Positive women monitoring change

A monitoring tool on access to care, treatment and support, sexual and reproductive health and rights and violence against women created by and for HIV positive women

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International Community of Women Living with HIV/AIDS (ICW)

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Introduction

How and why the tool was developed
In February 2005, the international Community of Women Living with HIV and AIDS (ICW) in collaboration with ActionAid-managed initiative Support for the International Partnership against AIDS in Africa (SIPAA), carried out workshops in Swaziland and Lesotho. The workshops aimed to examine the national response of each country to the HIV and AIDS pandemic, with particular reference to international policy commitments (in particular the GIPA principle, the Abuja Agreement of 2001, and the UNGASS Declaration of Commitment of 2001). First was an analysis of the lived experiences of the participants. An analysis of the documents was undertaken, first to see to what extent they addressed the rights, needs and concerns of HIV positive women, and second to see whether HIV positive women had experienced the effects of those political commitments on the ground. Further analysis was carried out into the monitoring and reporting systems used to report on progress against international policy processes, and finally, workshop participants developed their own monitoring and evaluation tool, to assess progress on issues both included and not included in the international policy documents.

The resulting tool is intended for use by HIV positive women, and other actors working in the field of HIV and AIDS with a commitment to gender, human rights and in particular the rights of HIV positive women. It can be used for advocacy and M&E purposes. While it refers directly to the Abuja, UNGASS and GIPA commitments mentioned above, it can also be adapted easily to monitor progress against, and identify gaps in the 3x5 initiative, the Millennium Development Goals (MDGs) and the President's Emergency Plan for AIDS Relief (PEPFAR) and national strategic plans to reduce the spread and mitigate the impacts of HIV and AIDS.

The workshop examined three key areas in which HIV positive women routinely come up against barriers in accessing their rights. These are: access to care, treatment and support (ACTS), sexual and reproductive rights (SRR), and violence against women (VAW). All three areas have resonance for all women regardless of their HIV status, but hold particular concerns for HIV positive women, who face additional barriers in accessing their rights, and for whom contravention of their rights may have disastrous or fatal consequences.

Most available national and international level monitoring and reporting tools are gender blind, or at best gender neutral, but do not draw particular attention to the priorities of women or assess positive improvement in the lives of women in general, or HIV positive women in particular. This tool intends to explore the realities of HIV-positive women's lives, including young HIV positive women (aged 18-30), whose voices are consistently left unheard in decision making fora, and whose rights, concerns and needs both differ from those of older women and are usually overlooked. The tool intends to provide a platform for the voices of other marginalised women too, such as disabled women and sex workers. Thus the first section of the tool looks at positive women's knowledge and awareness of rights and issues that concern them in the three areas mentioned above (ACTS, SRR and VAW), but also their lived experiences of putting or attempting to put that knowledge into practice, and the challenges that they face in doing so.

The second section of the tool looks at the experiences and attitudes of service providers working in the areas of ACTS, SRR and VAW. This section explores the strengths and weaknesses of available services, and also considers the constraints and barriers service providers themselves face in providing quality

care and support in resource poor, remote and under-prioritised settings. Women can use first part of tool to cross-check information they receive from service providers.

The third section of the tool takes the survey to government level, where it can be used to hold governments and ministries to account on their promises, and to advocate on priority issues using evidence from both HIV-positive women and service providers, as well as monitoring the progress of government commitments.

It is hoped that findings and reports can then be fed into policy making fora at local, national, regional and international level by HIV positive women living, using existing networks of positive women such as ICW, and national positive women's networks, or by establishing national chapters of ICW or other national networks of positive women. A user guide to accompany the tool is in the process of being developed.

A work in progress…

When the tool was used in Swaziland and South Africa[1] it was considered to be very useful in guiding day long discussions. However, in situations when time was of the essence shorter versions were developed. For this reason we include here short versions of all the nine sections of the tool for when you only have a limited time to ask questions. Questions in the long version have also been adapted in line with suggestions from these trials.

How the tool has been used

This section describes some of the (potential) ways the PWMC tool can or has been used, with direct examples from ICW's experience below. One of the most potentially transformative exercises we have found, however, has been the actual process of developing the tool in the first place, or working with other groups of women to develop their own tool – a process which involves the women engaging politically with their own experiences and environments, envisioning a potentially different future, and shaping their own messages, indicators or frameworks that reflect a contextualised 'ideal'. This process not only helps women analyse their context and situation, but also enables and motivates them for on-going advocacy using a tool over which they feel a sense of ownership, far more than through the use of a 'ready-made' tool.

Ways of using the PWMC tool:

- As a framework for gathering, analysing and presenting information. For example, in one on one interviews or to guide a group discussion and as a structure for developing reports.
- To raise collective awareness among positive women of issues affecting their lives as advocacy issues, and to mobilise around these issues through community assessments and needs assessments. It also offers a structure to bring positive women together to discuss issues that are often overlooked in other forums.
- To raise awareness and issues of concern among government representatives, service providers, civil society organisations, etc, (i.e., "have you thought about…?")
- Workshopping to help positive women prioritise issues and set advocacy agendas
- Evidence gathering for advocacy.
- Use as a check list when asking questions at a meeting.
- To monitor government commitment to rights in policy and practice.
- Push for academics to use the tool (or some of the questions) in their research. (NB Researchers can also use ICW's ethical guidelines to ensure that they involve positive women in a way that is not solely extractive, or in policy analysis)

[1] Please see the ICW website – www.icw.org – for more information about these programmes.

- CSOs can adapt it to monitor their own work or the work of others.
- In the development of ICW's M&E framework and to guide advocacy plans

Further benefits of the PWMC tool:

- The process of developing the tool for local contexts provides an opportunity and framework for positive women to engage with policy documents
- The tool was developed "by and for positive women" exemplifying a different focus for research whereby positive women are firmly at the centre of the process.
- With accompanying fact sheets and policy briefings on the issues it addresses, the tool provides direct information and learning on these issues.
- By incorporating a training curriculum, the PWMC package also can be used for building research and M&E skills and capacity

To date, ICW has used the tool in a number of different settings and for a variety of purposes. Where applicable, links are included to reports of these experiences for more detailed accounts and outcomes.

Swaziland and Lesotho, 2005 and on-going. The tool was developed through workshops held with HIV positive women in Swaziland and Lesotho (see above), with support from SIPAA/ActionAid. (Reports can be found on our website http://www.icw.org/node/129) Since then training workshops have taken place in different parts of Swaziland and Lesotho, using the tool's frameworks on ACTS, SRHR and VAW as models for awareness raising and defining current priorities as a basis for on-going ICW work in the countries. (Contact Emma at emma@icw.org for copies)

South Africa, 2006. The tool was adapted for a rapid assessment of positive women's experiences of accessing sexual and reproductive rights. A questionnaire was developed from the SRHR section of the tool, and used in focus groups of positive women. The women were also encouraged to use the questionnaire in their own communities and support groups. Findings from the rapid assessment were used to develop the framework for an advocacy training and development workshop and to develop a tool on advocacy and SRHR. The advocacy tool can be found at http://www.icw.org/node/206, and an article about the advocacy training, featured in Oxfam journal Gender and Development at http://www.icw.org/node/173

Uganda, 2007. The PWMC tool was adapted and used in collaboration with Interact Worldwide to do SRHR research with HIV positive women, health care providers and policymakers. Building on this, a rapid assessment on the SRHR experiences of HIV positive women in different parts of the country was also carried out. This has formed the basis of ICW advocacy on SRHR in Uganda. (Read more about this work at http://www.icw.org/node/345)

Namibia, 2005, 2008. The ACTS section of the tool was used to inform a mapping of treatment and care services available to HIV positive women commissioned by the WHO (see also Kenya and Tanzania) A report from this project is available at (http://www.icw.org/files/Namibia%20ACTS%20mapping.doc). This project gave rise to new ICW advocacy materials, reports and messages which were disseminated at the International AIDS conference in Toronto and informed in our global advocacy work in this area. During 2008, a Young Women's Dialogue Project was run in Namibia to build the capacity and develop an advocacy agenda for young HIV positive women in Namibia. Among a variety of workshops and other activities, young women were trained to use the tool for data gathering, and monitoring, and from it also developed a call for action, the Young Women's Dialogue Charter – Namibia. Reports from the YWD and the YWD Charter are available at - http://www.icw.org/node/398.

In **Mozambique** and other countries in the Southern Africa region, the tool has been used to shape discussions and mobilise positive women through workshops which aim to inform our advocacy and strategic directions in the region.

Kenya and Tanzania, 2005. Treatment mappings were carried out with support from the WHO (see also Namibia above) through focus groups framed by the relevant sections of the monitoring tool. Reports (available at http://www.icw.org/files/Kenya%20ACTS%20mapping.doc and http://www.icw.org/files/Tanzania%20ACTS%20mapping.doc respectively) have fed into much of our recent advocacy work and messages.

Botswana, 2008. Working in collaboration with the Botswana network on Ethics, Law and HIV/AIDS (BONELA), women from the Botswana network of women living with HIV and AIDS (Bomme Isago) have been involved in trainings around SRHR and have worked with the tool to carry out monitoring of sexual health services available to HIV positive women in the country. (Contact Luisa at Luisa@icw.org for further details and reports)

ICW global M&E framework, 2008. As a key informing document of much of our advocacy work around ACTS, SRHR and VAW, Positive Women Monitoring Change also forms the basis of our own M&E work. We are currently developing a new, universal M&E framework as part of our next international strategic plan. This will be launched in 2009.

Part 1 – Advocacy framework

HIV positive women's health and rights framework

ACTS Definition
ACTS refers to HIV positive women's ability to gain consistent access to all available care, treatment and support services, including anti-retrovirals, medication for opportunistic infections, advice and treatment for side effects of medication, diagnosis and treatment for sexual and reproductive health matters including treatment of STIs, information and advice on PMTCT, healthy pregnancy and motherhood; awareness, information and treatment for gender-specific illness; pre- and post-test counselling, on-going support in the form of counselling, and where necessary financial support to meet payment for treatment or doctor's fees; home based care and other care-in-the-community programmes and initiatives; workplace policies; supportive environments at home, in the community, workplace, place of learning, public and health service institutions.

ICW recognises that gender inequalities can constrain HIV positive women's access to care, treatment and support as well as their ability to use treatment, information and advise to improve the quality of their lives. We also recognise that the care, treatment and support needs of HIV positive are different to that of men.

Sexual and Reproductive Health and Rights Definition
Sexual and reproductive rights cover all aspects of women's sexual and reproductive health needs and recognise the different needs that women in different circumstances may have including HIV positive women, women living with disabilities, young women and older women.

Sexual rights are: the right to treatment for sexual health problems; the right to have consensual sexual relationships, and the right to choose how and where and with whom these are carried out; the right to protected sex; right to pleasurable sex; the right to bodily integrity and freedom from sexual intimidation, coercion or force.

Reproductive rights are: the right to choose whether and when to have children, how many, how to bring them up; the right to healthy motherhood including treatment, counselling and support before, during and after the pregnancy; the right to make an informed choice on whether to have a termination or sterilisation, and the right not to be forced or coerced into either; the right to safe, legal termination or sterilisation; the right to assisted conception, and a full range of contraceptive and protective technologies. (Adapted from definitions of SRHR in the ICPD and Beijing Platforms of Actions)

VAW Definition
Violence against women (VAW) can take many different forms including verbal, physical, sexual, emotional, financial, and psychological violence. It can also take the form of fear of any of the above. The understanding of the term as used in the workshops in which this tool was developed, includes the following types of violence or fear of these:
Rape; incest; statutory rape (sexual intercourse with children or young people below the legal age of consent); marital rape; refusal to use available protective technologies to safeguard against (re-)infection or transmission of STIs including HIV; domestic violence; battery and assault; verbal violence or bullying such as cursing and use of swear words and derogatory terms; sexual violence including sexual intimidation or threats; stigma and discrimination; refusal of medical examination or treatment; withdrawal of financial support; abandonment; community violence (eg setting fire to someone's house); violation of human rights; being deprived of access to and ownership of property after the death of spouse. (Beijing Platform of Action 1995)

Positive Women's Health and Rights – Indicators

HIV positive women:

- Comprehensive knowledge of options and services for HIV treatment, care and support, sexual and reproductive health and violence against women
- Access to appropriate and accurate information in local languages about CTS, SRHR and VAW
- Access to good quality, appropriate and comprehensive services for HIV-related care, treatment and support, sexual and reproductive health and violence against women including referral and follow-up services
- Decision making power, without fear of violence or abuse, in relation to sexual, reproductive, lifestyle, and health choices
- Treated with respect and dignity by all staff within the relevant services
- Ability to act upon and adhere to medical and psycho-social advice and treatment
- Knowledge of relevant polices around ACTS, SRHR and VAW
- Involvement at all levels of policy and programme consultation, design, development and implementation.

Services and service providers:

- Up-to-date knowledge, training and information regarding HIV positive women's health and rights in regards care, treatment and support, sexual and reproductive health and violence against women
- Provision of a full range of well-resourced services tailored to meet HIV positive women's needs?
- An understanding of the barriers and challenges that HIV positive women have in accessing, adhering to and acting on the advice of health care and support services
- Monitoring systems including complaints procedures for quality, effectiveness and improvement of services
- Involvement of HIV+ women in your programmes, including design, development and monitoring of services

Government:

- Policies and programmes that specifically address HIV positive women's ACTS, SRHR and experiences of violence
- Clear responsibility and accountability mechanisms for policy implementation and monitoring
- Adequate annual budget to address HIV+ women's CTS, SRHR and VAW
- Monitoring of international commitments, policies and programmes
- Support campaigns that raise awareness about HIV positive women's rights to quality care, treatment and support, sexual and reproductive health and to live free from violence and abuse
- Endorse research that supports the rights and health of HIV positive women
- Actively involve HIV positive women in policy making, implementing, monitoring, evaluation, reporting and improvement.

Part 2 – The questionnaire

Section 1: background information

Name

Ethnicity

Year of birth

Where you live (urban / rural)

Year of diagnosis

Current relationship status

Sexually active?

Length of time in current relationship(s)

People in household

Number of children

Disability

Education

Employment

Number of dependents

Nutritional status (do you always have enough to eat?)

Do you belong to, or have you in the past belonged to, any of the following categories?
- Lesbian
- Transgender
- Sex worker
- Injecting drug user
- Refugee or asylum seeker
- Internally displaced person
- Member of an indigenous group
- Migrant worker
- Prisoner
- Other (please specify)
- I don't belong to, and have not in the past belonged to, any of these categories

Section 2 - Access to Care, Treatment and Support (ACTS)

Definition
ACTS refers to HIV positive women's ability to gain consistent access to all available care, treatment and support services, including anti-retrovirals, medication for opportunistic infections, advice and treatment for side effects of medication, diagnosis and treatment for sexual and reproductive health matters including treatment of STIs, information and advice on PMTCT, healthy pregnancy and motherhood; awareness, information and treatment for gender-specific illness; pre- and post-test counselling, on-going support in the form of counselling, and where necessary financial support to meet payment for treatment or doctor's fees; home based care and other care-in-the-community programmes and initiatives; workplace policies; supportive environments at home, in the community, workplace, place of learning, public and health service institutions.

ICW recognises that gender inequalities can constrain HIV positive women's access to care, treatment and support as well as their ability to use treatment, information and advise to improve the quality of their lives. We also recognise that the care, treatment and support needs of HIV positive are different to that of men.

Interview tip:
We have found that when using the questionnaire, it can be intimidating to go through all the questions. You may prefer to start a 'conversation' with a general question related to each (sub-)section which will elicit a story from the person you are interviewing and get them talking. After a more general conversation, you can use the questions as a check list to see whether any key areas of information have been missed.
Example question:
Can you tell me about your experiences of accessing treatment, care and support services? This may include experiences of services, information, adherence/ability to use the advice or treatment offered, and monitoring / follow up of services

ACTS Questions for positive women

1. Information and knowledge of rights, services and treatments
What do you believe are your rights regarding access to care, treatment and support as an HIV positive woman?

	Where do you get information on the following areas?	Which of these do you need more information on?	What is your opinion of the information you have?
ARV treatment			
Your CD4 count			
Viral load			
Pap smears, Human Papilloma Virus and cervical cancers			
Diagnosis and treatment for STIs			

	Where do you get information on the following areas?	Which of these do you need more information on?	What is your opinion of the information you have?
Treatment for opportunistic infections			
adherence			
Side effects of treatment			
nutrition			
healthy living			
Hepatitis C			
Tuberculosis			

What questions do you have about Treatment, care and support?

2. Health seeking behaviour

Under what circumstances do you go to the clinic or hospital (as soon as you get sick, or wait until really ill before seeking treatment?)
What about other members of your family – partner, male children, female children?
As a positive woman, how do you try to stay healthy?
Do you have access to good nutrition and advice that can help you to stay in good health?
What barriers do you face in trying to stay healthy and accessing medication including ARVs?
Have you ever shared your ARV medication with another member of your family?

3. Services (including involvement in service provision at community level)

	What kind of care, treatment and support do you receive (including access to ARVs, and related to opportunistic infections, side effects, etc) from:	What are any of the barriers to care, treatment and support in each of these environments?	What changes are needed to improve care and support services in your area?
Your family:			
Your community: Your workplace:			
Health centres:			
Hospital:			
Your support group:			
Traditional healers			
Churches and faith-based organisations			
Other (please specify):			

Are you involved in providing any care or support activities in your community (eg HBC, support groups, OVC, counselling other HIV positive people, etc)?
What are the problems and challenges you face in providing care in your community?
Who supports you in this work and how?

4. Experience of services
How far away is the place where your nearest care and treatment service? How do you get there?
How comfortable are you with the different care and treatment services you have access to?
How well are you treated?
Are you on ARVs? (Please give details: first line / second line? What combination?)
Do you have to pay for the treatment? If not who does?
How long have you been on ARVs?
Have you had any changes or interruptions in your treatment regime? If so why?
What were the consequences for you?

Have you had any experiences of being forced into treatment, or feeling scared of taking certain kinds of treatment, or being given the wrong medication. What did you do?
Are there any conditions to receiving ARV treatment (such as use of certain contraceptives)?
Are the medication and other things you need always available when you go to the clinic or hospital?
Do you pay for other treatment and care services? If not who does?
Do you feel that your experience of services is different as an older/younger woman? Please give details.

5. What needs to change
How could services better suit your needs and address your concerns as an HIV positive woman?

ACTS Questions for service providers

1. Knowledge and information
What government policies and codes of conduct regarding care, treatment and support for HIV and AIDS are you aware of?
What training have you had on HIV and AIDS?
When was the last time you received any training or updated information around treatment, care and support for HIV positive women?
What do you believe to be HIV positive women's rights in terms of access to care, treatment and support?

2. Services (including information provided, equipment and medicines and cost)
What services do you provide? Who is the target group? Are they free?
What are some of your objectives and goals as a service provider?

3. Services particularly for women / women with HIV
Do you provide any service or programmes specially for women or HIV positive women or do any of your services address the specific needs of HIV positive women?
How are these service adapted to make them more suitable for HIV positive women? (eg female staff, different opening times, treatment for women-only medical problems, etc)
How do you ensure confidentiality for HIV positive service users?
What training is there for staff on positive women’s care, treatment and support issues?
Do you have any data on the number of HIV positive women and men, young and older that use your services?
Do you offer any services to couples?

Do you ever encourage women to return with their partner?
Do women have to meet any conditions if they want to access services? (for example, do they have to have the permission of a husband or guardian; are they required to be using a certain type of contraceptive in order to access ARV treatment?)

4. Problems and challenges
What problems do you encounter when treating and caring for HIV positive women, or ensuring that your services meet their needs? Do you have anyway of finding out what their needs are?
Do you have the necessary technical resources, equipment and knowledge needed for treating and caring for HIV positive women?
What can women do if they are mis-diagnosed or given the wrong treatment or are unhappy with the service in general?

5. Monitoring service users and services
How do you monitor how well a newly diagnosed person is understanding and coping with her status and whether they are getting the right treatment and support?
How do you monitor use and success of your services, including treatment provision, diagnostic services, care, etc for positive women?
How do you ensure continuity of care?

6. GIPA
How are HIV+ women involved in your programmes - as target groups only, or as specialists, consultants, managers and in leadership roles?
What role do you feel that HIV positive women should play in your programme development and delivery?

7. Future plans/What needs to change
What additional resources do you need to address the needs of HIV positive women?
What are your plans to improve the services available to HIV positive women?

ACTS Questions for government

1. Policy Index
What policies does the government have on ACTS for positive women? What stage are these at (consultation, draft, ratification, implementation, etc…)
Which are the departments, ministries, bodies, etc responsible for implementation of the policies?

2. Budget
What is the budget for HIV+ women's access to care, treatment and support within the annual budget?

3. Programmes and resources
What government supported programmes are there that support the implementation of commitments made through the Abuja agreement and UNGASS declarations of commitment and in their own national AIDS policies and strategic plans? What programmes and resources are provided that specifically address the needs of HIV positive women, including:

- on-going training for health service personnel concerning the needs of HIV positive women?
- equipment, medication, and care services for HIV positive women and/or adapted to their needs, including home-based care, ARV services?

4. Support

What government support is offered to HIV positive women who affected by poverty to carry on with treatment?
What ministry is responsible for these programmes?

5. Quality control
What is the government's procurement process of drugs used to treat HIV and HIV related infections?
What quality control measures are in place to ensure that drugs are not sub-standard (including those to prevent STIs, PMTCT, cervical and breast cancer, women-specific opportunistic infections)?

6. Monitoring
What indicators are used to monitor commitment on ACTS including UNGASS , Abuja declarations, and national policies and strategies?
Who is responsible for monitoring programmes committed to providing treatment, care and support for HIV positive women?

7. Campaigns
What government backed campaigns are there that raise awareness about women's rights, treatment issues which particularly affect women (for example on nutrition, prevention etc) in the media, through poster campaigns, in schools, etc?

8. Research
What policies to involve HIV positive women's groups in the design and implementation of research does the government have?
What regulations and protection exist for positive women and men who take part in medical research, especially drug trials?

9. GIPA
How and at what stage are HIV positive women involved in policy making, implementing, monitoring, evaluation and reporting?
Which issues, policies, programmes and services have HIV positive women been consulted on?
What mechanisms exist to involve representatives of HIV positive women's groups in matters that affect them?
What capacity building or training is offered to HIV positive women and men to enable them to be involved in work which affects their lives?
What capacity building or training is offered to government employees to enable them to engage at different levels with HIV positive people on issues and decisions that affect their lives?

10. Future plans and commitments
What government plans are there to roll out policies on ACTS to reach inaccessible communities and HIV positive women and girls?
What level of civil society involvement is there in the development and sharing of these plans, including HIV positive women's groups?
What plans does the government have to strengthen the distribution and computerisation of gender disaggregated data of ACTS nationwide?
What resources does the government plan to provide for providers of ACTS in the coming 12 months?

Section 3 - Sexual and Reproductive Rights (SRR)

Definition
Sexual and reproductive rights cover all aspects of women's sexual and reproductive health needs and recognise the different needs that women in different circumstances may have including HIV positive women, women living with disabilities, young women and older women.

Sexual rights are: the right to treatment for sexual health problems; the right to have consensual sexual relationships, and the right to choose how and where and with whom these are carried out; the right to protected sex; right to pleasurable sex; the right to bodily integrity and freedom from sexual intimidation, coercion or force.

Reproductive rights are: the right to choose whether and when to have children, how many, how to bring them up; the right to healthy motherhood including treatment, counselling and support before, during and after the pregnancy; the right to make an informed choice on whether to have a termination or sterilisation, and the right not to be forced or coerced into either; the right to safe, legal termination or sterilisation; the right to assisted conception, and a full range of contraceptive and protective technologies.

Interview tip:
We have found that when using the questionnaire, it can be intimidating to go through all the questions. You may prefer to start a 'conversation' with a general question related to each (sub-)section which will elicit a story from the person you are interviewing and get them talking. After a more general conversation, you can use the questions as a check list to see whether any key areas of information have been missed.
Example question:
Can you tell me about your experiences of sexual relationships?
Can you tell me about your experiences of having children and planning a family since you have been HIV+?
This may include experiences of services, information, adherence/ability to use the advice or treatment offered, and monitoring / follow up of services
Asking personal questions
Some people may feel that the questions in this section are too personal to ask or answer. If you or your interviewee feels this way, you could ask the questions in the third person, for example:
What are the experiences of HIV positive women in your community when deciding to have children or start new relationships?

SRR Questions for positive women

1. Knowledge
What do you understand to be your sexual rights?
What do you understand to be your reproductive rights?
Do you know what female-controlled barrier methods exist for preventing the transmission of HIV/AIDS?
If you decided to have a child, what would be your main concerns? Where could you find answers to these?
Are you aware of "prevention of mother to child transmission" (PMTCT) programmes? Do you know what these do?

	Where can you get information on	What do you need more information on?	What is your opinion of this information?
healthy motherhood planning for conception			
pregnancy			
ante-natal care and treatment			
delivery			
post partum care for mother and child			
Sexual health issues and services (eg sexually transmitted infection?)			
Family planning			
Abortion			
Sterilisation			
Assisted conception			
Infertility			
Pap smears			
Reproductive tract infections			

What questions do you have on sexual and reproductive rights?

2. Experience of rights / Decision making
Sexual rights:
Do you or your sexual partner(s) use a barrier method? Which one? Who decides what to use and when to use it?
Are you able to choose on how, when and how often to have sex? Who usually initiates sexual activities – you or your partner(s)?
Do you feel able to discuss sexual pleasure with your partner(s)?
Do(es) your partner(s) ever force you to have sex even if you don't want to? If yes, what do you do?
Are you able to ask him/them to use a condom? Do(es) he/ they ever refuse? If so, what do you do about it?
Do you disclose your HIV status to your partner(s)?
If no, why not?
If yes, how do they react?
Are you aware of your partner's(') status?
If yes, how did you find out?
If no, how does this affect your relationship?

Reproductive rights:
As an HIV positive woman, do you think you have the right to have (more) children?

Are you or your partner using a contraceptive? Which one? Who decides what to use and when to use it?
Have you had or are you planning to have children? (If no, go to the next section)
Who decides on if to have children, when to have them, and how many?
Are you likely to be stigmatised for your choice of feeding alternatives? (eg would you be forced to disclose status if you chose to bottle feed your baby to reduce risk?)

3. Access to services
How far away is your nearest health clinic? How do you get there?

	What sexual and reproductive health services do they provide? Please tick	Have you used them?	If the service is not available locally how much further do you have to travel?
STIs and other sexual health services			
abortion			
sterilisation			
PMTCT			
Healthy motherhood			
Ante-natal care and treatment			
delivery			
Post-partum care for mother and child			
assisted conception			
family planning			
healthy motherhood			
pap smears			
Infertility treatment			
Treatment for reproductive tract infections			

If PMTCT services are provided, do they care for the mother's health as well as the child's?
When you access PMTCT services, have you been given advice on sexual relationships, contraceptives, sexual health and STIs?
What different kinds of contraception and barrier methods are available?
Which of these are free?
What kind does the service provider recommend?
If you use a different one, please explain why.
What barriers have you experienced to accessing sexual and reproductive health services?
Are younger and older women able to access the same services with the same ease? What different problems do they face?

4. Experience of services

How often do you have a sexual health check up, including a pap smear? (Do you know what a pap smear is?)
Do the services provide continuity of care (including counselling) after pregnancy, abortion, treatment for STIs etc?
Do you feel comfortable accessing the services? If not, please explain what problems have you encountered?
Are there any conditions that need to qualify for services? (eg sterilisation if an abortion is sought)

5. What needs to change
What changes are needed to improve sexual and reproductive health services in your area?
How could services better suit your needs and address your concerns as an HIV positive woman?

SRR Questions for service providers

1. What services do you provide for HIV positive women?

	Which of the following services do you provide on sexual and reproductive health?	Is it free?	Who is the target group?	How are the services tailored especially for HIV positive women?
STIs and other sexual health services;				
abortion;				
sterilisation;				
PMTCT;				
assisted conception;				
family planning;				
healthy motherhood;				
pap smears;				
Breast exams;				
Advice, counselling and follow-up care on each of the above;				

What are some of your objectives and goals as a service provider?
What do you believe are the SRRs of HIV positive women?
What does your routine check up for HIV positive women involve?
How often is a pap smear done for HIV positive women?
What sexual and reproductive health advice is given to HIV positive women during a routine check-up?
What barrier and contraceptive methods do you make available?
Are contraceptives available to positive women? are they compulsory or not?
Do you offer any services to couples?
Do you ever encourage women to return with their partner?

Under your PMTCT programme, which of the following are routine procedure:

- Advice / counselling of positive women in planning for conception / pregnancy;
- monitoring and advice on health of mother during pregnancy
- Ante-natal classes
- Prevention treatment during delivery
- Choice of delivery methods / locations
- Advice on infant feeding options

- Awareness raising in communities
- Post partum care for the mother and child, including regular health checks, counselling, nutrition / healthy living advice, etc.

2. Quality and appropriateness of service:
What specially tailored services do you provide for young women, disabled women, women who speak different languages, older women, widows, and women's partners?
How do you ensure confidentiality to HIV positive service users?
How do you ensure continuity of care?
What advice do you give to HIV positive women about pregnancy, family planning and sexual health?
How do you monitor the health of (potential) mothers prior to conception, during pregnancy and after childbirth?
Is training offered to staff concerning the SRHR of HIV positive women?

3. Challenges
What are the main challenges your service providers face in providing services for HIV positive women?
What are the main challenges HIV positive women face in accessing your services and acting on advice and treatment given?
What is the procedure HIV positive women can pursue if they are unhappy with the service?
In what way are HIV positive female health staff encouraged to use the services offered?

4. GIPA
How are HIV+ women involved in your programmes - as target groups only, or as specialists, consultants, managers and in leadership roles?
What role do you feel that HIV positive women should play in your programme development and delivery?

5. Monitoring service users and services
How do you monitor use and success of your services, including treatment provision, diagnostic services, care, etc for positive women?
How do you ensure continuity of care?

6. Future plans/What needs to change
What additional resources do you need to address the needs of HIV positive women?
What are your plans to improve the services for HIV positive women?
What resources do you have to meet the needs of positive women (including specialised training)? Are they adequate?
How will HIV positive be involved?

SRR Questions for government

1. Policies / legislation
What government policies are there on the sexual and reproductive rights and/or health of positive women or related polices, including gender policy?
What are the international agreements and declarations to which the government is signatory (eg CEDAW, etc)?
Which ministries, departments, bodies, etc, are responsible for making and implementing laws and policies on women's rights in general and SRHR in particular?

2. Budget questions
What is the annual budget for SRH?
How much is specifically allocated to the SRH of HIV positive women?
How much is specifically allocated to women of different age groups?

3. Programmes and resources:
How many sexual and reproductive health centres are there in the country?
How many SRH centres are specifically for HIV positive women?
How many SRH centres have youth friendly services or clinics?
How often does the government updates and changes equipment provided in SRH centres?
How often and what type of training is provided to service providers?
What quality control measures exist to ensure standards of equipment, material, medication for SRH?
What level of provision of contraceptives, barriers, medication for the treatment of STIs, etc (free of charge) is carried out?

4. Campaigns
What government backed campaigns are there that raise awareness about women's rights, sexual and reproductive health, prevention, etc in the media, through poster campaigns, in schools, etc?

5. Research
What commitments to research on female controlled prevention technologies (microbicide research) are there?
What policies to involve HIV positive women's groups in the design and implementation of research are there?
What regulations and protection exist for positive women and men who take part in medical research, especially drug trials?

6. Monitoring
What reporting procedures on national policies and legislation exist on women's sexual and reproductive health and rights?
Which bodies are responsible and what methods are used for the gathering and analysis of data?
What indicators are used to monitor and evaluate the accessibility of ARVs and Nevirapine to HIV positive women?

7. GIPA
How are HIV positive women involved in the consultation, design and implementation of all relevant policies and legislation?
What government supported programmes or services are there that address the needs and rights of positive women on which HIV positive women were consulted?

8. Future plans / commitments
What are the government's plans to develop policies and legislation on the sexual and reproductive health and rights of HIV positive women?
What are the government's plans to ensure the quality, availability and appropriateness of services and treatments offered to HIV positive women?
What are the government's plans to reduce the incidence of unwanted pregnancy, especially among teenage women and girls?
What are the government's plans to expand PMTCT programmes, and ensure that the mother's health as well as the child's is properly monitored?
What level of civil society involvement is there in the development and sharing of these plans including HIV positive women's groups?

What resources the government plans to provide for sexual and reproductive health care providers of in the coming 12 months?
How do you plan to involve HIV positive women?

Section 4 - Violence Against Women (VAW)

Definition
Violence against women (VAW) can take many different forms including verbal, physical, sexual, emotional, financial, and psychological violence. It can also take the form of fear of any of the above. The understanding of the term as used in the workshops in which this tool was developed, includes the following types of violence or fear of these:
Rape; incest; statutory rape (sexual intercourse with children or young people below the legal age of consent); marital rape; refusal to use available protective technologies to safeguard against (re-)infection or transmission of STIs including HIV; domestic violence; battery and assault; verbal violence or bullying such as cursing and use of swear words and derogatory terms; sexual violence including sexual intimidation or threats; stigma and discrimination; refusal of medical examination or treatment; withdrawal of financial support; abandonment; community violence (eg setting fire to someone's house); violation of human rights; being deprived of access to and ownership of property after the death of spouse.

Interview tip:
We have found that when using the questionnaire, it can be intimidating to go through all the questions. You may prefer to start a 'conversation' with a general question related to each (sub-)section which will elicit a story from the person you are interviewing and get them talking. After a more general conversation, you can use the questions as a check list to see whether any key areas of information have been missed.
Example question:
Can you tell me about your experiences of violence against you or HIV positive women or girls that you know? This may also include experiences of services, information and referrals.
Asking personal questions
Some people may feel that the questions in this section are too personal to ask or answer. If you or your interviewee feels this way, you could ask the questions in the third person, for example:
What types of violence are commonly experienced by HIV positive women in your community, and what is the impact on their health and ability to access health care and other services?

VAW Questions for positive women

1. Knowledge
What do you understand by the term "Violence against women"?
In what ways do you think HIV/AIDS and Violence against Women are related?
Are you familiar with any policies, legislation, or international agreements which address VAW?
What impact do you think they are having? Do you think they are effective?
How would you describe women's position in this society?
What services are you aware of which assist women who have experienced violence including rape?
Are the services free and accessible? (medication expenses, legal representation)

2. Experience of Violence against Women
Has fear of violence ever prevented you from seeking care, treatment or support, acting on medical advice, or negotiating safe sex practices in your sexual relationship(s)? Please give details.
What forms of violence have you experienced? (If none, please go to the last section on change)
Have you experienced an increase of violence since your disclosure?
Do you feel that the violence you have experienced was due to your HIV status or gender? Please give examples.

Who did you go to for support after experiencing violence? (eg family members, friends community members, police, church, support group, counsellor, etc)

3. Experience of services
Have you ever:

1. reported an incidence of violence to the police?
2. Sought medical help?
3. Sought legal advice?
4. Had counselling related to violence?
5. Sought support from community groups including support and church groups?
6. Sought support from family and friends?

How comfortable were you with these services and support? How were you treated? What were you offered? What could have made the experience easier or more comfortable?
Which did you not approach and why?
Please describe your experiences of accessing any of the above services and support

	Please describe your experience of accessing the following, when reporting violence
Post exposure prophylaxis (PEP)	
Legal advice and assistance	
Referrals (medical, legal, counselling etc)	
Counselling	
Medical examination / report	
Financial assistance	
Safe house	
Female police officers / medical staff	
special room for interrogation	
Other	

4. Barriers
What barriers did you encounter in accessing any of the services and support mentioned above (for example, money, transport, or fear of negative consequences?

5. What needs to change
What changes are needed to improve services and support for HIV positive women who experience violence in your area?
How could services better suit your needs and address your concerns as an HIV positive woman?

VAW Questions for service providers

(This section is meant for people working in the following areas: Police, clinics, hospitals, NGO (with a VAW mandate), support groups and legal support organisations)

1. Services
What do you understand by the term Violence against women?
What services do you provide for women who have experienced violence against women?
How are these services tailored to address the particular concerns of HIV positive women? (eg how do you create an environment in which an HIV positive woman can talk openly about her status and experience of violence?)
Do you offer any services to couples?
Do you ever encourage women to return with their partner?

What kinds of violence can women report here?
What forms of violence are most commonly reported here?

2. Procedures and referrals:
What procedure do you follow if a woman who is HIV positive comes to report an incidence of violence?
Do you offer medical advice / services? If not, is a referral made on behalf of the service user?
Do you offer legal advice / services? If not, is a referral made on behalf of the service user?
Do you offer counselling services? If not, is a referral made on behalf of the service user?
Do you have a policy or programmes to protect the service user from further violence (eg safe houses, perpetrator rehabilitation, restraining orders)? Please give details.
How do you monitor the speed and effectiveness of referrals and follow-up actions?
What procedure exists for a woman to make a complaint about the service?

3. Legal action
How often do the cases go to court?
Of these how many result in convictions?
What is the average time frame from reporting the incident to sentencing a perpetrator of violence?
How often do women withdraw or drop cases after they have initiated a legal process? What are the reasons for this?

4. Resources / quality of services
What training on HIV and VAW do service providers receive? Do they include information and counselling on PEP?
What do you do to make the experiences as comfortable as possible for the women who report incidences of violence? How do you ensure women friendly services and positive attitudes among the police, health workers, counsellors, etc?
What constraints do you face in protecting the rights of HIV positive women who have experienced violence?

5. GIPA
How are HIV positive women involved in the consultation, design and implementation of all relevant policies and legislation? Are they paid staff or volunteers?
What government supported programmes or services are there that address the needs and rights of positive women on which HIV positive women were consulted?

6. Future plans/What needs to change

What additional resources do you need to address the needs of HIV positive women who have experienced violence?
What are your plans to improve the services for HIV positive women who have experienced violence?
In what way does your service help to reduce the rate of violence against women, in particular HIV positive women?

VAW Questions for government

1. Existing policies
What government policy exists on women's rights, gender, violence against women, including polices to revise customary and cultural practices, such as forced marriages, virginity testing, mourning rituals for widows, and others which violate HIV+ women's rights, or related polices, legislation and resources?
What are the international agreements and declarations to which the government is signatory (eg CEDAW, etc), and related policies, legislation and resources?
What are the national strategic plans addressing the rights and concerns of HIV positive women, mitigating the impact of the epidemic, and related polices, legislation and resources?
Which ministries, departments, and bodies are responsible for making and implementing laws and policies on women's rights in general and VAW in particular?

2. Budgets
What is the budget allocation for issues relating to VAW and violence against HIV positive women under the ministry of 1) justice, 2) home affairs 3) health?

3. What has been done – programmes, policies, support etc
What government supported programmes are there to reduce violence HIV positive women in the country?
How many institutions address violence against women and how?

4. Campaigns
What government backed campaigns are there that raise awareness about women's rights, and violence against women, particularly in relation to HIV and AIDS, in the media, through poster campaigns, in schools, etc?
What information has been produced and disseminated by the government on violence against women and women's rights?
Who are the target audiences of awareness arising campaigns?

5. Monitoring
What indicators and reporting procedures are used to monitor policy instruments such as CEDAW?
What are the procedures for reporting on VAW to international community?
What methods and mechanisms exist for measuring and disseminating national statistics relating to VAW?

6. GIPA
How have HIV positive women been involved in drafting gender policies or related policies?
What mechanisms exist for ensuring the participation of HIV positive women are included in decision making that affects their lives?
How are HIV positive women involved in implementation and monitoring of international policy commitments that concern them?

7. Future plans

What are the government's plans to develop, update and implement any draft policies relating to gender, women's rights or violence against women?
What are the government's plans to develop new policies, programmes and legislation to stop violence against women, including violence against HIV positive women?
What level of civil society involvement is there in the development and sharing of these plans including HIV positive women's groups?
What resources does the government plan to provide for providers of services for HIV positive women who experience violence in the coming 12 months?

Section 5 – short versions of the questionnaire

ACTS - short version

Definition
ACTS refers to HIV positive women's ability to gain consistent access to all available care, treatment and support services, including anti-retrovirals, medication for opportunistic infections, advice and treatment for side effects of medication, diagnosis and treatment for sexual and reproductive health matters including treatment of STIs, information and advice on PMTCT, healthy pregnancy and motherhood; awareness, information and treatment for gender-specific illness; pre- and post-test counselling, on-going support in the form of counselling, and where necessary financial support to meet payment for treatment or doctor's fees; home based care and other care-in-the-community programmes and initiatives; workplace policies; supportive environments at home, in the community, workplace, place of learning, public and health service institutions.

ICW recognises that gender inequalities can constrain HIV positive women's access to care, treatment and support as well as their ability to use treatment, information and advise to improve the quality of their lives. We also recognise that the care, treatment and support needs of HIV positive are different to that of men.

Questions for HIV positive women
- Back ground information – name, ethnicity, age, where you live (this information does not have to be given)
- Knowledge of treatment, care and support options, services and access to information. What do you know and how do you find out?
- Access to care, treatment and support – what barriers do you face to accessing services?
- Experiences of care treatment and support services – how comfortable are you using them? Are they appropriate to your needs?
- Knowledge of polices and what you would like to see change.
- Give some examples of how you have tried to improve rights for women at any level. What barriers and solutions do you encounter?

Questions for service providers
- Knowledge and information – what do you understand to be HIV positive women's rights in relation to ACTS?
- Services – what services do you provide and how do you tailor them to meet HIV positive women's needs?
- Problems and challenges - What problems do you encounter when treating and caring for HIV positive women, or ensuring that your services meet their needs?
- Monitoring service users and services – how do you monitor the effectiveness of your services?
- GIPA - How do you involve HIV+ women in your programmes?
- Future plans/What needs to change - What are your plans to improve the services available to HIV positive women? What resources do you need?

Questions for government
- Policies and programmes - What policies and programmes does the government have that specifically address HIV positive women's ACTS? What stage are these at? Who is responsible for implementation?
- Budget - What is the annual budget for HIV+ women's access to care, treatment and support?
- Monitoring – How are international commitments, policies and programmes monitored?
- Campaigns - What government backed campaigns are there that raise awareness about HIV positive women's rights to quality care, treatment and support?
- Research – how do you ensure that research in your country supports the rights and health of HIV positive women?
- GIPA **-** How does the government actively seek to involve HIV positive women in policy making, implementing, monitoring, evaluation and reporting?
- Future plans and commitments to HIV positive women's health and rights – what are they?

SRR – short version

Definition
Sexual rights are – rights to treatment for sexual health problems, right to choose how when, and how and where and with whom you have sex, right to protected sex; right to pleasurable sex.

Reproductive rights are – right to choose whether and when to have children, how many, how to bring them up, healthy motherhood including treatment, counselling and support before, during and after the pregnancy; the right to make an informed choice on whether to have a termination or sterilisation, and the right not to be forced or coerced into either. The right to safe, legal termination or sterilisation. The right to assisted conception, and a full range of contraceptive and protective technologies.

Questions for HIV positive women

- Back ground information – name, ethnicity, age, where you live (this information does not have to be given)
- Knowledge of sexual and reproductive rights and health and access to information - What do you know and how do you find out?
- Experiences of sexual and reproductive rights – how much decision-making power do you have in sexual relations and decisions to have and rear children?
- Access to sexual and reproductive services – what barriers do you face to accessing services?
- Experiences of sexual and reproductive health services – how comfortable are you using them? Are they appropriate to your needs?
- Knowledge of polices and what you would like to see change.
- Give some examples of how you have tried to improve rights for women at any level. What barriers and solutions do you encounter?

Questions for service providers

- Knowledge and information – what do you understand to be HIV positive women's rights in relation to sexual and reproductive health?
- Services – what services do you provide and how do you tailor them to meet HIV positive women's needs?
- Problems and challenges - What problems do you encounter when treating and caring for HIV positive women, or ensuring that your services meet their needs?
- Monitoring service users and services – how do you monitor the effectiveness of your services?
- GIPA - How do you involve HIV+ women in your programmes?
- Future plans/What needs to change - What are your plans to improve the services available to HIV positive women? What resources do you need?

Questions for government

- Policies and programmes - What policies and programmes does the government have that specifically address HIV positive women's SRR? What stage are these at? Who is responsible for implementation?
- Budget - What is the annual budget for programmes to support HIV positive women's SRR?
- Monitoring – How are international commitments, policies and programmes monitored?
- Campaigns - What government backed campaigns are there that raise awareness about HIV positive women's sexual and reproductive rights?
- Research – how do you ensure that research in your country supports the rights and health of HIV positive women?
- GIPA **-** How does the government actively seek to involve HIV positive women in policy making, implementing, monitoring, evaluation and reporting?
- Future plans and commitments to HIV positive women's health and rights – what are they?

VAW – short version

Definition
Violence against women (VAW) can take many different forms including verbal, physical, sexual, emotional, financial, and psychological violence. It can also take the form of fear of any of the above. The understanding of the term as used in the workshops in which this tool was developed, includes the following types of violence or fear of these:
Rape; incest; statutory rape (sexual intercourse with children or young people below the legal age of consent); marital rape; refusal to use available protective technologies to safeguard against (re-)infection or transmission of STIs including HIV; domestic violence; battery and assault; verbal violence or bullying such as cursing and use of swear words and derogatory terms; sexual violence including sexual intimidation or threats; stigma and discrimination; refusal of medical examination or treatment; withdrawal of financial support; abandonment; community violence (eg setting fire to someone's house); violation of human rights; being deprived of access to and ownership of property after the death of spouse.

Questions for HIV positive women

- Back ground information – name, ethnicity, age, where you live (this information does not have to be given)
- Knowledge of VAW and access to information. What do you know and how do you find out?
- Experiences of VAW – what violence have you experienced and how has the fear of violence impacted on your actions?
- Access to VAW services – what barriers do you face to accessing services?
- Experiences of VAW services – how comfortable are you using them? Are they appropriate to your needs?
- Knowledge of polices and what you would like to see change.
- Give some examples of how you have tried to improve rights for women at any level. What barriers and solutions do you encounter?

Questions for service providers

- Knowledge and information – what do you understand to be HIV positive women's rights in relation to VAW?
- Services – what services do you provide and how do you tailor them to meet HIV positive women's needs?
- Problems and challenges - What problems do you encounter when treating and caring for HIV positive women, or ensuring that your services meet their needs?
- Monitoring service users and services – how do you monitor the effectiveness of your services?
- GIPA - How do you involve HIV+ women in your programmes?
- Future plans/What needs to change - What are your plans to improve the services available to HIV positive women? What resources do you need?

Questions for government

- Policies and programmes - What policies and programmes does the government have that specifically address violence against HIV positive women? What stage are these at? Who is responsible for implementation?
- Budget - What is the annual budget for programmes that address violence against HIV positive women?
- Monitoring – How are international commitments, policies and programmes monitored?
- Campaigns - What government backed campaigns are there that raise awareness about violence against HIV positive women?
- Research – how do you ensure that research in your country supports the rights and health of HIV positive women?
- GIPA **-** How does the government actively seek to involve HIV positive women in policy making, implementing, monitoring, evaluation and reporting?
- Future plans and commitments to HIV positive women's health and rights – what are they?

Part 3 – training curriculum

Objectives:

1. Introduce the themes and the ICW tool 'Positive Women Monitoring Change'

2. Increase positive women's understanding of the different ways in which they can use the tool

3. Build capacity on:

- Data gathering
- Analysis
- Presentation

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
SESSION ONE - INTRODUCE VAW, SRHR, ACTS
XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

Time needed
One and a half hours

Materials needed
- Copy of the ICW briefing papers on VAW, ACTS, SRHR

Activity one (half an hour)
Ask the participants what do we mean by ACTS, SRHR and VAW? Write up definitions on three flipcharts.

Activity one (one hour)
In three groups, one looking at each area, ask them to write-up on a flip-chart what the main issues are facing HIV positive women in their country related to the area they are considering.
Groups present back to plenary.
The facilitator should ensure that they have considered at least all the issues mentioned in the briefing papers.

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SESSION TWO - INTRODUCE THE PWMC TOOL AS ANALYTICAL FRAMEWORK
XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

Objectives
- To ensure that participants understand why and how the tool was developed, what it contains, how it can be used and what some of the challenges are.

Time needed
One Hour

Materials needed
- Copy of the whole tool and summary for each participant

Activity one (30 minutes)
Facilitator will ensure that participant's understanding of the tool is complete by introducing elements that the participants do not raise.
- Developed by whom? HIV positive women in Swaziland and Lesotho in 2005
- Why? To monitor government commitment to the rights of HIV positive women.
- What topics does it cover? VAW, ACTS, SRHR
- With which groups? Positive women, health care providers and policy makers
- How has it been used? It has been used to gather information in RSA, Swaziland and Uganda
- How can it be used?
    - As a framework for gathering, analysing and presenting information. For example, in one on one interviews or to guide a group discussion and as a structure for developing reports.
    - For raising awareness of the issues with the three groups. It also offers a structure to bring positive women together to discuss issues that are often overlooked in other forums.
    - Workshopping to help positive women prioritise issues and set advocacy agendas
    - Evidence gathering for advocacy.

- To raise issues of concern among government representatives, service providers, civil society organisations, HIV positive women. Ie, have you thought about…..?
- Use as a check list when asking questions at a meeting.
- To monitor government commitment to rights in policy and practice.
- Push for academics to use the tool (or some of the questions) in their research. (NB Researchers can also use ICW's ethical guidelines to ensure that they involve positive women in a way that is not solely extractive, or in policy analysis)
- CSOs can adapt it to monitor their own work or the work of others.
- Mobilising positive women and other community groups around these issues through community assessments and needs assessments

- What are some of the challenges of using it? Length. Access to policy makers. Recording and using results to be used in advocacy
- Why is there a short version of the tool? In time sensitive situations and to guide less structured discussions, less intimidating.
- In what way is this a monitoring tool?

Activity two (30 minutes)

Choose a sub-section of the tool and go through the questions asking the participants why it is important to ask each question?

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
SESSION THREE - PARTICIPATORY APPROACHES
XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

Objectives

- To increase participants understanding of what a participatory approach is, why it is needed and what it entails.

Time needed
30 minutes

Materials needed
- flip chart paper

Activity one (30 mins)
Facilitator to ask group the following questions:

- What is meant by a participatory approach? Who do we want to participate? What are the different ways a person involved in a project can participate? E.g. workshop participant, interviewee/interviewer.
- Why is the participation of HIV positive women important?
- At what stage / in what role?
- How can participation in using the tool be facilitated? E.g. ensure that positive women are involved in prioritising the issues, carry out needs assessment, establish focal points to feedback, ensure that data gathering processes are informative, not just extractive – ie that women involved in the data gathering also take something away with them that they can share with others, or apply in their lives and work etc.
- What are some of the challenges?

Notes for facilitator

What is meant by a participatory approach?

ICW Definition of GIPA
The Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) was signed in 1994 by 42 national governments at the Paris AIDS Summit. The principle is critical to ethical and effective national responses to the epidemic.

ICW believes that when HIV-positive people are involved in all levels of decision-making of an organization, the organization is better able to respond to the concerns of people living with HIV/AIDS. For example, through personal experience, HIV-positive women and girls best understand the barriers that they face in accessing sexual and reproductive health and treatment and care services.

With first-hand knowledge of the needs of those living with HIV, we want our members to be consulted on the development, design, and delivery of better ways of making sexual and reproductive health and treatment and care services available to HIV positive women and girls around the world. Groups and individuals concerned with these issues should work in creative, interactive, and participatory ways with HIV-positive women as well as with others who work directly with community members and other relevant groups to enable us to create “services to fit people” rather than “people to fit services.” We believe that only through such collaborative efforts can we adequately address the barriers that prevent women and girls from accessing sexual and reproductive health services.

Why is this important?
- To ensure that intended changes are relevant, effective, sustainable and empowering

How can participation be aided and what are some of the challenges?
- Training in use of the tool so that positive women can lead on data gathering
- Positive women lead on prioritising which areas of the tool should be used, and adapt the tool to fit local circumstances, concerns and issues
- Support through human and financial resources
- Developing linkages and dialogues with service providers and policy makers

Challenges
- Time burden on women and staff, resources, communications
- Lack of skills and expertise, for example, how to analyse and write-up the results.
- Relating personal circumstances to the wider context.

XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX
SESSION FOUR – DATA GATHERING METHODS
XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX

Objectives
- To improve participants understanding of what research methods exist and how to use them and why.

Time needed
An hour and a half

Materials needed
- Flip chart paper
- Write instructions for activity three on a flip chart.

- Print out instructions for activity four

Activity one – methods (one hour)

- Brainstorm methods and make sure the following are mentioned – explain each one if participants do not know or get those that do to explain to group.
    - Transect walk
    - Mapping – examples include a map of the community and then indicating possible influences on women's health or barriers to health care or a body map and indicate related women's health issues.
    - Site visit
    - Timelines
    - Focus group
    - One-to-one interviews
    - Surveys / questionnaires
    - Semi-structured interviews
    - Structured interviews
    - Stories
    - Desk review/internet search
    - Role plays

- Why/when would each be used? What are the advantages and disadvantages of each type? NB some allow for more participation that others. It is very important that you cover one-on-one interviews and small group discussions as they are likely to form the basis of your data gathering.

NB – all these data gathering activities can be used for data gathering/research, needs assessment, community assessments, informing publications, or in participant learning, information exchange, and for mobilisation / workshopping (awareness raising, linking personal experience to policy and practice, setting priorities and developing advocacy agendas / action plans) around a certain issue or area, and for M&E.

Activity two - How to record information and who does this information belong to? (30 minutes)

- Ways of recording information
    - Tape recorders
    - Film
    - Notes / transcriptions
    - Maps and impermanent grids etc (PRA type stuff)
    - Photos
    - Drawings / diagrams
    - Flipcharts
    - Stories / researcher diary
- What are the advantages and disadvantages of each method?
- Who does this information belong to?
- How do we make this process less extractive?
- Importance of quotes and reflecting the voices of the participants.
- What other challenges are there?

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SESSION FIVE – DATA GATHERING IN PRACTICE

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Objectives

- Each participant will gain experience of using 2 research methods

Time needed
- Seven Hours

Materials needed
- Flip chart
- Thick pens
- Print-outs of instructions
- Recording apparatus (pen tape, recorder, flip chart, computer)
- Write questions for activity three on flip charts

Activity one - Plenary example of interviewing (An hour)
- Facilitators, with two (strong) participants, role play an example of a small focus group discussion. One facilitator is the interviewer and should illustrate good and bad interview techniques (or two role plays as a good example and a bad example).
- Role play a one-on-one interview.
- Ask the participants to give comments on what they saw. For example, facilitator keeps interrupting the interviewee. Elicit bad and good techniques.

(NB – role plays should be kept down to a minimum of 10 minutes – they do not need to show the whole interview / focus group discussion)

Good techniques that should be illustrated:
- Start with a small group discussion with members of a support group which can help give the women mutual support. But be aware that some women will not want to talk about their experiences in front of other group members, that certain women will dominate and that specific individual experiences such as coerced sterilization can be discussed in more detail (confidentially) in a one-on-one interview. It is good to use both techniques.
- Don't forget to gather background information for each participant.
- sure that the informants is aware that it takes about two hours to go through the tool thoroughly.
- Introduce the project and how the information gathered will be used. Tell the informant they will receive copies of any materials written on the basis of the information gathered.
- Ask the informant if you can come back to them if there is any follow-up or additional information required.
- Take detailed notes during the discussions. If you do not take notes then the information can not be used beyond the group. A tape recorder can be used but all interviews will have to be transcribed.
- Informants must be assured that their personal data would not end up in the public domain without their consent. Explain that confidentiality is shared between the informant and the interviewer. A code can be employed to allow the interviewer to share the information with their organization.
- Employ active listening techniques – e.g. eye contact, nodding. Pay attention and do not get distracted by for example, noise outside the room or your mobile phone. Ensure that your phone is switched off.
- If the questions are sensitive ask questions in the third person first to see if the informant will open up. 'In your community do women…?' rather than 'Do you…?'.
- Respect the individual's barriers and do not force the informant to divulge information they would not ordinarily release.
- Ask broad questions to encourage the informant to talk fluidly. 'Can you tell me about your experiences of reproductive health services in your community'? You can always ask more specific questions afterwards if the informant has not covered all the areas.
- Remember that there may be sections of the tool that are not relevant to all informants.
- Do not impose moral values on the informant or judge the informant's choices.
- Do not contradict the informant. For example, 'my sister-in-law works at your local health clinic and she told me that there is no discrimination against HIV positive women'.

- Tie up the interview by asking the informant if they have anything more they want to say, thank them and reiterate again that the information is confidential and also describe the channels of communications for the project – between organization, interviewer, support group, support group leader, and informants.
- You may want to offer information about your organization and issues being discussed e.g. the fact sheets in this curriculum.
- Cover their lunch and transport costs. Sometimes ICW also offers per diem.

NB – it is worth introducing at this stage choice of venue and timing of interview. Choose somewhere that is easy and safe for informants to get to, that is not too noisy and that is not too public. In most cases, support groups and interview informants are likely to be able to suggest a suitable venue. In arranging the time of the interview, it is important to make sure the time is convenient for the informant rather than the person conducting the interview.

Activity two - Introducing the practical session (half an hour)
Explain to participants that they will be using the tool with each other. The group will try out two methods of data gathering:

- Focus group discussions (First hour – in groups of not more than 8 not less than 6)
- One on one interviews (Second hour – in pairs to practise interview on each other)

Give out instructions and run through them with participants.

Other questions to ask in plenary before practice starts:

- Confidentiality – why is it important and how can we maintain it? Point out that today there may be some questions that participants do not want to answer and that is fine!

Instructions for focus group discussions:

- The group needs to decide who will facilitate, and who will record the discussion (possibly more than one person for each job) the rest of the group will be answering the questions.
- Choose one section of the tool to use. For example, the questions on VAW for HIV positive women.
- They will also decide what recording techniques they will use, tape recorder, writing notes on paper, photos, writing directly on to the computer, or getting participants to put their answers on flip charts. Whatever method you choose the results will have to be written up on computer at some point. Why? If you do not record information you will be failing the participants. Also, remember that quotes are powerful – a bullet-pointed list is ok, but it's good to be able to back up your bullet points with personal stories and experiences (even if these are very short – just a couple of lines), so you may want to use more than just flipcharts for recording the discussion
- The group also needs to think about what they will do with the information, how they will present it, and who it needs to go to.
- Looking at the questions, you will also need to decide what exercises / methods of data collection to use. (body mapping, community mappings)
- You will have time later to look at the data, analyse it, and prepare and give a presentation.

Instructions for one on one interviews:

- This will take 30 minutes for each interview, two interviews in total.
- Choose one section of the tool to use. For example, the questions on VAW for HIV positive women.
- You will also decide what recording techniques to use, tape recorder, writing notes on paper, and writing directly on to the computer. Whatever method you choose the results will have to be written up on computer at some point. Why? If you do not record information you will be failing the women.
- You may want to ask a general question that covers each sub-section of the section you are look at (see for example the short version of the tool). This will encourage women to tell their

experiences in a more fluid way – you will then fill in the relevant answers in the more detailed version. You can revisit gaps in answers after each sub-section has been discussed.
- You will have time later to look at the data, analyse it, and prepare and give a presentation.

Activity two – the workshops (2.5 hours)
- focus group discussion (if the whole group is larger than 14, it can break into 2 focus groups that can run concurrently (1 hour)
- 1-to-1 interviews (x2) (30 minutes each)
- Extra time is added to this session to allow for getting into groups, swapping roles, etc

Activity Three – Feedback on experiences of using the different technique (1 hour)
These will be a group session of participant's experiences
- How did you feel when carrying out / participating in the research?
- What worked best and why?
- What did not work so well and why?
- What challenges were encountered?
- What additional observations were made?

NB: feedback only on the experience of running / participating in / observing the workshops, NOT on the content or findings

Activity four – whole group – role play service providers and policymakers (1 hour)
- Select about 4 participants to act as service providers.
- For about 5 minutes as them to decide on their roles more specifically while in twos the rest of the participants select two questions they would like to ask service providers using ideas from the tool.
- Give twenty minutes for the participants to ask their questions of the panel and for the panel to respond.
- Repeat with a panel of policymakers.

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SESSION SIX - ANALYSIS AND PRESENTATION
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Objectives
- Participants learn to organise the data gathered and pull out key issues.

Time needed
- 3.5 hours

Materials
- Flip chart paper
- Cards or sticky notes
- Tape or blu-tac
- print instructions for activity two
- write instructions for activity three on flip chart.
- Write instructions for activity four on a flip chart.

Activity one - different ways of presenting (30 mins)
Brainstorm of presentation techniques – write on flip chart
- Meetings/ Workshops/ Conferences

- PowerPoint
- Website
- E-fora / E-groups
- Visual / etc (e.g. poster presentation, video, performance)
- Media – radio/TV/Newspaper
- Report/briefing paper
- Other orgs publications – e.g. articles

- Ask participants what are the pros and cons of each. (nb these might differ in terms of who you are presenting the data to – eg policy makers might prefer a power point presentation. Grassroots organisations may include people who don't read)
- Brainstorm on what other things might need to be included in the report – background information about ICW, methodology, annexes – e.g. tables, framework, questions, acknowledgements. – note on flip chart.

Activity two – (1.5 hours) – analysis of the data gathered

- In small group discuss issues that came out during the previous day's research – this needs to be recorded by you and organised according to your questions. Each question will form the main banner for each section. If other information was gathered that does not fit under those headings then an end section or addition headings can be created.
- Write the question at the top of flip chart - in your groups you will record the main relevant points under each one.
- What issues did not come out and why? (eg if using the short version of the tool for the focus groups or interview, go back to the detailed version to see whether all the points were covered. Which were missing? Were any additional points raised? If so these can be discussed and go into the development of the tool – don't forget, this is a working document, not set in stone.) Write on card and stick near relevant flip chart.
- In your analysis of the data think about how factors such as rural/urban, age, gender etc influence the experience of the participants. Record or highlight on flip charts in a different colour.
- Decide who will present the findings.

Think about actual examples the participants gave that can illustrate each of the above - quotes.

Present findings to plenary.

Activity three (1 hour) – using your findings

In groups think about what are the implications of the findings in terms of policy / practice and in terms of your own work. Do two flip charts one with lessons learnt and one with recommendations. Decide how you will present the findings.

- What are your recommendations (to policy and programme makers, and/or service providers?
- What are your lessons learnt for future use of these data gathering methods?

Present findings to plenary.

Activity four - In plenary ask participants (30 mins)

- How do you think the different methodologies impacted on the results?
- How can the findings of this exercise be used? Internally and Externally?
- How do we keep the participants involved?

Also, the presentations can be framed in terms of country policy / political commitments that are known about by the group.

Suggested structure for presenting data from a workshop, focus group or round of interviews using the ICW tool Positive Women Monitoring Change

1. Introduction
1.1 Objective
1.2 Reason for the data gathering activity (why we are here today)
1.3 Explain the activity (methodology) – for example: where and when the data gathering happened, who participated, how many, from where, how long it took, techniques used: e.g. focus groups discussions, interviews.

2. Introduction to ICW (depending on audience for report/presentation)

3. Findings

(You can use the short-version questions as a guide to **sub-headings**)

Suggested example – (Short questions from VAW – adapted to form subheadings):
3.1 Background information (participants' details: number, where from, range of ages, etc)
3.2 Knowledge of VAW and access to information.
3.3 Experiences of VAW – what violence have you experienced and how has the fear of violence impacted on your actions?
3.4 Access to VAW services
3.5 Experiences of VAW services
3.6 Knowledge of polices and changes called for
3.7 Examples of how women have tried to improve rights for women at any level.

4. Lessons learnt in terms of…

4.1 Key issues arising
4.2 Methodology / tool (strengths and weaknesses) – include for example how the methodology you employed influenced the findings and gaps in the information gained.
4.3 Moving forward from here

5. Recommendations

Annexes:
a) A list of questioned asked
b) Thank yous/acknowledgements (e.g. organisers, funders, participants)

Part 4 – supporting information

Section 1: health fact sheets – STIs, thrush, motherhood

Sexually transmitted infections (STIs)

Many people have STIs without being aware of it because they are often not symptomatic. This means that they may not feel any pain or discomfort. STIs are important to know about because if they are not treated they can have very damaging effects such as chronic pain, infertility and cervical cancer. If you are pregnant and have an untreated STI the risk of infecting the baby with HIV and other infections increases. It is now understood that the presence of an STI makes sexual transmission of HIV from one partner to another much more likely.

Protect yourself
It is important to protect yourself against STIs and practising safer sex and using condoms during penetrative sex is the only effective way to avoid STIs. STIs can really affect your health and may make HIV disease progress more rapidly.

Diagnosing
Diagnosing an STI if you have no symptoms is not easy in many countries as screening is not always widely available. However it it now recognised that screening for STIs and treating them is an effective way to slow down the numbers of new cases of HIV. This means that treatment is now increasingly being offered in ante natal clinics, maternal and child health clinics and family planning services. If your partner has symptoms of an STI but you don't, you should still go and get treatment. Both partners should be treated if one has an STI, to avoid reinfection.

Treatment
Treatment of STIs can be fairly cheap and simple. Sometimes it is just one dose of antibiotics. However different infections need different treatments so it is important to get medical advice. If you are pregnant or planning to get pregnant, it is important to have ante natal care and to treat and clear up any existing STIs. STIs can infect the baby at birth and cause serious damage. It is also important to tell your health practitioner if you are pregnant because this may affect the treatment you get.

STIs - what to look out for:
Although many women do not have symptoms you may have an STI if you have had sex and you notice:
- unusual bleeding from the vagina
- unusual stuff coming out of the vagina or your partner's penis ('discharge')
- sores, lumps or a rash on or around the vagina, anus or your partner's penis
- a burning feeling when you urinate
- itching around the vagina or anus or your partner feels it around the penis

If you have or suspect you have any STI you can seek advice and treatment at a health centre.

What about having sex if I am being treated for an STI?
With any STI the best way to avoid infection is to use condoms and practise safer sex every time you have sex. Avoiding oral sex during an outbreak of sores or blisters will reduce the risk of infection and also try to avoid touching any open sores, warts or blisters.

Some Sexually Transmitted Infections (STIs)
Chancroid
Chancroid is a bacterial infection which is common in tropical countries. It causes painful ulcers on the genitals. Chancroid can be identified by a laboratory test and cured with antibiotics.

Chlamydia
Chlamydia is an infection which affects the genitals. It is one of the most common sexually transmitted infections. Most women have no symptoms. It can be treated simply once diagnosed, with antibiotics.

Gonorrhoea

Gonorrhoea is caused by bacteria and again many women will have no symptoms. Gonorrhoea is passed from one person to another through penetrative vaginal, anal, and oral sex. It is very easy to catch. It can also be passed on to babies during birth, causing eye infections and blindness. To diagnose gonorrhoea a swab is taken from the cervix, urethra or the throat. Treatment is usually with antibiotics. If you don't have treatment gonorrhoea can lead to Pelvic Inflammatory Disease (PID) which can make it impossible to have a baby.

Genital Warts

Genital warts are small pinkish/white fleshy growths which may appear anywhere in the genital or anal area. They are caused by a virus called Human Papilloma Virus (HPV). Women with untreated genital warts may be at increased risk of developing genital cancers.

Warts are spread through skin to skin contact. If you have unprotected vaginal or anal sex or genital contact with someone who has genital warts you may develop them.

After being infected with the wart virus it usually takes between one to three months for warts to appear on the genitals of women and men. They may itch but are usually painless. There are several methods used to treat genital warts. The most common one is to paint them with chemicals, which can be done either by your doctor or yourself. Other methods include freezing with liquid nitrogen, injecting them or burning off with a laser.

Genital Herpes

Genital herpes is caused by the herpes simplex virus (HSV). It causes painful tingling or itching blisters or ulcers. Some people have aching muscles and fever.

Herpes Type I causes sores around the nose and mouth.

Herpes Type II causes sores or blisters around the genital and anal area.

Herpes is passed on through direct contact with the infected part of the person's body.

- Herpes sores on your mouth or your partner's mouth can infect the genital area of the other person
- Avoid sharing towels and wash cloths (face flannels) with partners, family members or friends. Unlike HIV, the herpes virus can be passed on in this way
- Always wash hands with soap after touching the sores.

Is there anything you can do to help yourself?

There are several things you can do to soothe the affected area:

- If the pain is severe, try taking pain killers (aspirin/paracetamol), if they are available
- Keep the affected area as dry and clean as possible. Try gently bathing the sore areas with a salt solution (half a teaspoon of salt to half a pint of warm water). You can add 5 drops of tea tree oil in warm salt water too. It may soothe and help dry up the sores
- Put gentian violet onto the sores to prevent secondary infection
- Honey applied to herpes sores will burn for a minute and then soothe and help to heal
- Take 50mg zinc and 500mg vitamin E daily from the moment the herpes pimple appears. (Taking 50mg zinc and 200mg vitamin E all the time helps to prevent re-occurrence of a herpes attack.)
- If you can get it Zovirax (Acyclovir) will shorten and ease a herpes attack. Take it with the zinc and vitamin E
- Wear loose clothing so that the air can circulate around the sore areas
- Place an ice pack wrapped in a clean cloth or towel on the affected area
- Get plenty of rest
- Drink plenty of fluids

Syphilis

Syphilis is a bacterial infection. It is usually sexually transmitted through vaginal, anal or oral sex. It can also be passed from an infected mother to her unborn baby.

The signs and symptoms are the same in both men and women and usually a sore appears on the penis or vagina, anus or mouth about ten days to three weeks after sex with an infected person. The sore disappears in a week or two but the bacteria remain in the body. However, most women do not see the sore and may not have any symptoms. The only way to be sure is to have a blood test.

During the secondary stage which may occur during the next two years a rash may appear on the hands and feet, the face and other parts of the body.

Treatment at any time during these first two stages of syphilis will cure the infection. But if it is left untreated a later stage will occur some years later which will cause very serious damage to your health.

A Positive Woman's Survival Kit, March 1999, ICW, www.icw.org

Thrush

What is thrush (Candida albicans)?

Many women have thrush at some time in their life. It is common in adults who are stressed or have damaged immune systems because of HIV infection. Many babies also get it.

Thrush is caused by a tiny yeast-like organism called Candida albicans that normally lives quite harmlessly on your skin and in your mouth and gut.

Thrush is more likely to develop if you:
- -Are pregnant
- -Are taking certain antibiotics
- -Have diabetes
- -Are unwell or ill
- -Are taking the contraceptive pill
- -Have unprotected penetrative sex with someone who has thrush
- -Eat lots of sugar or sugar-based products
- -Wear very tight jeans or trousers or nylon underwear

How can you tell if you have thrush?
You may have one or more of the following symptoms:
- -Sore spots or thick white fur on the tongue, mouth or gums
- -Itching, soreness and redness around your vagina, vulva or anus
- -Thick white discharge from your vagina that looks white and lumpy and smells like yeast
- -Swollen vulva
- -Pain when you have penetrative sex
- -Pain when you urinate

Treatment
Medical treatment for thrush is easy, usually consisting of cream and pessaries (suppositories), or tablets.
Is there anything you can do yourself to relieve the symptoms of thrush?
- -At the first sign of irritation, stop using soap and clean yourself with water
- -Stop wearing tight pants or jeans - it helps to let as much air circulate as possible
- -Don't be tempted to have frequent baths or to wash yourself more often. It may feel soothing for a short while but it tends to make the irritation worse
- -Don't put disinfectant or bubble bath in the water. However, you can put some vinegar in your bath, or 10 drops of tea tree oil

In places where live yoghurt is available, some women with thrush have applied it to the outside of the vagina where it soothes the irritation. Some women also put live yoghurt into their vagina with a syringe or on a tampon. The beneficial bacteria found naturally in live yoghurt is thought to destroy thrush. It works for some women but not all. Garlic is an alternative which may work for

you. Peel a clove, slit it and dip it in oil. Insert it into the vagina. Insert a clove once in the morning. Remove and insert a new clove in the evening. Repeat next day or until the symptoms improve.

Can you prevent thrush?

There are no simple solutions. But there are a number of things you can do to prevent getting it so frequently:

• -For thrush in the mouth avoid sugar at all times, particularly when you have an attack

• -If you have an attack of thrush avoid fruit, honey and yeast until you are clear of the thrush for at least three weeks

• -Avoid wearing tights, underwear made with nylon, tight jeans or trousers

• -Use sanitary pads rather than tampons if you are menstruating

• -Avoid perfumed soaps, genital sprays and deodorants, and disinfectants. Also avoid vaginal douching with chemical mixtures. All of these upset the beneficial balance inside the vagina

• -After defecating, always reach from behind and wipe away from the vagina. You want to avoid getting faecal matter in your vagina

• -If you are prescribed an antibiotic for some other infection, remind your doctor that you tend to get thrush.

Can you have sex while having treatment?

It is best not to have penetrative vaginal or anal sex or oral sex until you have had your final check up with your health practitioner. If you have thrush in your mouth, stop kissing until you are well again. Hugging and cuddling are always fine.

A Positive Woman's Survival Kit*, factsheet 7, ICW.* www.icw.org

Pregnancy, Childbirth and feeding your baby

This is a short summary of a much longer document which is available by e-mail from info@icw.org Or you can download it from http://www.icw.org/
ICW supports the right of all women to choose for themselves whether they want to have children or not. HIV positive women who want to have children should be able to access the treatments and care which they need to have healthy pregnancies and healthy HIV negative babies. This sheet summarises the information positive women need to minimise the risk of transmitting HIV to their babies.

HIV can be passed to babies from their mothers' bodies during pregnancy, during childbirth or through breastfeeding. Around 50%-60% of children born to HIV positive women are likely *not* be HIV positive themselves. With some basic precautions, transmission rates during pregnancy, childbirth and breastfeeding can be considerably reduced. The possibility of passing on the virus can be reduced to as low as 2% in many settings. Understanding of these issues is constantly improving, but there are many parts of the world where women are still not able to gain access to the information, care or treatment which is their right. This is why ICW campaigns for global access to care, information and treatment for *all* HIV positive women and why we have written this information sheet.

This information sheet explains how the risk of transmitting HIV from mother to child can be greatly reduced. The information is as up to date as possible, (as of August 2003) but research is still going on and we suggest that you should, if possible, ***consult a health professional*** about your pregnancy, to learn about your best options. If you have access to the internet you can also check http://www.aidsmap.com/web/pb3/eng/1a3edd95-c60b-4bff-83d5-ce706aa88191.htm or www.unaidsorg for the latest available information.

Reducing the Risk of HIV transmission

If **you** are able to keep healthy, this will be better for you as well as for your baby. There are a number of ways that you may be able to reduce the risk of infection being passed to your baby during pregnancy, during childbirth and if you breastfeed.

- ✓ **Know your HIV status.** If you know your status, this will help you to decide what steps you might be able to take to reduce the risk of transmission to your baby.
- ✓ **Seek medical advice.** Contact with health workers before or early in your pregnancy means that they can monitor your health and advise you about reducing the risk of transmission to your baby. It is best that your delivery is attended by a trained health professional who is aware of your status if you are HIV positive, who is therefore able to take the necessary steps to reduce the risk of transmission.
- ✓ **Try, if you can, to look after your health.** Pregnant or breastfeeding women who are sick because of HIV are more likely to transmit HIV to their babies than women who are well.
- ✓ **Use condoms, especially if you have sex during your pregnancy and while you are breastfeeding**, to protect yourself against other strains of HIV and other sexually transmitted infections, which can otherwise affect your own health and affect your baby too. If using condoms is a problem for your partner, it may help if you or the health professional can explain to him that using condoms may reduce the risk of transmission to the baby.
- ✓ **Try to eat a healthy balanced diet***, including, for instance, red meat and eggs, green vegetables, fruit and cereals.*
- ✓ **Rest** is also important.
- ✓ **Take anti-retroviral medicine** *(if you have access to it)* (carefully following medical advice about what to take and when) in order to reduce the amount of virus in your blood. These can both reduce the progression of HIV in your own body and reduce the chances of transmission of HIV to your baby. There is more about anti-retrovirals below.

NB All babies are born with their mother's antibodies in their blood. So it can take up to 15 months before an HIV antibody test is able to show whether the baby is HIV positive or negative.

More about pregnancy

All HIV positive pregnant women ideally need to have regular follow-up and care during pregnancy. Seeking early antenatal care means that tests can be carried out, illnesses identified (such as malaria or intestinal worms, which can cause anaemia) and, where necessary, treatment given. Maintaining your own health, by eating well, avoiding illness, using condoms, resting and taking ARVs, is one of the most effective ways of staying well, of looking after yourself and of reducing the risk of transmitting HIV to your baby.

More about childbirth

Strategies to reduce transmission of HIV during childbirth include:

- Providing ARVs to women before and during delivery (and usually AZT or nevirapine to the baby after delivery).
- Preventing prolonged and/or difficult labours. Birth attendants should not break the waters artificially.
- Avoiding interventions that cause bleeding such as episiotomies, using forceps to deliver or applying electrodes to the baby's scalp.
- Having a caesarean section (CS) if you are HIV positive but not on long-term combination therapy. *Is this available near you?*
- If you are HIV positive, and have a CS you should be provided with antibiotics to reduce the risk of infection.

Feeding your baby

Breast milk is the best food for a new baby. However, breastfeeding is a route of HIV transmission. This sheet highlights issues to consider when deciding whether or not to breastfeed. For more information see the longer ICW Information Sheet for HIV positive women '*Pregnancy, Child birth and feeding your baby'* and try to discuss the matter with a health provider.

- Some HIV positive women are now expressing their breast milk regularly and then pasteurising it, by heating it just until it starts to bubble round the edge of the pan, then letting it cool before feeding it to their baby. Preliminary research suggests that this might be a safe way of destroying the HIV virus in the milk. You can read more about this in the longer ICW information sheet.
- If you would prefer not to breastfeed, how easy will it be for you to prepare a safe alternative to breast milk?
  Do you have access to safe, clean water?
  Can you afford a replacement milk supply for six to twelve months?
  Do you have access to adequate utensils for feeding?
  Do you have access to fuel for sterilising equipments and heating the milk?
- Will people guess that you might be HIV positive if you do not breastfeed?
  Will that cause problems for you?
  Can you think of another reason to say to people who ask why you are not breastfeeding? (for instance, that it hurts your breasts too much. Quite a few women find this anyway).

More about Anti-retrovirals (ARVs)

A healthy mother is more likely to result in a healthy baby. If a woman needs anti-retroviral therapy for her own health, then giving these drugs to her is more likely to result in a) her own continued good health and, in addition, b) reduced transmission to her baby. In some situations when a mother does not require therapy at present, "monotherapy" (normally zidovudine, also known as AZT, or nevirapine) can be given to her before and during delivery, and to the baby after delivery. Monotherapy can also be given in situations where combination therapy is not available (but where the mother ideally should have combination therapy). Although this reduces risk of transmission to the baby, it does have drawbacks for the mother's health.

How do they work? ARVs reduce the amount of virus in the bloodstream, and therefore reduce the risk of transmission to a baby during pregnancy, delivery or through breastfeeding. ARVs may have side effects for both you and/or your baby. Many women believe that the benefits of having an HIV negative baby outweigh the risk of complications in pregnancy or of the very low possible risk of birth defects.

Why should I take more than one set of ARVs? A single drug ('monotherapy' – normally AZT or nevirapine) can reduce the risk of transmission to the baby during labour/delivery but not as effectively as combination therapy. *Ask your medical advisor about this*. Monotherapy may also lead to the development of drug resistance in the mother. *Again, it's best to ask your medical advisor about this.*

***A Positive Woman's Survival Kit*, factsheet 3, updated August 2003. ICW. www.icw.org**

Access to Care, Treatment and Support (ACTS) Briefing[2]

This briefing for ICW members frames key issues and advocacy messages based on the findings of our project work on HIV positive women's ACTS. ICW briefing papers on violence against women and sexual and reproductive health and rights are also available. Your feedback on this briefing is welcome.

ACTS refers to HIV positive women's ability to gain consistent access to all available care, treatment and support services, including:

Supportive environments	Health services and information	SRHR, VAW and ACTS
Supportive environments at home, in the community, workplace, place of learning, public and health service institutions - understanding and recognition of HIV positive women's health and rights issues.	Non-judgemental, confidential, voluntary, informed, comprehensive and appropriate treatment and related services.	Diagnosis, prophylaxis and treatment for opportunistic infections, STIs and reproductive health matters with advice and treatment for side effects or complications of medication.
Workplace policies in all settings (e.g. factories, shops, schools, banks, agricultural cooperatives etc.)	All staff in the health care setting understand the barriers that HIV positive women face in accessing services and acting on advice and treatments given.	Non-judgemental, comprehensive Information, advice and services on healthy pregnancy and motherhood.
Home based care and other care-in-the-community programs and palliative care initiatives.	Free anti-retrovirals with advice and treatment for side effects, including lipodystrophy, and complications of medication and regular monitoring of treatment.	HIV treatment policies and programmes recognise the impact of violence or fear of violence on positive women's ability to access care, treatment and support.
Financial support to meet related costs such as for transport and nutrition	On-going support in the form of counselling and referrals.	HIV treatment services, staff policies and programmes recognise the connection between SRHR issues and ACTS.

ICW recognises that gender inequalities can constrain HIV positive women's access to care, treatment and support as well as their ability to use treatment, information and advice to improve the quality of their lives. We also recognise that the care, treatment and support needs of HIV positive women are different to that of men.

Barriers to care, treatment and support include:
Gender Inequalities and Limited Access to Treatment

- Limited range of service locations and knowledge of treatment options and trials that may be available.
- Even when anti-retrovirals (ARVs) are free women have found that costs associated with travel, good nutrition, childcare and treatment for related health problems puts the chance of leading a healthy life with HIV out of their reach. *We have been having some changes and interruptions in our treatment regimes because many times when we go for ARVs clinic we are being asked for some money so we tend to miss the dose even for a week or month till we get some money to pay for that service. Another problem is lack of enough food especially to us women who are under treatment. The consequences were; not finishing my dose which caused infections, staying without a dose till the clinic day and lie to the service provider that I have finished my dose, fighting with my husband or even chasing me out of the house when I refuse giving him my dose.* (ICW member Tanzania)
- Lack of decision-making power - a woman may have to ask relatives for permission to access services.
- Stigma, discrimination and violence can prevent an HIV positive woman accessing services, and being able to act on advice and treatment given. *'We face a common problem that our husbands or partners tend to force us to give them our ARVs dose while he has not tested for HIV and doesn't know his CD4 counts. They do not want to go for testing while they show all HIV symptoms. Even if you refuse he will find where you keep your medicine and steal them.'* (ICW member Tanzania).
- Family healthcare demands - if a woman's children (and other relatives) are not on treatment she is likely to feel guilt or pressure to share her treatment.
- The demands of looking after a family often preclude one's own health care needs and our members also report selling medication on the black market to pay for much needed food.

[2] Adapted from ICW fact sheet on ACTS (2005) developed for the Global Coalition on Women and AIDS (GCWA). Updated 2008.

Lack of Quality, Comprehensive Care and Services

- Gender-related stigma and discrimination are sometimes reflected in the attitudes of staff in health settings.
- Limited healthcare provider knowledge about the health needs of positive women.
- Lack of treatment literacy that specifically address women's treatment issues, including gender- or age-specific side effects and opportunistic infections and STIs, healthy pregnancy/motherhood and family planning options.
- Lack of women, race and age-specific clinical research and health centre data availability exacerbates the knowledge gaps and confusion concerning treatment options for women.
- Data on client sex and age are normally collected at health centre level but often get 'reaggregated' further up the ladder.
- Lack of comprehensive care, treatment, support, monitoring and referrals for such problems as STIs, violence, reproductive health issues, human papilloma virus (HPV), cervical cancer and other HIV-related health factors, including side effects and complications of ARVs and other treatments.
- ARV treatment conditional on acceptance of injectible contraceptives or sterilisation.
- Overburdened healthcare services that impacts the availability of qualified personnel and comprehensiveness and quality of services, including regular supplies of treatments.

Care and support

- Lack of positive women's leadership within HIV positive people's support groups.
- Gender, age and other areas of discrimination within support groups.
- Women, especially HIV positive women and girls are over-burdened by care work which is generally voluntary and unrecognised.

Recommendations:
Gendered and generation-specific research and data reporting

- Different treatment and care regimes call for the development of proper gender equitable and age-related research trials, and client data reporting, both on drugs and on other aspects of care and treatment.
- More research into opportunistic infections specific to women and HIV related conditions such as cervical cancer, and more research and investment into screening and treatment options for these.
- Research into the interactions between hormonal contraceptives and ARVs.

Equitable access

- Train health staff to understand the treatment and support needs of HIV positive women and girls and the challenges they face accessing treatment of any kind.
- Ensure that appropriate treatment and services are available (including in mobile and decentralized locations) and that treatment is monitored.
- Provide accessible screening and treatment for opportunistic infections, STIs and other HIV-related conditions, as part of the treatment package for HIV positive women and girls.
- Ensure that HIV positive women have accessible information about their rights and about available treatment and services.

Meaningful involvement

- HIV positive women are consulted, trained and employed to help develop treatment, care and support programmes including ARV distribution and literacy.

Care and support – not just drugs

- Develop on-going programmes which promote care, support and respect for HIV positive people within communities and health services.
- Support holistic comprehensive approaches to quality of life issues, covering psychosocial, physical, nutritional and material support, as well as SRHR.
- Support programmes which recognise women's roles as care givers and the traumatic impact of death and illness on them.

Workplace policies

- Encourage the involvement of HIV positive women in workplace policy development and implementation, which promotes the retention and employment of HIV positive staff, including women, and which ensures that benefits to staff include a range of appropriate care and support, which is not just drug specific.
- Promote a proactive awareness of the way in which HIV can affect all our lives throughout the whole management and staff body.

Sexual and Reproductive Health and Rights Briefing[3]

This briefing for ICW members frames key issues and advocacy messages based on the findings of our project work on SRHR. ICW briefing papers on access to care, treatment and support and violence against HIV positive women are also available. Your feedback on this briefing is welcome.

What are our sexual and reproductive health rights?

- Sexual health: Includes healthy sexual development, equitable and responsible relationships and sexual fulfilment, freedom from illness, disease, disability, violence and other harmful practices related to sexuality.
- Sexual rights: the rights of all people to decide freely and responsibly on all aspects of their sexuality, including protecting and promoting their sexual health, be free from discrimination, coercion or violence in their sexual lives and in all sexual decisions, expect and demand equality, full consent, mutual respect and shared responsibility in sexual relationships. We also have the right to say 'no' to sex if we do not want it.
- Reproductive health: The complete physical, mental and social well-being in all matters related to the reproductive system including a satisfying and safe sex life, capacity to have children and, freedom to decide if, when and how often to do so.
- Reproductive rights: The rights of couples and individuals to decide freely and responsibly the number and spacing of their children, to have the information, education and means to do so, attain the highest standards of sexual and reproductive health and, make decisions about reproduction free of discrimination, coercion and violence.
- Reproductive care: Includes, at a minimum family planning services, counselling and information, antenatal, postnatal and delivery care, health care for infants, treatment for reproductive tract infections and sexually transmitted diseases, safe abortion services where legal and management of abortion-related complications, prevention and appropriate treatment for infertility, information, education and counselling on human sexuality, reproductive health and responsible parenting and discouragement of harmful practices. If additional services, such as the treatment of breast and reproductive system cancers and HIV/AIDS are not offered, a system should be in place to provide referrals for such care.

Adapted from definitions of SRHR in the ICPD and Beijing Platforms of Actions

Instruments that enshrine SRHR and wider rights to equality, health, life and dignity:

- The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), 1979 - CEDAW is a binding treaty so any countries that have signed up to it are committed to ensure respect for women's and girls' human rights and fundamental freedoms. Although none of these specifically address HIV positive women, HIV positive women have the right not to be discriminated against and therefore are entitled to all the rights that their government has signed up to.
- International Conference on Population and Development (ICPD) and Programme of Action, 1994 (often known as the Cairo Declaration) - The ICPD PoA was the first and most comprehensive international document to embody concepts of reproductive health and rights and sexual health. The Beijing Platform of Action, 1995, was the first declaration to embody the concept of sexual rights.
- United Nations Special Session on HIV/AIDS: Keeping the Promise: Declaration of Commitment on HIV/AIDS, 2001 (often known as UNGASS) - UNGASS recognises the importance of empowering women, PMTCT, VCT, the rights of women and sexual and reproductive health, and female controlled methods such as microbicides.

What are our concerns?
Within families and communities:

- Pressures from families and communities to have or not to have children and concerning feeding practices can compromise HIV positive women's decision-making around SRH and choices.
- Violence and fear of violence may inhibit HIV positive women's ability to disclose their status and negotiate protected, satisfying sex and the timing and spacing of children.
- Community disapproval in general for continuing to have sexual relationships which impacts on our ability to enjoy sexual fulfilment and maintain our sexual health.
- Violation of women's wider rights such as widow inheritance, lack of access to property inheritance and unequal employment opportunities leave us unable to protect our SRHR.

Within health care services:

- Lack of access to treatments for STI's and reproductive tract infections, regular sexual health screening including pap smears, prevention tools like female condoms, services to support safe conception.

[3] Adapted from ICW fact sheet on SRHR (2005) developed for the Global Coalition on Women and AIDS (GCWA). Updated 2008.

- Ignorance, fear and judgmental attitudes on the part of staff and decision-makers in the health system can lead to negligence or denial of certain services such as safe conception and appropriate contraception.
- PMTCT programmes that reinforce that focus on the health of the child and ignore the health of the mother.
- Pressure to abort, be sterilised or take contraceptives in order to access treatment or other services, or withholding of such services. *'I have five children and am expected to have another because I do not have a son. I went to the hospital to be sterilised. They wanted the husbands consent, but he wouldn't as he did not have a boy child.' (ICW member, South Africa)*
- HIV testing that is not informed, voluntary and confidential can leave HIV positive women vulnerable to abuse. Pregnant women find themselves under particular pressure to test in Ante Natal Clinics.

Choices around pregnancy:
This is my first pregnancy. I would really love to have a child. (ICW Member from Zimbabwe)
I wanted to make the family perfect. If we had no child, he wouldn't stay with me and I would be alone. (Thailand)
My husband paid lobola and he must have a child. (Zimbabwe).
I decided on my own to have the abortion and get sterilized at the same time at a hospital. I did that because I had the infection. Because… wasn't the baby in my body? (Thailand)

Other concerns:
- Lack of commitment to accelerated research on microbicides and other women-controlled barrier methods;
- Lack of involvement of HIV positive women in policies and programmes.
- HIV positive women are often portrayed as either victims of male sexual aggression or duplicity, or potential or actual mothers, not as sexual agents in their own right leading to the mis-targeting of sexual health programmes and advocacy on SRHR.

Recommendations:
Meaningful involvement:
- Advocate for and enhance meaningful participation of HIV positive women at all levels of policy and programme formulation around the areas of HIV/AIDS and SRHR.
- Build capacity of women living with HIV in the area of Human Rights, SRR and Gender.

Services and technologies:
- Maximise access to quality, non judgemental SRH services and information for all HIV positive women.
- Mainstream SRHR at all levels of treatment preparedness and delivery.
- Ensure that HIV testing remains informed and voluntary and is supported by counselling and referrals on SRHR and treatment.
- Adopt the development of microbicides and other female controlled barrier methods as goals in our responses to HIV and AIDS and incorporate HIV positive women's needs and rights in this research.
- Support ethical biomedical and social research on HIV positive women's SRHR.

Legal reform:
- Support HIV positive women to reclaim their rights using local and national laws, national constitutions and international instruments.
- Support research, documentation and litigation around human rights abuses against HIV positive women, for example, forced sterilisation or abortion or denial of SRH services.
- Advocate for accessible legal services for positive women.
- Decriminalise HIV transmission.

National response and monitoring implementation:
- Incorporate enforceable human rights and gender indicators in the national response to HIV and AIDS.
- Create public awareness of the SRHR of HIV positive women through media campaigns, workshops, etc.

Empowerment:
- Empower women to have control over their SRHR through awareness raising and training.
- Legislation that promotes gender equality including access to equal employment and education opportunities and productive assets.
- Community based awareness campaigns to address gender inequalities and promote a woman's right to control what happens to her body and enjoy satisfying sexual relationships, or choose not to have sex.

Violence against HIV Positive Women Briefing[4]

This briefing for ICW members frames key issues and advocacy messages based on the findings of our project work on violence against HIV positive women. ICW briefing papers on access to care, treatment and support and sexual and reproductive rights are also available. Your feedback on this briefing is welcome.

The term "violence against women" (VAW) means any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life. Accordingly, VAW encompasses but is not limited to the following:

- Physical, sexual and psychological violence occurring in the family, including battering, sexual abuse of female children in the household, dowry-related violence, marital rape, female genital mutilation and other traditional practices harmful to women, non- spousal violence and violence related to exploitation;
- Physical, sexual and psychological violence occurring within the general community, including rape, sexual abuse, sexual harassment and intimidation at work, in educational institutions and elsewhere, trafficking in women and forced prostitution;
- Physical, sexual and psychological violence perpetrated or condoned by the State, wherever it occurs.

Other acts of VAW include violation of the human rights of women in situations of armed conflict, in particular murder, systematic rape, sexual slavery and forced pregnancy. Acts of VAW also include forced sterilization and forced abortion, coercive/forced use of contraceptives, female infanticide and prenatal sex selection.
Definition of Violence against Women from the Beijing Platform for Action 1995

Most of the research conducted to date on the link between VAW and HIV has focused on sexual violence and its role in increasing women's vulnerability to HIV infection. Here we consider the connection between violence and gender inequality for women that are already HIV positive.[5]

Violence against HIV Positive Women:

- Women are often the first member of a household to discover their status, through ante-natal testing. This can result in blame, violence and rejection from partners or in-laws, family, friends and community. *'When I was diagnosed I had a partner. The relationship became more violent – he said I brought a new problem into the family. The violence became more, he had other relationships. You get told off because you have HIV.'* (ICW member Swaziland)
- Assaults, battery and the rape of HIV positive women and children, especially girls perpetuate the spread of HIV directly (in the case of rape) and indirectly through promoting intra-familial fear that might prevent disclosure by a positive partner to a negative partner or prevent negotiation of safer sex. Certain situations such as conflict, migration and sex work can exacerbate the risk and impact of violence on women including HIV positive women.
- Gender and HIV–related discrimination leads to social tolerance of violence against HIV positive women, including marital rape. This prevents women from discussing the issue, leaving or confronting an abusive situation or seeking help.
- Stigma and discrimination may mean that people living with HIV feel ashamed of themselves and of their status. This can undermine their confidence to leave or confront an abusive situation. *'He says "you have AIDS anyhow so you can't compete with me. I have to have a life. You have HIV and won't be around. So understand my other relationships"'.* (ICW member South Africa).

[4] Adapted from ICW fact sheet on VAW (2005) developed for the Global Coalition on Women and AIDS (GCWA). Updated 2008.
[5] The GCWA has produced an Issue Brief on violence against women, the focus of which is on vulnerability to HIV and examples of work addressing the issues. See: http://womenandaids.unaids.org/themes/docs/UNAIDS%20VAW%20Brief.pdf.

- Exposure to re-infection by refusal to wear condoms, or the violation of a woman's reproductive rights (e.g. if a woman is forced or coerced into pregnancies and childbirth that she is not willing to undergo) can endanger her life due to HIV-related complications.

Accessing services:

- Many women do not know where to find information about VAW nor where to report incidences or seek help.
- Violence and fear of violence can lead to women feeling fearful to seek care, treatment and support.
- Fear of disclosure due to the threat of violence or abandonment by partners, can be a barrier to accessing treatment, especially where women have to travel a long distance to reach health services, hospitals or clinics, and may need husbands' permission to make or pay for the journey. The result can be that women seek help at the last minute when they are really sick.
- Fear of disclosure may prevent a woman from accessing available PMTCT programmes, and using safer infant feeding options, as a woman who does not breastfeed her child may be suspected of being HIV positive.

Information and experiences of services:

- VAW services are generally limited and lack referral systems to HIV services. Similarly HIV and health services often lack referral systems to ensure that positive women experiencing violence access appropriate counselling, treatments, advice and legal remedies.
- The health and legal system often do not take the issue seriously, particularly, rape in marriage. When a woman is known to be HIV positive judgements are likely to be made about her behaviour which hold her responsible for violence against her and perversely she may face blame for putting her assailant 'at risk'.
- HIV positive women also face pressure to abort, be sterilised or take contraceptives in order to access treatment and other health services – all of which are forms of VAW.
- Property grabbing by in-laws on the death of a spouse is a form of violence against women that is frequently reported by our members.

Recommendations:

We urge policymakers and programmers to:

- Consider violence against HIV positive women as rooted in unequal gender relations and HIV-related stigma and discrimination and not just to see VAW as a mode of HIV transmission but also as a result of HIV status.
- Monitor the impact of public HIV policies and programmes, including HIV testing, treatment, partner notification and criminalisation on violence against HIV positive women.
- Monitor the impact on violence against HIV positive women of legislation which has relevance to gender relations, such as that relating to marriage, property ownership, domestic relationships and child custody.
- Ensure that public services (legal/justice, medical and social) address the links between being HIV positive, gender and violence.
- Understand the complexities of VAW, including physical, sexual, psychological, financial and institutional violence.
- Support safe spaces for HIV positive women to share histories and seek mutual support. We also feel that if HIV positive women have the space and time together they can break down the barriers to discussing hidden or taboo areas. This could help challenge aspects of 'internalised' acceptance of male violence and male 'right' to sexual access to women, or, for example, the necessity of genital mutilation in order to attract a husband.

Part 5 – Feedback

1. Feedback form for using the Positive Women Monitoring Change tool (PWMC)

Name of Organisation: ……………………………………………….

Country where PWMC tool was used: ……………………………………..

Was this part of a bigger project? Yes / No

If yes, please give title, scope and main goal of the project / programme:
……
……

Please use this box to briefly describe how you used PWMC in your work

Please use this box to describe how HIV positive women were involved in this work

What were the most useful parts of the tool and how did you use them?

What were the main outcomes of using PWMC?

- …
- …
- …

What challenges did you encounter?

- …
- …
- …

Lessons Learnt

Recommendations

Do you have any particular **story/stories** you would like to share with us from your experience of using PWMC?

2. Feedback form for using the training curriculum

Name of Organisation: …………………………………………….

Country where PWMC tool was used: …………………………………..

Was this part of a bigger project? Yes / No

If yes, please give title, scope and main goal of the project / programme:
……
……

Who was involved in the training?...
………

How many days did the training last? ………………………………

Did it combine any other training (eg SRHR, advocacy, etc)?
…………………………………………………………………………………………………..

How many of the participants were HIV positive women? ……………………………………

How will you be continuing to support these women in future activities?
……
………..

To what extent were the objectives of the training met?

- Introduce the ICW tool 'Positive Women Monitoring Change'
- Increase positive women's understanding of the different ways in which they can use the tool
- Build capacity on:
  - Data gathering
  - Analysis
  - Presentation

Which parts of the Training Curriculum did you find most useful?
- …
- …

Which parts did you find least useful?
- …
- …

Do you have any **recommendations** for how the Training Curriculum can be improved?

Please use this box to share any **stories** or specific **outcomes** of the training with us!