



Moving Beyond Lip Service:

*Meaningful Engagement
of Women Living with HIV
and Civil Society in Efforts
to Prevent Vertical
Transmission of HIV*



About Us

Global Network of People Living with HIV (GNP+) is the global network for and by people living with HIV. GNP+ advocates to improve the quality of life of people living with HIV. As a network of networks, GNP+ is driven by the needs of people living with HIV worldwide. Based on emancipation and self-determination, GNP+ works with independent and autonomous regional and national networks of people living with.

GNP+ promotes the sexual and reproductive health and rights of people living with HIV. GNP+ supports networks of people living with HIV to gather evidence about the experiences and needs of people living with HIV in accessing family planning and antenatal services to promote their health and prevent new HIV infections. In addition, GNP+ is co-chairing the IATT PMTCT's Community Engagement Working Group.

International Community of Women Living with HIV (ICW Global) is the only global network by, for, and of women living with HIV. Founded in 1992, It works to increase the visibility of women living with HIV within the global response to HIV and AIDS and to ensure that women are equal partners in all decisions which impact their lives. ICW Global envisions a world where all women living with HIV know and exercise their rights to health, including sexual and reproductive health, and dignity.

Through its involvement with the Global Task Team, Global Steering Group (GSG), ICW-Work Group in Support of the GSG, and the Interagency Task Team on the Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and their Children (IATT), ICW Global and its membership are primed to engage in political and technical assistance efforts to ensure that we meet the Global Plan targets by 2015.

International Treatment Preparedness Coalition (ITPC) is the only international coalition of people living with HIV/AIDS and their supporters solely devoted to advocacy on HIV/AIDS treatment access. As a community voice, it has been successful in communicating the concerns of people living with HIV/AIDS who need treatment to governments, United Nations agencies, pharmaceutical manufacturers, and other public and private bodies that influence the progress of the establishment, scale-up and sustainability of HIV/AIDS treatment programmes.

ITPC has been advocating for a more comprehensive approach in efforts to prevent vertical transmission of HIV that places emphasis on women's own health needs. It has facilitated community-led research and advocacy on this issue in 11 countries globally.

For more information on the Global Plan and materials on the comprehensive approach to preventing vertical transmission visit the Four4Women website www.four4women.org



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Acronyms

CCM	Country Coordinating Mechanism [of the Global Fund]
GNP+	Global Network of People Living with HIV
GSG	Global Steering Group
IATT	Interagency Task Team for Prevention and Treatment of HIV Infection in Pregnant Women, Mothers, and their Children
ICASA	International Conference on AIDS and STIs in Africa
ICW	International Community of Women Living with HIV
ITPC	International Treatment Preparedness Coalition
M2M	Mothers2Mothers
NEPHAK	National Empowerment Network for People Living with HIV in Kenya
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission [preferred terminology is prevention of vertical transmission]
SRH	Sexual and Reproductive Health
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
WLHIV	Women living with HIV



Introduction

WHAT IS THE GLOBAL PLAN?

The Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive (Global Plan) was launched in July 2011 at the United Nations General Assembly Special Session (UNGASS) High Level Meeting by a Global Task Team, led by UNAIDS and PEPFAR. This plan covers all low- and middle-income countries, but focuses on the 22 countries¹ with the highest estimates of pregnant women living with HIV. The Global Plan sets out how by 2015 countries can work to ensure that mothers are supported to stay healthy and that children are born without HIV.

The Global Plan sets two targets for the global community to achieve by 2015:

- Global Target #1: Reduce the number of new HIV infections among children by 90%
- Global Target #2: Reduce the number of AIDS-related maternal deaths by 50%

The Global Plan is a critical advocacy tool which aims to meet the needs of children AND their mothers, saving the lives of both. One of the key principles of the Global

¹ Angola, Botswana, Burundi, Cameroon, Chad, Côte d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Uganda, United Republic of Tanzania, Swaziland, Zambia and Zimbabwe

Plan is that “women living with HIV must be at the centre” of developing programmes for prevention of vertical transmission and maternal health. Yet the ambitious goals and comprehensive approach is not translating into national plans and programmes.

The Global Steering Group (GSG) for the Global Plan, co-chaired by UNAIDS and the US Government, is primarily responsible for ensuring the on-going political momentum behind the Global Plan. ICW Global, National Empowerment Network for People Living with HIV in Kenya (NEPHAK), Mothers2Mothers International (M2M), and Caritas Internationalis represent the civil society voices on the GSG and frequently consult with civil society members to ensure their input is considered by all partners involved.

The GSG civil society representatives asked the International Treatment Preparedness Coalition (ITPC) to help facilitate greater civil society feedback and engagement, especially from women living with HIV, in the Global Plan. This report provides an overview of civil society feedback from an online survey conducted by ITPC in October 2011 and two consultations conducted jointly by GNP+, ICW Global and ITPC at the International Conference on AIDS and STIs in Africa (ICASA) in December 2011.

More information about the Global Plan including a short briefing paper as well as a link to the Plan is available at <http://four4women.org/globalplan>.

Executive Summary

The civil society representatives on the GSG for the Plan aim to ensure that a wide range of civil society voices are heard as governments, UN agencies, donors and others work to make the Global Plan a reality. This report brings together the voices and messages heard from an online survey and two face-to-face consultations about the Global Plan. This included:

- An online survey in French and English which garnered approximately 140 responses from more than 40 countries during October 2011;
- A community consultation in the Global Village at the International Conference on AIDS and STIs in Africa (ICASA), held in Addis Ababa, Ethiopia in December 2011 with more than 100 ICASA attendees, representing more than 20 countries; and
- A closed, by invitation only, consultation with people living with HIV in the Global Village during ICASA. The consultation was facilitated by two women living with HIV and was attended by approximately 40 women and men living with HIV from at least nine countries.

WHAT WE LEARNED

Although each consultation had unique questions and participants who offered different opinions and responses, several overarching themes about the current state of prevention of vertical transmission programmes and expectations for the Global Plan can be seen across the consultations. These themes include:

1 Many respondents in all three consultations highlighted the lack of a comprehensive approach that puts women's health at center of prevention of vertical transmission programmes.

- In most countries, prevention of vertical transmission, often referred to as prevention of mother-to-child transmission (PMTCT), have a focus on prong 3 and saving the infant rather than a comprehensive approach based on the four-pillar UN framework that takes the mother's health into account as well.
- Women's sexual and reproductive health rights and their right to treatment is not a focus in most countries. This plays out through stigma in health-care settings and the high cost of diagnostics and antenatal care that make it difficult or impossible for women to access all of the care they need.

U.N. FRAMEWORK TO PREVENT VERTICAL TRANSMISSION OF HIV

PILLAR 1

Preventing HIV among women of reproductive age



PILLAR 2

Meeting the unmet family planning needs for women living with HIV



PILLAR 3

Preventing HIV transmission to infants during pregnancy, delivery and breastfeeding



PILLAR 4

HIV treatment and care for women living with HIV and their families



- In almost all settings and countries, respondents say that male partners are not adequately engaged.
- Many countries continue to offer women sub-optimal drugs for prevention of vertical transmission, endangering the health of women and their babies.

“PMTCT [Prevention of Mother-to-child Transmission], when you talk about it, it is one prong/pillar. I tested HIV positive when I was pregnant. They give me medicine and I gave birth to my baby. I went back to the clinic, but they act like they don’t know me after the birth.”

Woman living with HIV from Cameroon at the closed consultation, December 2011

“The Global Plan is missing something very important, that is, the involvement of men. In Africa, the culture has not given equal opportunity to men and women. Many women don’t have the opportunity to go to the clinic if the husband doesn’t permit... Sometimes a woman cannot go to the hospital unless accompanied by men. Africa is ultra conservative. There must be the four prongs plus one, so that men can be brought on board so that they can be educated.”

Physician from Nigeria at the open consultation, December 2011

2

Most respondents in all three consultations noted a clear lack of civil society involvement in the development of national plans, despite the great desire of many in civil society to be involved in developing and implementing these plans.

- Women living with HIV are particularly excluded. These consultations showed their voices to be almost completely absent.
- In many countries, respondents noted that civil society representatives and Women living with HIV are not asked to be on technical working groups or, if they are asked to be on these groups, their voices and ideas are ignored.
- Respondents also noted that when they are involved, the involvement of civil society and women living with HIV is often tokenistic, lacking adequate resources and capacity building support.

“Civil society is always brought in for the consultation stage, but have little to no significance with how final decisions are taken.”

Activist and health care worker from Delhi, India in the online survey, October 2011

“I sit on the technical working group in Kenya. Among doctors, there are often [few] women living with HIV in the setting. I contribute, but they don’t take it seriously.”

Woman living with HIV from Kenya at the closed consultation, December 2011

3

Many of the respondents in all three consultations were unaware of the Global Plan or knew little or nothing about it. In discussion at the in-person consultations, attendees attributed this lack of awareness to a range of problems.

- The national plans do not reflect global ambition. Also, respondents felt that the plan was developed by UNAIDS and other international agencies away from the countries where the problems are greatest.
- The community is not mobilised to focus on the Global Plan or national policies.
- The Global Plan and national plans do not respond to the realities that women face in most countries. There is a wide gap between policy and practice.

“One of the things I’ve learned is that there is [a] big disconnect between what is going in Geneva or New York and on the ground. National programmes are often disjointed from the framework. How do we ensure that we are not excluded as women and men living with HIV. I want to be part of this movement to ensure that women are not excluded.”

Man living with HIV from Zambia
at the closed consultation, December 2011

“Currently countries are revising their PMTCT programmes to be in line with the Global Plan. The revisions started in October. When we have the plans explained, we are just going to be informed the day before.”

Woman living with HIV from Zimbabwe
at the open consultation, December 2011

In addition to the above themes and in response to specific questions, participants in the online survey provided strong ideas on how the GSG could support civil society efforts at a national level and the importance of having an advisory group of women living with HIV.

Role of the GSG:

“Have country level (North, South, East, West) community-based focal points who can communicate the Global Plan priorities and ensure that the community’s feedback and the reality of implementation directly reaches the GSG.”

Activist and health care worker from India,
October 2011

“Build in-country capacity to help in resource mobilization and track progress in PMTCT programmes.”

Activist, woman living with HIV, and mentor mother, Kenya,
October 2011

Need and role of a women’s advisory/reference group:

“As a watchdog group that caters to positive women, to follow up the implementation of the plan.”

Woman living with HIV, Cameroon, October 2011

“I think women should be involved on every stage - designing, implementing, monitoring and evaluation, setting priorities, and saying where the problems are.”

Activist, Russia, October 2011



“Say No to sd-NVP” postcards used as a campaign tool

CONCLUSIONS AND RECOMMENDATIONS

The three consultations with a range of civil society participants from Africa and around the world clearly highlight the need for more engagement from civil society in the Global Plan and in national plans. It is critical for women living with HIV and civil society who have valuable information and experiences to be actively involved at the international and national levels if the ambitious goals of the Global Plan have any hope of being met. And, as the vast majority of respondents in all three consultations have expressed, civil society stands ready to help.

Three key recommendations from civil society emerged from these consultations and we look to the GSG of the Global Plan to help make them a reality.

➔ **Involve women living with HIV and invest in their networks.** All stakeholders need to ensure better representation of women living with HIV on technical working groups and other policy-making bodies. They must ensure that these women are meaningfully engaged in designing, promoting and monitoring of the Global Plan and national plans and support this by building their capacity and adequately funding their networks.

➔ **Prioritize women’s health.** National plans must embrace a comprehensive approach that also emphasises preventing HIV among young women, promotes their sexual and reproductive health and rights, provides the most effective prophylaxis and correct infant feeding guidance and ensures the best quality treatment, nutrition and other support for women and their families and involves male partners.

➔ **Move from commitments to budgets and actions.** The disconnect between an ambitious global plan and women’s reality on the ground must be closed. Fading political will, shrinking AIDS budgets and dangerous trade agreements do not bode well for meeting the targets of this goal. There must be action at global and national levels to fund and support the rollout of a comprehensive Global Plan.



Women in Kampala marching for increased HIV treatment-HEPS with the National Community of Women Living with HIV/AIDS

transmission services available in health facilities and running support groups. Their lack of engagement in technical working groups on vertical transmission and their limited knowledge of policy processes and structures are missed opportunities to ensure that experiences on the field are informing the direction of programmes to support women living with HIV, their children, and families.

“I don’t know anything about PMTCT technical working groups. There is a Technical Working Group for care, treatment and support.”

Woman living with HIV, Swaziland

“The voices are clearly not being heard, even at international level. What we need to do is have policies that clearly states that how the national organizations can be involved in the Global Plan instead ... Just state clearly how we could be involved. At global level, it would be great for GSG to say that women at national level are not there.”

Woman living with HIV, Swaziland

“These opportunities are there or [is it] that we are not involved where we should be. We need to create a space for ourselves and demand a space. We should be able to know who is represented there. If we are not represented, we should demand representation.”

Woman living with HIV, Kenya

LACK OF MEANINGFUL INVOLVEMENT

In the few instances of representation on technical working groups on vertical transmission, women and men living with HIV feel they are not heard and are not meaningfully involved.

“I sit on the technical working group in Kenya. Among doctors, there are often little women living with HIV in the setting. I contribute, but they don’t take it seriously.”

Woman living with HIV, Kenya

“In terms of involvement, when you count the faces, there are representatives sitting at different bodies (e.g. CCMs, National AIDS Councils, technical working groups). In reality, our involvement is quite failed. We are not making a great impact. The reason is that... when it comes to implementation, [the] involvement [of women living with HIV] remains in consultations. As our involvement goes on, other companies are given money, they take on broader implementation.”

Woman living with HIV, Uganda

Lack of a comprehensive approach that puts women's health at centre

Participants who were aware of the Global Plan noted that the plan professes to utilize an approach based on the principle that women living with HIV will be at the centre. However, programmes and efforts thus far have seemed to exclude many key populations.

"It is important to include women with disability in the Global Plan. In developing countries, there are very little facilities that provide access to prevention for care and support services for women with disabilities."

Female activist, Mali

"How will Global Plan work with sex workers who are women living with HIV and want abortions but have no information for that?"

Woman who works with sex workers, Kenya

Men not engaged adequately

Participants reiterated the importance of involving men at the outset of Global Plan efforts.

"The Global Plan is missing something very important, that is, the involvement of men. In Africa, the culture has not given equal opportunity to men and women. Many women don't have the opportunity to go to the clinic if the husband doesn't permit... Sometimes a woman cannot go to the hospital unless accompanied by men. Africa is ultra conservative. There must be the four prongs plus one, so that men can be brought on board so that they can be educated."

Male physician working with Physicians for Social Justice, Nigeria

Lack of civil society / women living with HIV involvement in development of national plans

Participants noted that the voices of women living with HIV are notably absent from most national plan development settings, despite their eagerness to be meaningfully involved.

This may be the result of structural challenges. National AIDS Councils are accustomed to the involvement of women and men living with HIV in their work. However, efforts to prevent vertical transmission, including "PMTCT Technical Working Groups," in many of the Global Plan countries have traditionally been managed by the Maternal and Child Health arms of the Ministry of Health who have not typically engaged women and men living with HIV.

"We have a PMTCT Technical Working Group with 30+ members, including M2M and coalition of women living with HIV. [However,] women living with HIV don't have a [strong] voice on the TWG..."

A woman activist, Zambia

Where their voices may be represented on a technical working group, their comments are not taken seriously.

"In our experience, PMTCT technical working groups are composed of government officials and physicians from major organizations. A lot of the decisions are made there (e.g. national elimination plan are informed by analyses that do not consider the community). One thing that needs to be done is that the Global Plan should put in structures that mandate that women living with HIV and community groups must approve the plan and it should be explained to them so that they can be involved."

Female representative of the Elizabeth Glaser Pediatric AIDS Foundation

Tokenistic involvement without adequate resources and capacity building support

Often times, involvement of women and men living with HIV is tokenistic and they are invited late in the process.

"Currently countries are revising their PMTCT programmes to be in line with the Global Plan. The revisions started in October. When we have the plans explained, we are just going to be informed the day before."

Woman living with HIV, Zimbabwe



Online Survey

METHODOLOGY

ITPC, with input from civil society representatives on the Global Plan's GSG, developed a survey to gather feedback and build future engagement on Global Plan implementation. The survey, which was disseminated in October 2011 in English and French through partners and list serves, included 19 questions. There were approximately 140 responses received representing more than 40 countries.

The survey focused on:

- Perceptions of the state of prevention of vertical transmission programmes in their countries,
- Level of community involvement in national prevention of vertical transmission plans,
- Interest in future engagement (including with the Global Plan),
- How the civil society/community should be involved with national plans, and
- Support needed from GSG civil society representatives.

KEY FINDINGS

1

The greatest obstacles to an effective and comprehensive programme to prevent vertical transmission reported include:

- Inadequate funding for health facilities and properly trained health care workers/ poverty,
- Lack of political will/ corruption,
- Lack of information, education and awareness—many women do not know they are HIV-positive or that prevention of vertical transmission services are available,
- Lack of involvement of women in planning and implementing programmes,
- Not reaching out to male partners and lack of sensitization on gender issues,
- Stigma and discrimination encountered by women, and
- Lack of access to complete care, treatment and support package for PLHIV women and their families.

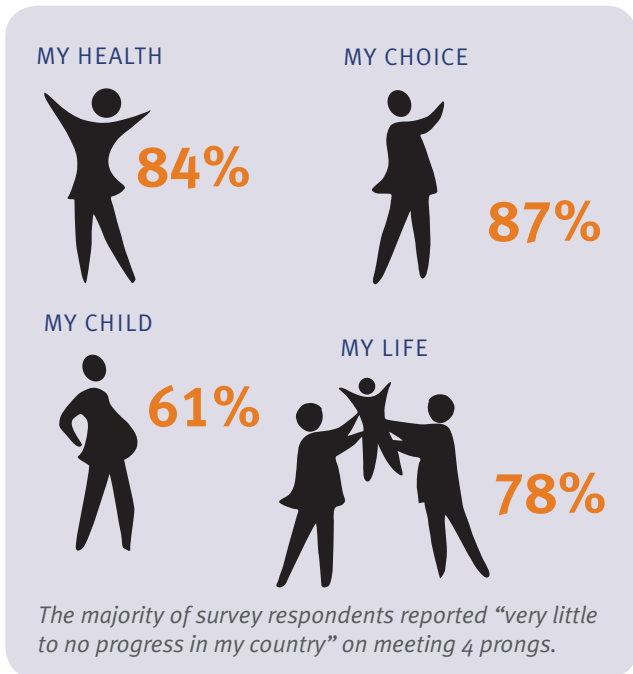
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A comprehensive approach that puts women's health at the centre is lacking in prevention of vertical transmission programmes, and very little progress has been made on meeting all four prongs.

→ **Approach is not comprehensive:**

“The programme concentrates mainly on the prong 3, and there is little knowledge about other aspects.”

Health care worker and activist, India
(Echoed in Zimbabwe, Mexico, and other countries)



➔ **Particularly, Prongs/Pillars 1 and 2 are not addressed:**

“Prong 1 and 2 are poorly implemented. For instance, there is no focus on integrating SRH and HIV services at all service points, including HIV testing and counselling.”

Local NGO staff member, Kenya
(Echoed in Nigeria, Ghana and others)

➔ **Women need follow-up care and social support:**

“The national budget for women’s health in Guatemala is inadequate and there is inadequate provision for HIV-positive mothers to receive follow-up care after giving birth.”

Health care worker, Guatemala
(Echoed in Malawi, South Africa and others)

➔ **Health systems lack investment:**

“Basic necessities for expectant mothers are not available at most health centres leading to death at time of delivery.”

CBO staff member and health care worker, Uganda

➔ **Stock-outs are commonplace:**

“We have stock-outs of nevirapine and also pediatric formulas.”

Activist, Russia

➔ **No strategies to engage men:**

“Men aren’t involved and women’s fear of discrimination is not taken into account.”

CBO staff from Mali

➔ **Gap between policy and practice:**

“Our National PMTCT programme adequately addresses the four prongs in paper and pen, comes to the implementation there are still gaps.”

Woman living with HIV, health care worker and mentor mother, Nigeria

3 A lack of civil society / women living with HIV involvement in development of national plans despite a great desire to be involved.

➔ **Civil society representatives and women living with HIV not included on technical working groups or their voices ignored:**

“Civil society is always brought in for the consultation stage, but have little to no significance with how final decisions are taken.”

Activist and health care worker, Delhi, India

“There are no advances in recognizing and including women from most at risk groups in the design, implementation and monitoring of services and programmes.”

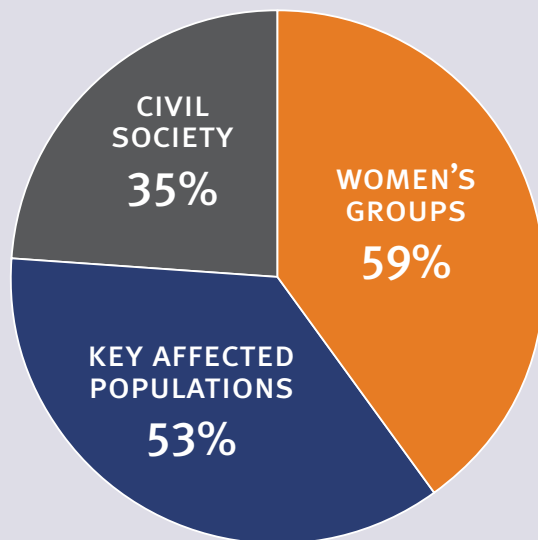
Activist and woman living with HIV, Argentina

“Civil society can keep on engaging the authorities... though most often we end up banging our heads against a tightly closed door.”

Activist and health care worker, Pune, India

93% participants said that they would be interested in continuing to provide feedback and engage with the Global Plan but...

Women living with HIV are particularly excluded



Percent of respondents that said the following groups were involved very little or not at all in developing their countries' "PMTCT" plan

"These groups must be involved from the needs assessment to the implementation and monitoring and evaluation of the new national plan."

Activist and woman living with HIV, Rwanda



Cambodian women participate in a workshop about prevention of vertical transmission.

➔ **Involvement of civil society is tokenistic without adequate resources and capacity building support:**

"Civil society organizations in my country are still very weak and need to be strengthened to carry out their functions."

National AIDS Commission employee, Liberia

➔ **Civil society and women living with HIV involvement is critical:**

"Genuine discussion and openness to learning from civil society is needed ... not just at national level where policies are made, but at provincial level where they are often applied unilaterally, without prior consultation."

FBO staff member, South Africa



How the Global Steering Group for the Global Plan Can Help

“Have country level (North, South, East, West) community-based focal points who can communicate the Global Plan priorities and ensure that the community’s feedback and the reality of implementation directly reaches the Global Steering Group.”

Activist and health care worker, India

“If we could be supported in getting this information to the grassroots populations, then they could demand for what is due to them.”

Activist, woman living with HIV,
and CBO staff member, Uganda

“Make consultation a requirement for any country plan.”

Local NGO staff member, Kenya

“Build in-country capacity to help in resource mobilization and track progress in PMTCT programmes.”

Activist, woman living with HIV,
and mentor mother, Kenya

“The Global Steering Group should lobby the governments for participation of civil society organizations in decision-making and planning processes.”

CBO staff member, Ethiopia

“Develop and distribute brief papers on the Global Strategy, made widely available to women’s groups; Advocate for UN agencies’ support for local women’s groups; Advocate for more funding available to women’s groups, to build the capacity of women in grassroots communities.”

Activist and woman living with HIV, Argentina

“The Global Steering Group should provide technical support and capacity building training for the local institutions. Engagement with the government is no problem because the government itself is already involved in the national response to HIV and AIDS.”

National AIDS Commission employee, Liberia

“Provide technical and financial support.”

Activist, woman living with HIV,
and mentor mother, Moldova



Role of a positive women's reference group

“As a watchdog group that caters to positive women, to follow up the implementation of the plan.”

Woman living with HIV, Cameroon

“It could bring information/testimonies about how services are really operating.”

Activist, Argentina

“Providing evaluation and assessment of quality of service delivery.”

Activist, mentor mother and woman living with HIV, Zimbabwe

“I think women should be involved on every stage – designing, implementing, monitoring and evaluation, setting priorities, and saying where the problems are.”

Activist, Russia

“Inform the development of plan. Establish community links with community groups of women. Build awareness and educate the community on their role and responsibility in the implementation of the project. Develop and use monitoring tools to track and evaluate the impact of community involvement and efficient spending of AIDS money.”

Activist, woman living with HIV, and CBO staff member, Jamaica

“Not just women! We need to engage men too. Not HIV-positive women's groups but HIV-positive groups. The fact that we keep focusing on women is a problem. This is all our responsibility.”

Anonymous

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