing in this program, for taking part in it, and for supporting it from the start.

THANK YOU to all the men and women who helped make a difference (i.e. WLHIV, facilitators, community organization directors, research team and decision-makers)!

And finally, we'd like to thank **CATIE** for allowing us to share this experience with you and for giving other WLHIV the opportunity to learn about this program model.



S7: Presentation Plan

By the end of this presentation, you will know what “*Sharing Together For Life*” is all about (its history, its objectives, its guiding principles and its structure). During this webinar, you will also discover challenges surrounding this type of program, as well as tips on how to implement and facilitate the program.

We will share the results of our 2008-2011 program evaluation, conducted with 85 Quebec WLHIV, and tell you about practical tools at your disposal (such as the Facilitator’s Guide and Case Study available on the CATIE site and the collection “*Pouvoir partager entre femmes*”, available only in French on the “*Sharing Together For Life*” portal: www.pouvoirpartager.uqam.ca).

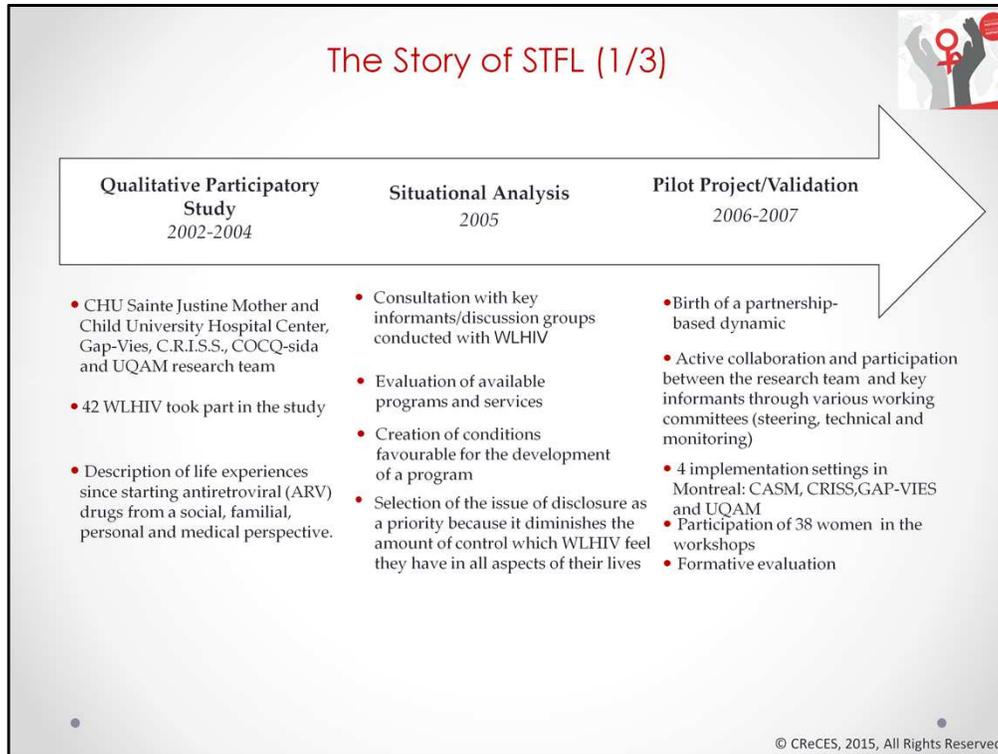
Here are the main points that will be discussed during the presentation.

- ✓ The Story of “*Sharing Together For Life* ” (STFL)
- ✓ The program objectives (general and specific)
- ✓ A description of the program
- ✓ Guiding principles of the program
- ✓ The approach proposed to participants
- ✓ The structure of the program
- ✓ The structure of each workshop

- ✓ A summary table of the program meetings + examples of activities
- ✓ Required materials
- ✓ Barriers and factors that assist with program implementation
- ✓ Program implementation and facilitation tips and advice
- ✓ The impacts of the program on the women
- ✓ Participant testimonials
- ✓ Where to obtain the Facilitator's Guide
- ✓ Questions



S8: Program Presentation



S9: The Story of STFL (1/3)

Qualitative Study (2002-2004)

In 2002-2004, a qualitative participatory study was conducted among WLHIV in the Montreal area to better understand their needs and to explore their life experiences since the introduction of antiretroviral therapy (ART). Forty-two women of Caucasian, Haitian and African descent aged 25 to 51 took part in the study and shared the impact of these therapies from a social, familial and domestic, individual and relational perspective.

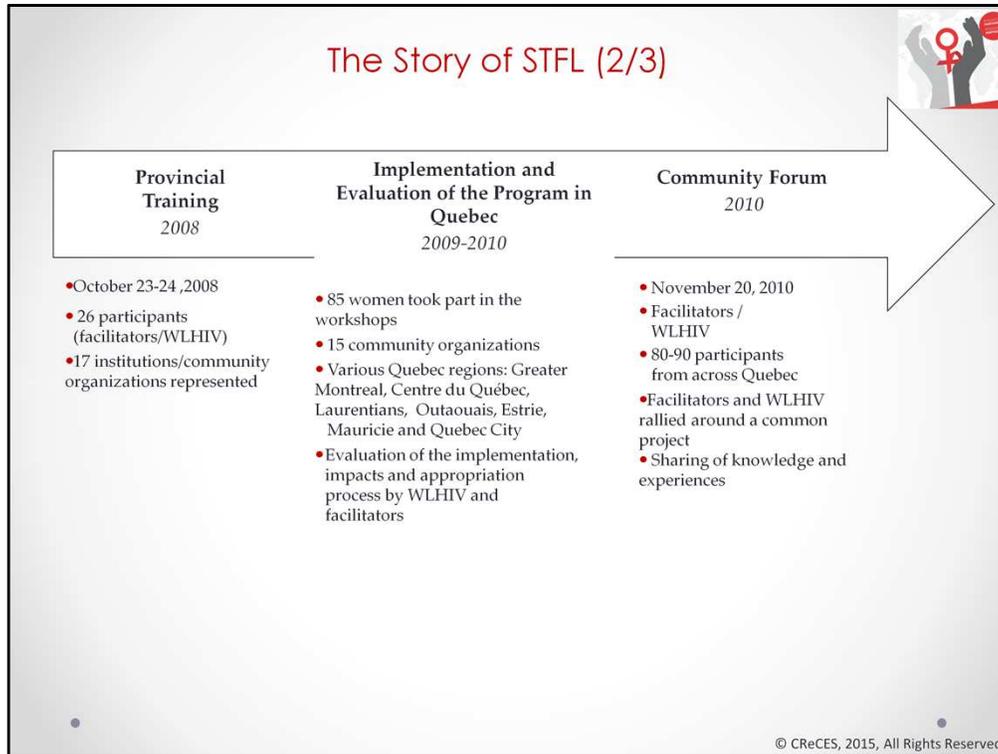
Situational Analysis (2005)

In the summer of 2005, a consultation with 35 key informants, some of them WLHIV, allowed us to garner a portrait of the programs and services available to WLHIV in the Montreal area.

This first step allowed the creation of a true partnership-based dynamic within which 14 local HIV/AIDS advocacy groups met and rallied around the same project: developing an intervention program for WLHIV. The issue of disclosure was then officially chosen as a priority for program development, as the question of disclosure diminishes the amount of control which WLHIV feel they have in all aspects of their lives.

Pilot Project/Validation (2006-2007)

A pilot project was undertaken in 2006-2007 in Montreal to develop, implement and validate intervention mapping for these women to give them greater control over the decision to disclose their status or to keep it a secret, in the different spheres of their lives. This pilot project, called “Sharing Together for Life”, was designed and implemented in collaboration with stakeholders from community, social and health organizations and with the participation of 38 WLHIV in the Montreal area. The results obtained through the validation of the program confirm its relevance and usefulness and demonstrate that the program improves the ability of women to disclose their HIV-positive status (or to keep it a secret) in a well thought-out and proactive manner.



S10: The Story of STFL (2/3)

2008 Provincial Workshop

In 2008-2011, the program was improved and implemented throughout Quebec so that a greater number of women could benefit from it. At the outset of this process, a committee of WLHIV who had taken part in the pilot project designed training sessions to teach individuals how to use the facilitator's guide for the program.

This training was offered and assessed during "*Outillons-Nous*" educational sessions provided by the *Coalition des organismes communautaires québécois de lutte contre le VIH (COCQ-SIDA)* to 26 stakeholders from several regions in Quebec.

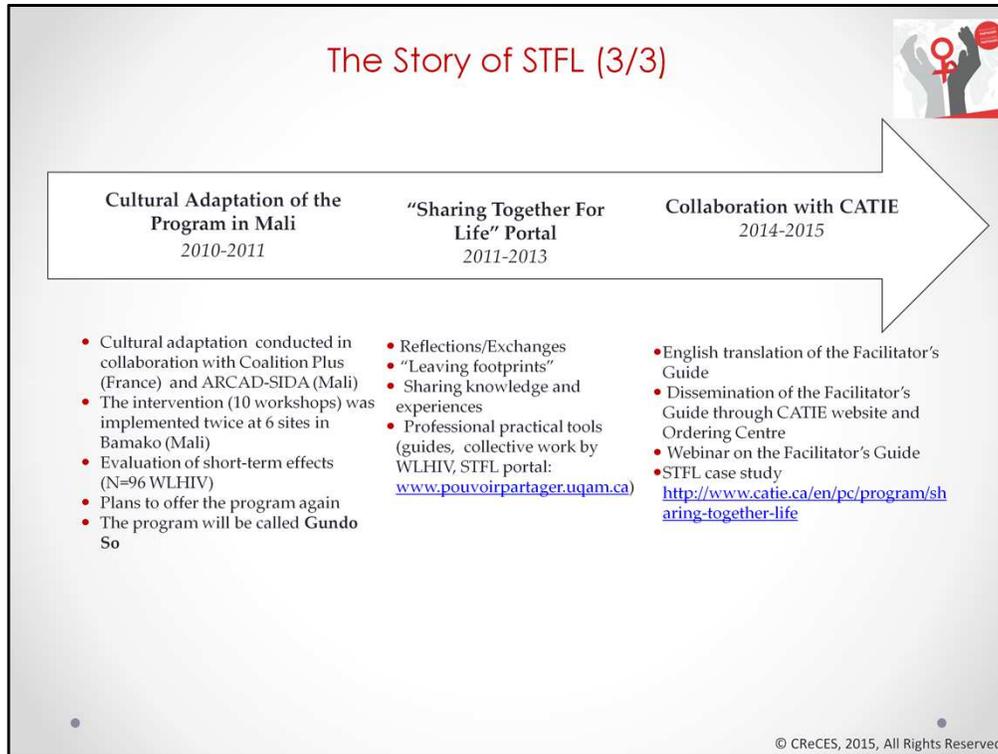
Program Evaluation and Implementation in Quebec

In 2009-2010, the revised program was offered by 13 stakeholders and 7 volunteers (WLHIV) who had received the training. The impact of the program was assessed through the active and ongoing involvement of 15 agencies in Quebec as well as 85 women. The results of this assessment confirm those obtained during the pilot phase and demonstrate that not only does the program have significant short-term impacts for the Quebec participants but that these effects last over time (six months after the intervention)

The assessment also provides lessons learned about the implementation of this type of program in rural areas or in other socio-cultural settings and about factors that promote a sense of ownership over such a program for WLHIV and for the organizations that support them. The provincial evaluation also allowed WLHIV and stakeholders to talk with the research team about aspects of the Facilitator's Guide they felt needed to be improved or revised.

Community Forum

On November 20, 2010, a community forum was organized by the program facilitators. All the WLHIV and the facilitators who were directly or indirectly involved in STFL were asked to take part in this event, and 80-90 women attended. The aim of this event was to create a specific forum which would allow the participants to share the experiences they had had throughout this project. These experiences related to what they learned about the issue of disclosure, personal, community and organizational empowerment, etc. The forum led to STFL experience testimonials in each area where the program was implemented, testimonials from loved ones about the issue of telling or not telling, the presentation of group murals created during the final program workshops, a reflection workshop on concrete disclosure management strategies, the presentation of study results, and information on new developments in criminal laws regarding the non-disclosure of a person's HIV-positive status.



S11: The Story of STFL (3/3)

Cultural Adaptation of the Program in Mali

Although the social and cultural context is different, the issue of disclosure greatly impacts day-to-day life in Mali, as it does for WLHIV in Quebec. Keeping a secret is often a short-term solution and disclosing to one’s spouse is often complicated for many Malian women (which is also the case in Quebec), especially in the context of polygamy. Given these circumstances, the ARCAD-SIDA team wanted to help women acquire practical tools to make educated decisions and to implement action plans to live with their decision. Thanks to the support of the Canadian Institutes for Health Research and the Fondation de France, the team in Mali and the Canada Research Chair in Health Education at UQAM (in partnership with Coalition Plus, of which COCQ-SIDA is a member) reviewed the program in detail and adapted it to the reality of the women who use their services. These efforts led to GUNDO SO (the Mali version of STFL). While the program is currently in the evaluation phase, it has also been shown to be effective. Eighty-five women attended these adapted workshops. Afterwards, the women said they didn’t feel as burdened by their secret. They also said they appreciated the moral support they received from other WLHIV and felt more in control of their lives.

“Sharing Together For Life” Portal

In collaboration with facilitators from community organizations, WLHIV and the research team, professional practice tools were developed in order to provide long-term active support and to “leave footprints” of the positive impacts which this project had on the lives of facilitators and Quebec WLHIV. To this end, the Facilitator’s Guide was reviewed and improved a second time by the facilitators, a collective book was created by the WLHIV who took part in STFL, and a Website dedicated to the theme of disclosure or non-disclosure was created. This online portal provides access to professional practice tools and to information for WLHIV on the issue of disclosure. The ultimate goal of this portal is to allow the positive impacts of this research project to reach as many women as possible in order to improve their lives and the practices of facilitators who help WLHIV manage their disease.

Collaboration with CATIE

Thanks to the support of ViiV Health Care and CATIE, the Facilitator’s Guide was recently translated into English and will be distributed across Canada through the Ordering Centre, to ensure that even more WLHIV can come together and share their experiences, especially those related to the sensitive subject of disclosure. CATIE also created a “Programming Connection” case study about the program, which can be accessed through the CATIE website.

Program Description



- ✓ “Sharing Together For Life” (STFL) is an empowerment program created **WITH, BY** and **FOR** women living with HIV (WLHIV).
- ✓ It addresses the following themes:
 - The HIV adaptation process;
 - Situations where the issue of disclosing one’s HIV status may come up;
 - Potential challenges surrounding the disclosure of one’s HIV status; and
 - Potential strategies related to the issue of disclosing or not disclosing one’s HIV status
- ✓ STFL is seeking to fill a void given that there are so few programs and services for WLHIV that deal with the issue of disclosure.

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S12: Program Description

“*Sharing Together For Life*” is an empowerment program that draws on the experiences of WLHIV surrounding their daily decisions to disclose or not disclose their HIV-positive status.

Various themes are covered within the program: the **HIV adaptation process**, disclosure and non-disclosure **contexts** (i.e. the people, places, and situations where women may have to deal with the issue); **the challenges** surrounding disclosure and non-disclosure, and the contexts and strategies for women to consider so they can disclose their secret under the best possible conditions or keep their secret if this is what is best for them.

STFL is one of the first programs for WLHIV dealing with the theme of HIV disclosure to have been developed, evaluated, culturally adapted, and validated for its effectiveness.

Program Implementation Approaches



- ✓ In the form of discussion groups (4 to 8 women):
 - This program can be offered as 9 weekly meetings:
 - during the day, or
 - in the evening (standard approach),
 - On weekends, as part of a closed or open retreat (intensive approach)
- ✓ In the form of individual meetings (1x or 2x/week)
- ✓ An intensive weekend retreat and individual meetings offers the best approach in contexts where it's difficult to have the women meet several times or if the organization doesn't reach many women.

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S13: Implementation Modes

Discussion Groups

The program can be offered in the form of a discussion group (4-8 participants) so that women can support each other's disclosure or non-disclosure decisions.

You should choose the time period that is most convenient for the majority of the participants (1 meeting/week during the day or in the evening). This is the standard approach.

The program can also be offered on a weekend (plus a 3rd day) as part of a closed or open retreat. This is what is referred to as the intensive approach.

Individual meetings

Depending on the needs of each woman and their own journey, it may be best to give the women individual support within which the program workshops can be adapted or to lead the women towards adapted resources.

This can take various forms depending on the number of women you wish to reach, their physical and emotional availability, and their ability to commit to a change and personal growth process for their own well-being and that of other women living

with HIV.

Ultimately, the program can be adapted to best meet the needs and schedules of women themselves.



Program Objectives (General and Specific)

- ✓ The program gives WLHIV the tools they need to deal with the daily challenges they face surrounding the disclosure or non-disclosure of their HIV-positive status.
- ✓ The aim of this program **IS NOT TO PROMOTE** disclosure of HIV status, but **RATHER** to allow women to **SHARE** the experiences they have had when faced with the decision to disclose or not disclose their status.
- ✓ **Specific objectives:**
 - Make a proactive and thoughtful decision about whether or not to disclose their HIV status in various contexts
 - Plan strategies allowing them to move forward with the decision to disclose or not disclose their HIV status
 - Better manage difficult situations or negative experiences in the context of a planned disclosure or unwanted disclosure

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S14: Program Objectives

“*Sharing Together For Life*” gives WLHIV the tools they need to deal with the daily challenges they face surrounding the disclosure or non-disclosure of their HIV-positive status.

The aim of this program **IS NOT TO PROMOTE** disclosure of their HIV status, but **RATHER** to allow women to **SHARE** the experiences they have had when faced with the decision to disclose or not disclose their status.

With the help of facilitators and peer-assistants, the participants learn the skills they need to:

- Make a **proactive and thoughtful decision** about whether or not to disclose their HIV status in various contexts;
- **Plan strategies** allowing them to move forward with the decision to disclose or not disclose their HIV status; and
- **Better manage** difficult situations or negative experiences in the context of a planned disclosure or an unwanted disclosure

Concretely, the program helps women deal with situations where the issue of disclosure is problematic. The women are initially asked to consider a possible decision and to weigh the pros and cons of that decision (do I feel the need to tell or do I want to keep it to myself? What reasons are motivating my decision?). They are then given strategies to help them to move forward with their decision and deal with its aftermath.



Approach Proposed to Participants

The program allows the women to:

- ✓ See where they are when it comes to disclosing or not disclosing their HIV-positive status to the people in their lives.
- ✓ Gain a better understanding of the challenges surrounding the issue of disclosure and non-disclosure.
- ✓ Better deal with the burden of their secret
- ✓ Make a non-coerced and informed decision based on the specific context
- ✓ Move forward with their decision after developing an action plan and creating disclosure/non-disclosure management strategies



So women can gain more control over their lives

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S15: Approach Proposed to Participants

•This program allows women to:

✓See where they are when it comes to disclosing or not disclosing their HIV-positive status to the people in their lives.

•This program also allows women to start a process that will help them to:

✓Gain a better understanding of the challenges surrounding disclosure and non-disclosure

✓Better deal with the burden of their secret

✓Make a non-coerced and informed decision based on the specific context

✓Develop an action plan and create disclosure/non-disclosure management strategies

So women can gain more control over their lives

Guiding Principles of the Program (1/3)



- ✓ Every woman can **FIND HER OWN SOLUTIONS**.
- ✓ Disclosure is a recurring issue in the life of every woman living with HIV.
- ✓ Every woman living with HIV goes through her own journey.
- ✓ The program neither promotes disclosure nor non-disclosure of HIV status.
- ✓ By sharing their experiences and journey, women gain insights and support.
- ✓ No one is forced to share and those who do are always treated with respect.

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S16 : Guiding Principles of the Program (1/3)

The program is guided by general principles, the following of which are the cornerstone of the program.

•**Every woman can FIND HER OWN SOLUTIONS.**

- ✓ Whom does she plan to tell or not tell? When? Where? Under what conditions? How?
- ✓ Solutions to deal with the negative or positive reactions of those in question.
- ✓ Solutions to deal with being “outed”.

•**Disclosure is a recurring issue in the life of every woman living with HIV.**

- ✓ Over time, women have to keep re-evaluating disclosure-related issues, as situations may change.
- ✓ The program gives women the tools they need to evaluate these issues as contexts change or as new contexts emerge.

•**Every woman living with HIV goes through her own journey.**

- ✓ Women may become overwhelmed or upset on their journey to adapting to life with HIV and may experience a wide range of emotions related to their condition.
- ✓ Every woman deals with her HIV status at her own pace and in her own way.

✓ The aim of the program is to help women understand the stages involved in adapting to life with HIV and to find their bearings at each stage.

• **The program neither promotes disclosure nor non-disclosure of HIV status.**

✓ Rather, the aim of the program is to allow women to share experiences surrounding the issue of disclosure and to help them become more thoughtful and proactive when it comes to deciding whether or not to reveal their status in various contexts.

• **By sharing their experiences and journey, women gain insights and support.**

✓ The program allows the discussion group participants to emerge from their isolation, to benefit from the support and experience of other women and to make friends.

✓ The program clearly shows that these benefits are significant among women who share their reality and their concerns with other women living with HIV.

• **No one is forced to share and those who do are always treated with respect.**

✓ It is extremely important that facilitators remind the participants that sharing is voluntary, that everyone must be treated with warmth and respect, and that no one is forced to share their personal experiences if they do not wish to do so. During the welcome meeting, each woman must sign a Moral Commitment and Confidentiality Agreement, a symbolic gesture showing that each woman is committed to maintaining the confidentiality of the statements made by the other participants during the meetings.



Guiding Principles of the Program(2/3)

- ✓ **Attitudes between facilitators and participants**
 - Respectful and non-judgmental
 - Attentive and empathetic
 - Formal commitment to maintaining confidentiality
 - Supportive

- ✓ **Expected roles of facilitators**
 - Guide, coach and facilitate
 - Not direct the women
 - Not give their personal opinions
 - Not impose their personal values
 - Inform the participants of their rights and obligations in regards to disclosure of their HIV-positive status
 - Be qualified to facilitate a focus and support group

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S17: Guiding Principles of the Program (2/3)

Attitudes between facilitators and participants

- Everyone has a role to play in this type of intervention. However, both facilitators and participants are expected to maintain certain attitudes to ensure the success of the meetings, i.e. respecting differences, listening to others, maintaining personal confidentiality, supportiveness, and a willingness to share with other participants.

Roles of facilitators

- The main tasks of facilitators are to encourage mutual support and the sharing of strategies and experiences between participants to ensure that exchanges are beneficial for everyone. It is important that facilitators act as guides, coaches and information agents, which means they cannot dictate a specific line of conduct to the women. If required, the facilitators should also be available to offer support to those who need it.
- Facilitators must also understand the reality of WLHIV and know the most recent laws regarding HIV-positive status disclosure.
- Facilitators must have taken a group facilitating workshop or have the required skills to facilitate focus and support groups. Otherwise, one of the co-facilitators should be a professional from the organization where the program has been

organized or have group facilitation experience.

Guiding Principles of the Program(3/3)



- ✓ **Expected roles of participants**
 - Own their emotions and speak in the first person (“I”)
 - Explore the pros and cons of disclosure in each situation
 - Share their strategies with the other participants
 - Support the other participants
 - Validate the other participants’ strengths

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S18: Guiding Principles of the Program (3/3)

Roles of participants

- Participants are encouraged to own their emotions and to speak in the first person (“I”) during meetings to avoid misunderstandings.
- To encourage the growth of the participants and the group, participants are encouraged to explore the pros and cons of disclosure in each situation they are faced with, to share their strategies with the other participants, to support them and to validate their respective strengths.
- And while no one is forced to share, some level of commitment is necessary; for example, everyone is expected to participate during individual or group activities.

Summary Table of Program Meetings



1-WELCOME	Outlining expectations and commitment of the program
2-PORTRAITS OF WOMEN	Setting the tone
3-LEARNING TO LIVE WITH HIV	Learning about the HIV adaptation process
4-LIFE SITUATIONS	Exploring of the various situations surrounding the issue of disclosing or not disclosing one's HIV-positive status
5-CONTROLLING MY OWN DESTINY	Making the decision to disclose and planning strategies for disclosure
6-SHARING TO BETTER SUPPORT EACH OTHER	Making the decision to keep the secret and planning strategies
7-SECRETS TO KEEPING YOUR SECRET	Making the decision to keep the secret and planning strategies
8-ONE, TWO, THREE, HUSH!	Making the decision to keep the secret and planning strategies
9-MESSAGES FROM WOMEN	Assessing skills learned and developing solidarity

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S19: Meetings Summary Table

The intervention consists of nine 3-hour meetings.

- 1- The first meeting (**Meeting 1: Welcome**) provides women with more information about the program (goals, themes of meetings, duration, type of activities) and enables them to think about their expectations of the program and to discuss their level of engagement.
- 2-The second meeting (**Meeting 2: Portraits of women**) is a social event, an opportunity for women to share personal stories. Participants get to know the group's participation rules and the importance of their role within the group.
- 3- The third meeting (**Meeting 3: Learning to live with HIV**) deals with the adaptation processes related to HIV. This meeting allows women to take stock when it comes to accepting their status and to realize that it is possible to live positively with HIV.
- 4 - At the fourth meeting (**Meeting 4: Life situations**) women also identify everyday situations in which the issue of disclosing or keeping a secret is brought up.
- 5- Subsequently, they evaluate potential issues surrounding disclosure in a given situation (**Meeting 5: Controlling my own destiny**),
- 6- they work to plan strategies they deem appropriate and achievable (**Meeting 6: Sharing to better support each other**),

7 & 8-then use their knowledge in a second situation where they would be confronted with dealing with the issue of keeping a secret (**Meeting 7: Secrets to keeping your secret** and **Meeting 8: One, two, three, HUSH!**).

In the final meeting (**Meeting 9: Participants' messages**) the program comes full circle through the creation of a collective mural. It also enables participants to describe how they feel after these meetings and how together they can help other WLHIV.

Various types of educational activities are used as part of the program:

- + Group discussions
- + Interactive games
- + Drawing-based reflection exercises
- + Impact techniques using movement, expression, objects or images
- + Documentary, testimonies and video

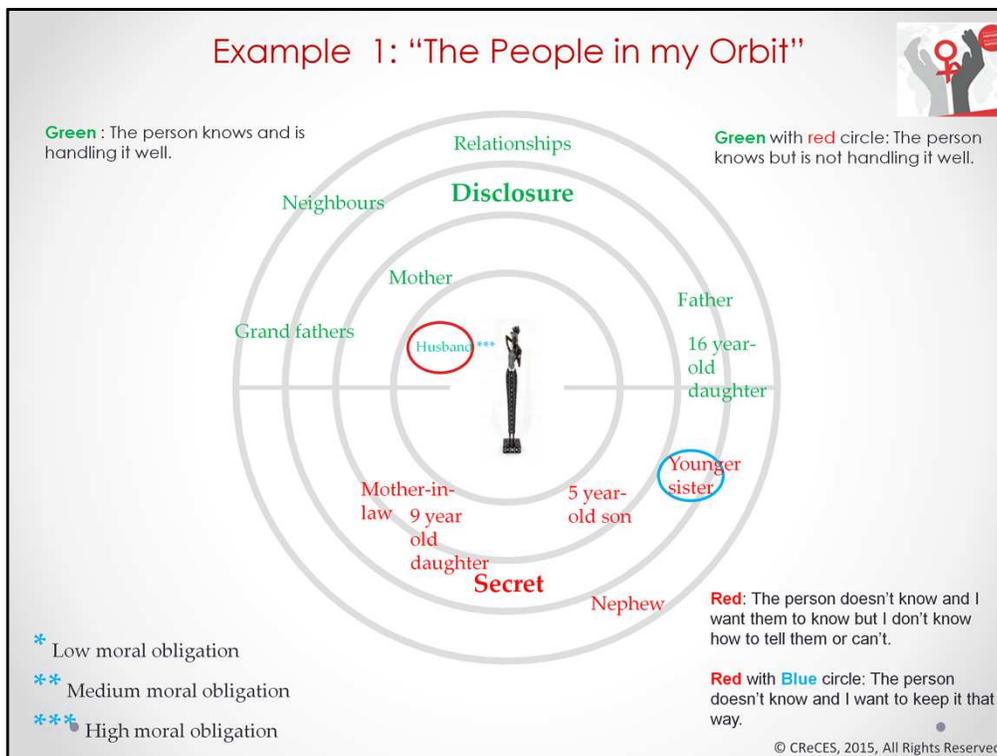
Meeting Procedure

- ✓ Each meeting is structured in the same way.
- ✓ Duration: 3 hours
 - Welcome – review of the previous meeting.
 - Presentation of the theme and objective of the meeting.
 - Sharing personal experiences and feelings about the theme of the meeting.
 - 1st interactive activity
 - Break
 - 2nd interactive activity
 - Group discussion
 - Meeting debrief

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S20: Meeting Procedure

- As an introduction, each participant is asked to recall the previous meeting and to talk about how it impacted their daily life. Those who wish can also talk about how they feel about the theme of the current meeting (e.g. The HIV adaptation process, challenges and possible strategies surrounding disclosure or non-disclosure).
- Next, two experiential activities (interactive games, thinking exercises with drawings and objects, impact techniques using movement, expression, objects or images) help participants to express an opinion on their real-life experiences. There is often a break between these activities.
- Meetings end with a group discussion that allows each participant to take stock of their own situation.
- Finally, some time is spent debriefing the meeting. During this period, participants are invited to express how they feel after the meeting and to share what they liked most and least along with their favourite moment of the meeting.
- It should be noted that over the course of the program, participants create a logbook as they engage in each activity, which they can keep or review with their facilitator during individual follow-ups.



S21: Activity Example #1

Here's a first example of an interactive activity called "The People in my Orbit" (duration: 60 min.).

This activity is offered during Meeting #4 (Life Situations) and allows the participants to see where they are in their life when it comes to the issue of disclosure.

The participants are first asked to create a list of the people in their orbit with whom the issue of disclosure has come up. They must then:

1. Indicate in green, in the upper semi-circle, the people who know about their HIV-positive status.
2. Indicate in red, in the lower semi-circle, the people who do not know about their HIV-positive status and whom they do not wish to tell.
3. Circle in red, in the upper semi-circle, the people who have had the most difficulty accepting their status.
4. Circle in blue, in the lower semi-circle, the people they would like to tell.
5. Determine the extent of the moral obligation ***they feel to disclose their HIV-positive status to certain people using blue asterisks.

- + The facilitator asks the participants to put the names of the people in their orbit in the various concentric circles according to their importance in their lives (the closer to the middle they are, the more important these people are to them).
 - +To keep the activity simple, the participants need only list one or two people in each circle.
 - +Once everyone has completed the exercise, the facilitator leads a group discussion and asks the participants about the people in their orbit.
 - +Those who wish to share can then tell the rest of the group about the experiences they have had with the people in their orbit.
-
- The concentric circle exercise is a great way for the participants to visualize all the people who are gravitating around them, as it provides a true picture of the configuration of their social network.
 - This exercise also allows them to list the people with whom they have daily interactions. By putting an image of themselves inside this network, it becomes easier to see how many people they have to tell or not tell about their HIV-positive status. It also allows them to see the people they have told who are very important to them, the people they have a good or not so good relationship with, etc.
 - It also allows participants to determine to what extent they feel a moral obligation to disclose their HIV-positive status and to re-evaluate the importance of this obligation as part of their decision-making process.

Example 2: My Savings Account



Context: Not telling my kids		
Pros	Deposit	
Protecting them from being stigmatized	10	10
Not making them sad	10	10
	Total Pros	20
Cons	Withdrawals	
Lying about my situation	6	6
Having to hide my medication	8	8
	Total Cons	14
Grand Total		
Total Pros – Total Cons		6



Well-being

+ 10

0



Energy spent

10

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S22: Activity Example #2

Here’s a second example of an interactive activity called “My Savings Account” (duration: 40 min). This activity is offered during Meeting #7 (Secrets to Keeping your Secret) and allows the participants to determine if it’s worth keeping their secret in a given context.

Participants are asked to choose a context where the issue of keeping their HIV-positive status a secret may come up (past or anticipated situation).

The women must then list the “pros” and “cons” of keeping their secret on the “My Savings Account” activity sheet (a maximum of 3 “pros” and 3 “cons” is suggested).

On a scale of 0 to 10, the participants must then determine what each “pro” brings to their well-being and what each “con” costs them energy-wise.

The participants must then calculate their grand total by performing the following calculation: **TOTAL PRO SCORE – TOTAL CON SCORE = GRAND TOTAL** (the result can be positive or negative). The idea is for them to add up their deposits (benefits) and withdrawals (energy spent) when it comes to keeping their secret in a given context, or in other words, to determine whether it is worth it to keep the secret in that

context.

+ If the GRAND TOTAL is positive (X), then keeping their secret benefits them more than it costs them energy-wise. At present, it may be better for the woman to keep her secret.

+ If the GRAND TOTAL is negative ($-X$), then keeping their secret costs them more energy-wise than it benefits them. It may be better for the woman to reveal her secret.

Required Materials



- ✓ Logbook for each participant
- ✓ Art supplies for each participant (colour crayons – wood/wax/felt-scissors, glue, varied colour boxes, varied stickers, magazines, etc.)
- ✓ Positive Women: Exposing Injustice documentary and accompanying guide
- ✓ TV and DVD player
- ✓ Blackboard or flip-chart – chalk or crayons.
- ✓ Ink pens.
- ✓ Monopoly-type money (\$1, \$2, \$5, \$10, \$20 bills).
- ✓ Opaque box or closed container containing feathers.
- ✓ Large cardboard or large piece of fabric (to create a mural)
- ✓ Private room
- ✓ Refreshments and snacks (or meal).
- ✓ Music player

Total approximate cost: \$500 (including meals and materials):

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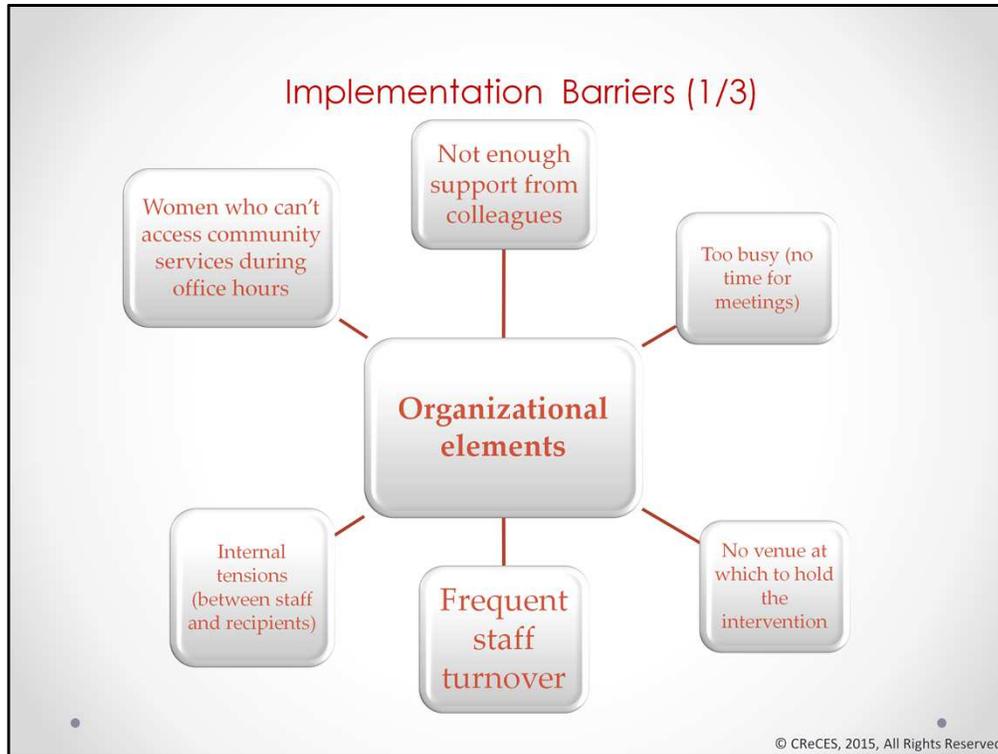
S23: Required Materials

To facilitate the program, you will need:

- A kit for each woman, including a personal logbook and art supplies (colour crayons, scissors, glue, varied colour boxes and varied magazines for cutting things out)
- The documentary Positive Women: Exposing Injustice and its accompanying guide, available online: <http://www.positivewomenthemovie.org/video.html>
- A blackboard or flip-chart with chalk or crayons.
- Monopoly-type money (\$1, \$2, \$5, \$10, \$20 bills).
- An opaque box or a closed container containing feathers.
- A large cardboard or a large piece of fabric (to create a group mural during the last workshop)
- A private room that is spacious enough to hold role-playing activities and to create the group mural during the last workshop)
- Refreshments and snacks.



S8: Program Implementation



S25: Implementation Barriers (1/3)

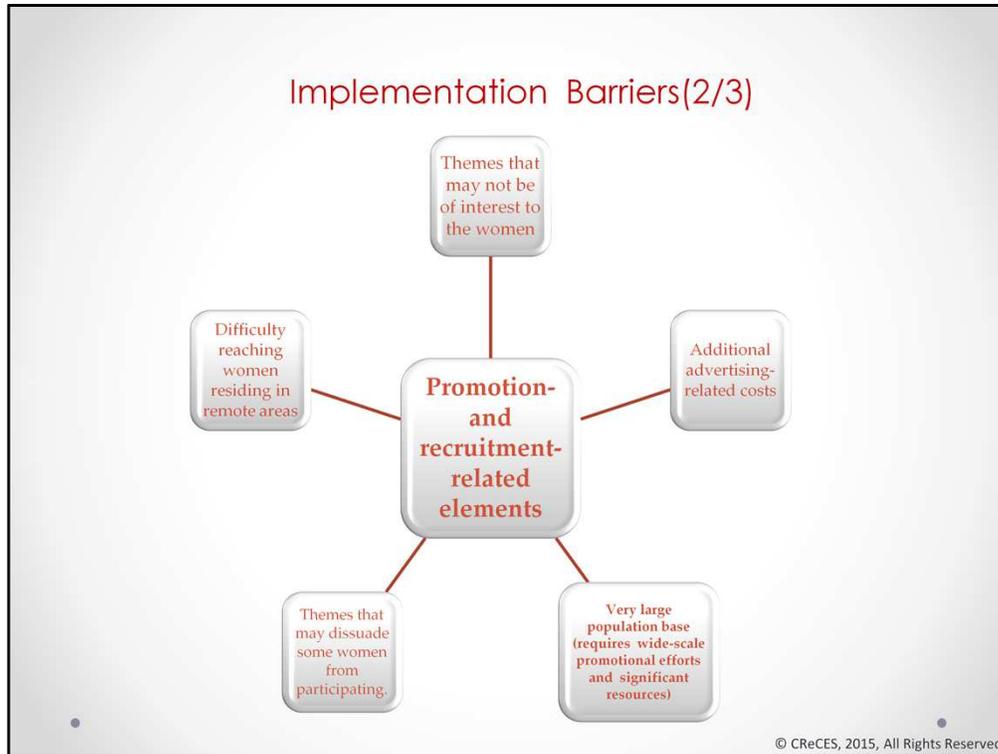
A number of barriers may occur when implementing the program.

These barriers can be grouped into three categories:

- 1-organizational elements
- 2-promotion and recruitment-related elements
- 3-Program structure-related elements

In terms of **organizational elements**, there may be issues related to...

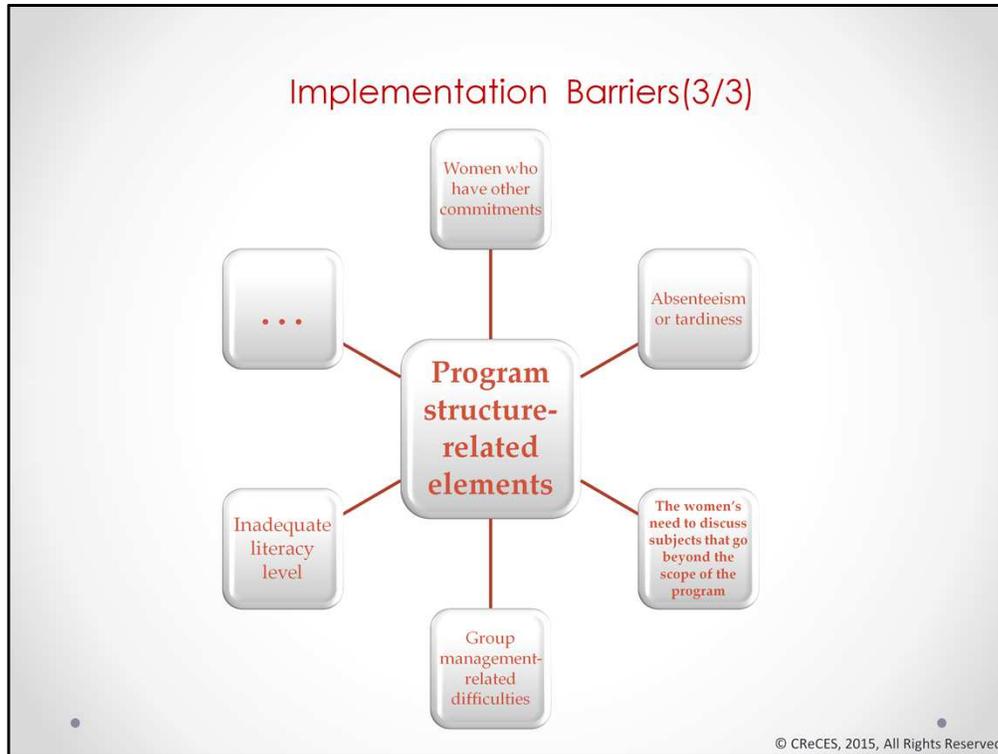
- Not enough support from management and colleagues when it comes to implementing the program
- Not enough time and human resources to invest in the program
- No venue at which to hold the program meetings
- Frequent staff turnover and internal tensions
- Women not having access to the organization's services during normal office hours (due to time constraints: school, work, taking care of their young kids, etc.).
- Situations where the goal of the program does not fit the organization's mission, making the program more difficult to implement.



S26: Implementation Barriers (2/3)

In terms of **promotion- and recruitment-related elements**, there may be issues related to...

- Themes that are not of interest to certain women. For example, those who don't hide their HIV-positive status or those who don't want to reveal it may have no interest in being involved with HIV/AIDS advocacy groups.
- Your organization finding it difficult to reach very isolated women through its promotional strategies (especially in remote areas and because of the greater scope of the territory it covers, which requires more wide-scale promotional efforts and significant resources).
- Themes that may dissuade some women from participating because they feel that the program promotes disclosing their HIV status.
- Recruiting women in rural areas, where infection rates are lower and where HIV-positive women are isolated from HIV/AIDS advocacy groups. Indeed, it isn't always easy to find women, especially in rural areas, over the age of 18, who were diagnosed at least six months ago and who feel comfortable talking about their situation in a group setting.



S27: Implementation Barriers (3/3)

In terms of **program-structure related elements**, there may be issues related to...

- Getting the women together on a regular basis (other commitments).
- Frequent absenteeism and tardiness (lack of motivation, health issues, daily commitments to meet, etc.).
- The women needing to emerge from their isolation and to discuss subjects that go beyond the scope of the program
- Managing problems within the group (gossip, conflicts between certain women, outbursts, etc.)
- The participants finding it difficult to understand activity instructions (women with little education, difficulty reading, different mother tongue)
- ...

Implementation and Facilitation Tips and Advice (1/3)

- ✓ Before the start of the program
 - Promotion
 - Recruitment strategies
 - Group composition and characteristics
 - Program implementation approaches
 - Documentation
 - Arrangements and incentives
 - Preparation of facilitators and support

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S28: Tips and Advice before the Start of the Program (1/3)

Program Promotion

- The facilitators should not abruptly introduce the program using only the term “disclosure” because this may make it difficult to mobilize women. They could explain that the program is a discussion and reflection group for WLHIV and that the experiences and insights shared by the participants will help them better deal with the daily issues and challenges they face. Make it clear that the program neither promotes disclosure nor non-disclosure of HIV-positive status, but rather educates WLHIV so they can make thoughtful and informed decisions and take control of their lives.

Recruitment Strategies

- You should try to obtain as much visibility as possible in order to recruit as many women as possible. The women targeted by the program should have access to information about the program (for example, you could make announcements in your organization’s newsletter, distribute flyers and post signs in your area.)
- You can also call the women who use the organization’s resources.
- It may be helpful to team up with hospitals offering specialized services to PLHIV (an immunodeficiency clinic) to promote the program, so feel free to meet with them and to get them involved in promoting your services.

- And finally, word-of-mouth is another great promotional tool.

Group Composition

- It is preferable to have 4 to 8 participants per group since including more people could make it more difficult to schedule meetings and would give the participants less time to share.
- Forming homogenous or heterogeneous groups (following the participants' profile) remains at your discretion. This decision should be made based on the participants' socio-demographic characteristics (age, sexual orientation, socio-economic status, ethnicity, number of years since diagnosis, etc.).
- Having women with different views on the issue of disclosure can be beneficial as others' opinions and experiences may open the participants up to new ways of thinking and dealing with their situation.
- Some participants may be illiterate or have a different mother tongue. It is therefore important to consider this when facilitating program activities (for example, the facilitator could read the exercise instructions and the co-facilitator could translate into the person's mother tongue, if possible).

Implementation Approaches

- The program should ideally be offered at times that are convenient for the participants.
- Shorter meetings can be held weekly or an intensive workshop can be held over a weekend, during a stay at a cottage, etc.
- Partnering with other organizations could make it easier to launch the program (more material, financial and human resources).
- The interventions can be offered in groups, individually (one facilitator and one participant) or in dyads (two participants and one facilitator)

Documentation

- You can give the participants various documents, brochures, and flyers as the meetings progress. A list of relevant documents is included in appendices 1, 2 and 3. You are also encouraged to update these lists.
- You can provide phone numbers where the participants can obtain more information (e.g.: HIV and sexual health hotlines, support and referral organizations).
- You can post articles or posters on HIV to create an atmosphere that is conducive to learning.

Arrangements and Incentives

- To encourage and facilitate the women's participation, the organization can offer to provide daycare to those with kids, give bus and subway tickets to cover travel

expenses, serve snacks at the break, or offer any other incentive that is likely to appeal to the participants.

- Meetings could take place outside the organization's office hours. If no one is in the office, some women may feel more comfortable attending the group meetings.

Preparation of Facilitators and Support

- Facilitators who moderate meetings must understand the reality of WLHIV and know the most recent laws regarding HIV-positive status disclosure.
- Facilitators must have taken a group facilitating workshop or have the required skills to facilitate discussion and support groups. Otherwise, one of the co-facilitators should be a professional from the organization where the program has been organized or have group facilitation experience.
- Finally, facilitators must be able to get help and support from colleagues and officers of the organization where the program has been organized (before, during and after the intervention).

Implementation and Facilitation Tips and Advice(2/3)

- ✓ During the program
 - Support of facilitators
 - Support of participants

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S29: Tips and Advice during the Program (2/3)

Support of Facilitators

- You will require personal, professional and organizational support. Your work team can be a major resource to help you with your work, as is your co-facilitator
- During the program, it may be helpful to share the experiences, difficulties and successes you are having, above all, with each other, but also with your coordinator or colleagues: you should identify a colleague or someone in the field whom you can talk to, if necessary. If you can't talk to someone in the field, you should talk to someone you know, taking care to maintain the anonymity of participants.

Support of Participants

- You may occasionally have to offer post-meeting support to participants who have been more affected by certain activities, so be sure to set time aside to provide this support, when needed.

Implementation and Facilitation Tips and Advice(3/3)

- ✓ During each meeting
 - Program facilitation

- ✓ After each meeting
 - Thank the participants
 - Complete the logbook
 - Offer moral support to participants

- ✓ Sustainability factors
 - Active participation of the WLHIV

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S30: Tips and Advice during and after Meetings (3/3)

1-During Meetings

Program Facilitation

- Given the serious nature of the topic and to ensure that program meetings run smoothly, we strongly suggest joint delivery of the program, i.e. that it be delivered by two facilitators. The co-facilitators must ensure that they are always available to participants by arriving in advance and staying until the last person has left.
- Since the program neither promotes disclosure nor non-disclosure of HIV-positive status, it is essential that you respect the decision-making process of each participant. Facilitators are resource people whose role is to provide the participants with support and guidance.
- You are responsible for carrying out program activities, answering the women's questions and providing them with information relevant to their reality, while organizing the discussions and synthesizing the information so the women can draw their own conclusions. If you are unable to answer some of the participants' questions, you must direct the women to the appropriate resources or bring answers to the next meeting.
- It is also important that you give the women time to speak. You should scan the

room and look at everyone during group discussions, not just some people. This way, you will be able to see the raised hands of participants who wish to speak.

- Before each meeting, you are encouraged to identify specific tasks to be performed in order to clearly establish who will do what and to ensure an equitable division of labour.

A few possible scenarios:

- Each facilitator can identify the activities she would like to moderate during a meeting.
- One facilitator can moderate the whole meeting and the other facilitator can prepare the room and materials, help the participants during activities, etc. Then, for the next meeting, the roles can be reversed.
- Many other scenarios are also possible. What is important is that the co-facilitators clearly identify and split up their tasks ahead of time.

2-After each Meeting

Thank the Participants

- After each meeting, be sure to thank each participant for her commitment and for sharing with the group.

Complete the Logbook

- You should also set aside up to 30 minutes to put the materials away and review the meeting with your co-facilitator.
- If you deem it necessary, you can both take notes to be kept in your logbook (e.g. what went well, what didn't go as well, points to follow up on at the next meeting, etc.).

Offer Moral Support to Participants

- You may have to offer moral support to participants who need additional support after the meetings.

3- Future of the Program

Active Participation of WLHIV

- Ultimately, the program would benefit from having former participants become facilitators, providing they have taken facilitation workshops first and have the skills to coach women dealing with the issue of disclosure. This would be a wonderful opportunity for WLHIV seeking to get involved with the organization to support their peers. It would allow WLHIV to take control of their health and well-

being and that of others, to improve the quality of their own lives and that of others, and to ensure the future of the program.

Adaptation

- ✓ Can STFL be offered to other groups, such as men, mixed groups, men who have sexual relations with other men, transgender people?

It can by:

- **Adopting a multicultural approach in our practices**
- **Adapting the tools (activity sheets) to the target clientele**

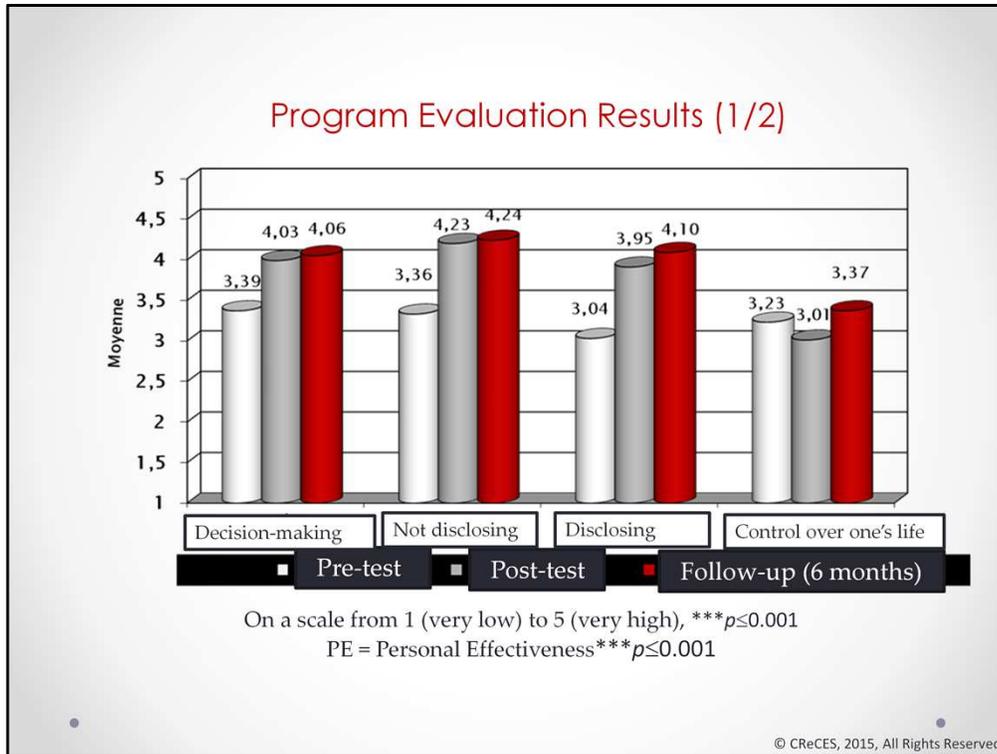
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S31: Adaptation

STFL could likely be offered to other groups, such as men, mixed groups, men who have sexual relations with other men, transgender people, by **adopting a multicultural approach in its adaptation, and by adapting the tools (activity sheets) to the target clientele**



S48: Program Impacts



S49: Program Evaluation Results

- Four measures allowed us to evaluate the program impacts. These measures correspond to the sense of personal effectiveness (PE) surrounding the decision-making process, the issue of non-disclosure, the issue of disclosure, and the sense of control which participants felt about their lives after taking part in the program.
- The following table indicates that the program seems to promote the development of skills in WLHIV and a **sense of empowerment** in regards to their decision-making process and to their decisions to not disclose or disclose their HIV-positive status. In the mid-term, the women say the program generally allowed them to gain control over their lives.
- The results also indicate that the program impacts on the participants can be observed over the short-term and are **maintained across time** (6 months later) for all the women (African, Haitian and Quebec participants).

Program Evaluation Results(2/2)

Factors related to mid-term impacts

- ✓ While the mid-term program impacts **do not seem to vary** by implementation setting, age, country of origin, mother tongue, marital status, income, being treated or not treated for HIV, or the percentage of people who disclosed their HIV status...
- ✓ ...it seems that the program impacts are greater among:
 - **Mothers**;
 - Women with a higher education; and
 - Women living with HIV **for a shorter period of time**.

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S Program Evaluation Results

- **The program impacts do not vary** by implementation setting, age, country of origin, mother tongue, marital status, income, being treated or not treated for HIV, or the percentage of people who disclosed their HIV status.
- However, these impacts seem to be greater and more significant **among the mothers** of our sample, women with a **higher education**, and women living with HIV **for a shorter period of time**.

Participant Testimonials

"Sharing Together For Life allowed me to develop tools and to meet and share with other women who are dealing with the same issues." (Charlotte, from Quebec, 30-39 age group)

"It gave me courage and self-esteem. I know who, where and when to tell or not tell. It also encouraged me to continue my involvement with HIV support groups and organizations...." (Simone, originally from Congo, 40-49 age group)

"I used to think I should tell everyone about my status but the meetings allowed me to see who I really needed to tell and how to go about it." (Marie, originally from Burundi, 20-29 age group)

"I don't rush into telling now. I take my time. I think about it more and ask myself if it's really necessary for this person to know my status and, more importantly, I now realize that not disclosing it doesn't make me a liar." (Dominique, from Quebec, 40-49 age group)

"When I decide to tell someone now, I'm prepared and less anxious to get it over with. It doesn't matter if things don't go exactly as planned because now I feel in control." (Sophie, originally from Asia, 40-49 age group)

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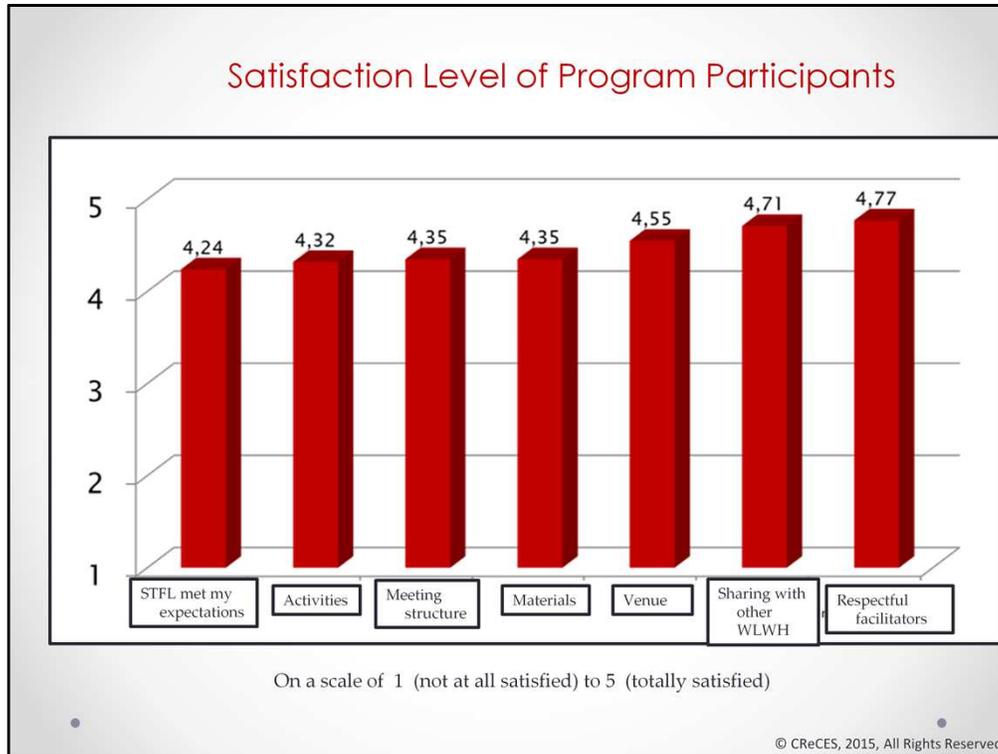
S Participant Testimonials

- When asked about their experience, the women said the program allowed them to **emerge from their isolation, to make friends and to share their reality and their concerns** with other women, as stated by Charlotte and Simone.
- The women also said they had learned what strategies to use before telling or not telling, as stated by Marie.
- The women also said they were **better equipped to deal with their decision to not disclose their HIV-positive status** to certain people. Like Dominique, several participants now feel less of a moral obligation to disclose their status in order to be seen as honest.
- The participants also said they had more faith in their ability to make a decision as to whether or not to disclose their HIV-positive status and their ability to disclose it, if that is their decision. (READ 4th EXTRACT).

"I don't rush into telling now. I take my time. I think about it more and ask myself if it's

really necessary for this person to know my status and, more importantly, I now realize that not disclosing it doesn't make me a liar. (Dominique, from Quebec, 40-49 age group)

- And, like Sophie, some women said they felt more in control of the decision-making process, even if things don't go as planned when they choose to disclose their HIV-positive status.



S52: Satisfaction Level of Program Participants

- Overall, **the participants said they enjoyed the program, which they felt was relevant to the reality of their daily lives:** to tell or not to tell? In which contexts? At what cost and **ABOVE ALL, how? And TO WHOM?**
- The participants said they enjoyed most of the activities, the structure of the meetings, and the educational materials used.
- Without question, the two elements that seem to have been most appreciated by the **“Sharing Together For Life”** participants was **the opportunity to share their experiences** with other women **and the respectful attitudes shown by the program facilitators.**



S53: Where to obtain the Facilitator's Guide

In closing, here are the Websites which you can visit to obtain further information on the program.

The Facilitator's Guide is now available **free of charge** in French and in English both online and through CATIE's Odeur Centre

You can also **consult** a PDF version of the guide at the "*Sharing Together For Life*" after completing an online evaluation, which only takes a few minutes and which you may have already completed in preparation for today's webinar