

# **Salamander Trust values and preferences survey: sexual and reproductive health and human rights for women living with HIV**

## **Welcome and introduction**

Welcome to the Salamander Trust values and preferences survey on the sexual and reproductive health and human rights of women living with HIV.

Salamander Trust is conducting a community consultation to find out what are the most important things for women living with HIV in relation to our sexual and reproductive health and human rights. The priorities we identify will contribute to an updated WHO Guideline on the sexual and reproductive health and human rights of women living with HIV in all of our diversity, including trans women living with HIV.

The aims of the survey are:

- To collect, understand and promote the sexual, reproductive health and rights priorities of women living with HIV
- To use a life course approach, to see the whole of women's lives (i.e. from conception to birth to growing up to ageing to death)
- To create a groundswell of voices to champion and claim our rights
- To give voice to women with HIV to tell our stories
- To provide an educational/ interactive tool which is short and simple to use
- To feed into the WHO Guidelines to reflect the realities of women's lives, and provide direction for new priority areas for research
- Set the basis for our advocacy agendas at country and regional level

(Details about Salamander Trust and how to contact us can be found at the end of the survey.)

## How this survey is organized

Please read this carefully before you start the survey.

The survey STARTS on Page 4: these questions require an answer for you to be able to continue.

PART 1 of the survey asks for your PERSONAL DATA. Some of these questions require an answer, and some do not. Questions where an answer is required are marked with a star\*

PART 2 asks about your EXPERIENCE of using sexual and reproductive health services and PRIORITY ISSUES. This is the most important part of the survey. It takes about 10 minutes to complete. If you only have a short time, please just fill in your personal data and this section. Some of the questions require an answer(\*) and some do not.

PART 3 focuses on a number of OPTIONAL KEY TOPICS which have been identified by a Working Group of women living with HIV. If you have more time, please choose which of these topics you would like to answer. Each topic takes a maximum of 5 minutes to complete. You are welcome to answer all the questions in the survey if you have time!

Menu of optional topics in Part 3:

1. Healthy sex-life
2. Pregnancy and fertility
3. Violence against women living with HIV
4. Mental health issues
5. Women living with HIV in all of our diversity
6. Puberty, menstrual issues and menopause
7. HIV Treatment and side-effects
8. Financial issues affecting access to services

The very last page gives you space for any FINAL COMMENTS you would like to make before leaving the survey

## **Preamble: What are our sexual and reproductive health and human rights?**

In 2006 the International Community of Women Living with HIV and AIDS (ICW) developed the following definitions around the sexual and reproductive health and human rights of women living with HIV.

- **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.



## Part 1 – Personal Data

So that we can ensure that women in all their diversity are meaningfully represented in the findings of the consultation, please tell us a little bit about yourself.

* Country where I am from	Country where I am living now (if different)	My age
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Relationship Status (please **highlight** or **bold** the answer which most closely applies to you now)

- ◆ I am not sexually active
- ◆ I am sexually active, but do not have a partner
- ◆ I have one or more partner(s) living with HIV (sero-concordant)
- ◆ I have one or more partner(s) not living with HIV (sero-different/sero-discordant)
- ◆ I have two or more sexual partners, one or more is living with HIV and one or more is not living with HIV

**Special issues/ identities to do with HIV.** (Please **highlight** or **bold** all that you feel apply to you):

- ◆ I do or have done sex work
- ◆ I inject/use or have injected/used drugs
- ◆ My sexual partner(s) injects/uses or has injected/used drugs
- ◆ I am a client of opioid substitution therapy programme
- ◆ I am/ have been in prison
- ◆ I am / have been in a detention centre
- ◆ I am living with one or more disability
- ◆ I have or have had active TB
- ◆ I have or have had Hepatitis C
- ◆ I have or have had malaria
- ◆ I migrated from one country to another for economic reasons
- ◆ I migrated from one country to another for political reasons
- ◆ I am lesbian, bisexual or have sex with women
- ◆ I am a trans woman
- ◆ I am a heterosexual woman
- ◆ I am married, or in a stable relationship
- ◆ I am intersex
- ◆ I have experienced any form of female genital cutting or mutilation, including circumcision
- ◆ I am or have been homeless
- ◆ I am an indigenous woman

I also identify as (optional)

## Part 2 – Top Priorities and Human Rights

If you only have a short amount of time, please just answer the questions in this section. It will take about 10 minutes.

If you have more time to spare, please go on to Part 3 after completing this section.

**\*Please tell us about your experience of accessing sexual and reproductive health services as a woman living with HIV.** (Please choose one answer for each statement and mark with an X)

**Strongly agree**   **Agree**   **Disagree**   **Strongly Don't disagree know**

I experience the same service as any other women, when I go for sexual and reproductive health services

I am aware of sexual and reproductive health treatments, information, services and commodities that exist in my country

I can get sexual and reproductive health treatments, information, services or commodities, when I need them

I find the service providers well-trained and knowledgeable, friendly, and supportive

My experience of accessing sexual and reproductive health care has been good, and I have confidence in the advice and treatment I receive

I believe my service provider offers a full range of choices for sexual and reproductive health care, including family planning options and prevention, diagnosis and treatment of sexually transmitted infections (STIs)

I am given all the information I need to make a decision about proceeding with a service or treatment, without feeling any pressure from the service provider

I trust the service providers not to share my HIV status or any other details about me without my permission

My service provider listens to me, and gives advice based on my needs and realities as a woman living with HIV

I know my rights, and if I experience a rights violation within the health service, I know where I can go to make a complaint

**Please feel free to give more information on your experience of accessing your sexual and reproductive health and human rights if you would like to**

**\* The following issues have come out of discussions led by a Working Group of women living with HIV who have helped develop this survey. Which of these issues do you see as the highest priority to be included in the WHO Guideline?**

(Please choose one answer for each issue, and mark with an X)

**A: Overarching Issues**

	Absolute must	High priority	Lower priority
Review, reform and amend laws and policies to decriminalize issues related to sexual and reproductive health and HIV (including HIV exposure and transmission, and access to reproductive health and HIV services)			
Ensure laws, policy and regulations are grounded in human rights for women and girls with HIV in all our diversity			
Ensure provision of care is grounded in human rights for women and girls with HIV in all our diversity			
Provide comprehensive sexuality education and choice of sexual and reproductive health services, which promote women’s sexual pleasure, respectful relationships, gender equality, and human rights for all irrespective of sexual identity, gender orientation and HIV status			
Expand the evidence base around the linkages between HIV and sexual and reproductive health and human rights for girls or women with HIV at all stages of our lives			
Create and expand spaces for women living with HIV to be meaningfully involved in policy-making and programming about our sexual and reproductive health and human rights			
Provide integrated HIV and sexual and reproductive health services and referrals			

**Other priorities (optional)**

**\*B: Gender-based violence**

	Absolute must	High priority	Lower priority
Address gender based violence, including intimate partner violence, violence from other family members and violence against women with HIV who are from key affected populations (including sex work, drug use, same-sex relationships, trans*)			
Acknowledge and address all health facility-based rights violations against women with HIV (e.g. stigma and discrimination; provider bias; coerced or forced abortion or sterilization; lack of choice, privacy, or information; etc)			
Address gender inequality in society at all levels (e.g. end harmful			

<b>Absolute must</b>	<b>High priority</b>	<b>Lower priority</b>
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gender norms and practices such as child marriage and female genital cutting; ensure equal employment opportunities and equal pay for men and women; ensure equal property and inheritance rights, etc)

**Other priorities (optional)**

**\*C: Access to clinical care, treatment and support**

<b>Absolute must</b>	<b>High priority</b>	<b>Lower priority</b>
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Ensure high qualities of dignity, respect and non-discriminatory care of girls and women living with HIV at all stages of the life-cycle (including by addressing provider bias, which can act as a barrier to accessing services)

Ensure Universal Precautions are in place in all health settings (e.g. sterilizing or using new equipment for each patient regardless of the previous patient's HIV status.)

Ensure access to a full range of age-appropriate contraceptive choices and services for HIV and sexually transmitted infections (STIs)

Understand the interaction between anti-retroviral treatment (ART) and family planning options, including safe medical and surgical abortion

Understand the impacts of HIV and/or anti-retroviral treatment (ART) on the libido and sexual pleasure among women living with HIV at all stages of our life

Understand the ways in which HIV and/or anti-retroviral treatment (ART) cause menstrual irregularities, including heavy / irregular / prolonged / painful periods; and other gynecological disorders including fibroids

Understand the ways in which HIV and/or anti-retroviral treatment (ART) adherence affect the onset, course and duration of the menopause in women living with HIV

Understand, support and treat the wide range of mental health issues faced by girls and women living with HIV (including chronic anxiety and depression)

Understand co-morbidities including TB, Malaria, Hepatitis C, Cancer and other sexually transmitted infections in the context of the sexual and reproductive health and human rights of women with HIV

**Other priorities (optional)**

**\* D: Sexual relationships**

Absolute must	High priority	Lower priority
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Promote the involvement of sexual partners (men and/or women), in seeking, accessing and utilizing sexual and reproductive health services for women with HIV. (For example, couple counselling for HIV testing, disclosure, family planning, and mental health issues)

Promote accurate and up-to-date fertility and conception advice among couples with the same (sero-concordant) or couples with different (sero-discordant) HIV status

Promote sexual health, well-being, safely and pleasure

Other priorities (optional)

**\* E: Care and support for children of women living with HIV**

Absolute must	High priority	Lower priority
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Ensure that women with HIV are given full support to care for our children, whether or not they are also living with HIV.

Other priorities optional)

**What would you like to say to decision makers and policy makers IN YOUR COUNTRY about how they can help to promote and protect your sexual and reproductive health and human rights? Please try to be as specific as possible.**

**What's the most important issue that you would like to see the WHO Guidelines address in order to make it the most useful tool for you? Please be as specific as possible**

## **Part 3 – Context and realities for women living with HIV**

The following section is divided into 8 optional topic areas:

1. Healthy sex-life
2. Pregnancy and Fertility
3. Violence against women living with HIV
4. Mental health issues
5. Women living with HIV in all of our diversity
6. Puberty, menstrual issues and menopause
7. HIV treatment and side-effects
8. Financial issues affecting access to services

Each area contains optional short and long answer questions and takes about 5 minutes to complete. You can choose to fill in all or any of the areas. You can move forwards and backwards through the survey by clicking "next" or "prev" at the bottom of each page. Please note, however, you cannot save your answers and come back to the survey later.

# 1. Healthy sex-life

As women living with HIV, we have the same right and possibility as all women to enjoy a healthy, safe and satisfying sex life, free from force, coercion, discrimination or violence. We would like to hear what is most important to make sure you are able to have a satisfying and pleasurable sex life.

**\* Please tell us about your experiences of positive, pleasurable sex** (Please choose one answer for each issue, and mark with an X)

	Always	Usually	Sometimes	Never	Don't know	Not applicable
I have a strong libido (I want to have sex often / have strong feelings of sexual desire)						
I find sex pleasurable for myself and for my partner(s)						
For me, sex is mainly about my partner's pleasure						
I am comfortable to initiate sex with my partner(s) and to make suggestions about how we have sex						
I have sex when I want to						
I have sex when my partner(s) want(s) to						
I find it easy to climax ("come" / have an orgasm) during sex						
My body makes enough lubrication (how "wet" you feel when you want to have sex)						
I am happy and confident about the way my body looks when I want to have sex						
I know I can get information on sexually transmitted infections, safer sex, condom use, and contraception						
I am able to have sex without fear of getting any sexually transmitted infections (STIs) from my partner						
If I have an STI I am able to get diagnosis and treatment for it without fear of judgement from the health provider						
I am able to have sex without fear of getting pregnant						
I am able to have sex without fear of passing on HIV to my partner(s)						
I am able to have sex with the person I want when I want to						
I feel safe with my partner(s)						
I am able to talk to my health care provider about my sexual health and needs						
I am able to access the products I need to have a						

Always Usually Sometimes Never Don't know Not applicable

good sex life (eg lubricants, dental dams, female condoms, male condoms, contraceptives)

I am able to discuss my HIV status with my partner(s)

My partner is happy to use a male condom if I want him to

I am able to use a female condom if I want to

**As a woman living with HIV, what has helped you MOST to achieve a satisfying and enjoyable sex life?**

**What has been the BIGGEST barrier to you enjoying a satisfying sex life, or what do you think most urgently needs to change?**

**What would improve your sexual health, safety, well-being and pleasure? (These could be psychological, physical, sexual, spiritual financial, legal and/or institutional support – or something else. It's entirely up to you.) Please try to be as specific as possible.**

## 2. Pregnancy and fertility

As women living with HIV, we have the same right as all women to make choices about when and whether we would like to have children, and to do this in a safe, informed and supportive environment, knowing that we can be healthy mothers to healthy children - or can be supported in our choice not to have children if we don't want to. We would like to hear from you what is most important for you to be able to make these choices.

**\* Please tell us about your experiences of pregnancy and fertility as an HIV positive woman**  
(Please choose one answer for each issue, and mark with an X)

	Yes	No	Don't know	Not applicable
I have been supported by my partner(s) to make choices about my fertility (to decide whether or not to have a child/children)				
I have been supported my by health provider to make choices about my fertility				
I have been supported by my family and community to make choices about my fertility				
I have been given advice about safe conception (getting pregnant without putting myself or my partner at risk of transmission of HIV or other sexually transmitted infections)				
I have been given support with safe conception				
I can talk to my service provider about my fertility desires				
I have been/am able to access fertility treatment if I need it				
I have chosen to test for HIV during pregnancy and was given adequate counseling before and after the test				
I have been given counseling on family planning and advice on child spacing				
I have had one or more unplanned pregnancy				
I have been given advice on how to disclose my HIV status to my partner(s) and my children, if I want to				
I have access to safe and affordable abortion, if I need it				
I have access to post-abortion / -miscarriage care, if I need it				
I have access to prevention of vertical transmission programmes ("PMTCT")				
I know I can speak to other women living with HIV who will give me advice on healthy motherhood if I want to				
I have been able to make choices about how I want to deliver my baby				
I have been supported to make decisions about how to feed my baby without fear of what people will say				
I can decide to have a(nother) child without fear of what				

	Yes	No	Don't know	Not applicable
people will say				
I can decide NOT to have a(nother) child without fear of what people will say				
I can access the family planning / contraception that I prefer				
I am able to use the family planning / contraception that I prefer without resistance from my partner(s)				
I have access to emergency contraception (the "morning after" pill) if I need it				
I can access legal counseling on adoption choices				
I can access pre-exposure prophylaxis, if I need it				
I can access post-exposure prophylaxis, if I need it				

**As a woman living with HIV, what is the BEST experience you have had to support your decisions and desires about having children – or not having children?**

**What has been the BIGGEST barrier for you to make choices about your fertility desires?**

**What would improve your reproductive health and human rights? (These could be psychological, physical, sexual, spiritual financial, legal and/or institutional support – or something else. It's entirely up to you.) Please try to be as specific as possible.**

### 3. Violence against women living with HIV

Violence against women is: “Any act of gender based violence that results in, or is likely to result in physical, sexual or mental harm or suffering, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life” (UNGA 48/104). Violence against women includes sexual abuse of children, rape, intimate partner violence, sexual assault and harassment, trafficking and harmful traditional practices including female genital cutting

Intimate partner violence is: “actual or threatened physical or sexual violence or psychological and emotional abuse directed towards a spouse, ex-spouse, current or former boyfriend or girlfriend, or current or former dating partner” (Saltzman et al, 1999). Intimate partner violence includes: slapping, kicking, burning, strangulation (physical); coerced sex through force, threats, intimidation, etc. (sexual); isolation, verbal aggression, humiliation, stalking, economic violence, controlling victim’s access to health care or employment (psychological)

Violence against women living with HIV is: “Any act, structure or process on which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV” (Fiona Hale and MariJo Vazquez, 2011). Violence against women living with HIV in different contexts is described in more detail below

**A: Violence from a sexual partner or spouse** could include: hitting, kicking, punching; threats of physical or emotional violence (for example threatening to leave you); making you have sex when you don’t want to; making you have sex without a condom; blame, name-calling; making you feel stupid; stopping you from seeing friends; working; leaving the house; seeking medical care for you or your children.

**\*I have experienced violence from a sexual partner or spouse** (please **highlight** or **bold** all the answers that apply)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don’t know
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**B: Violence from a member of my family / neighbours** could include: refusing to share food / utensils; name-calling; blame; rejection; abandonment; physical violence like hitting, kicking, or pulling hair; a member of the family or neighbour touching, kissing or making you have sex when you don’t want to.

**\*I have experienced violence from a member of my family / neighbours:** (please **highlight** or **bold** all the answers that apply)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don’t know
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**C: Violence in the community** could include: gossip, bad words, rejection, avoidance, children being stigmatized or avoided; being attacked or beaten by a stranger; being touched or made to

have sex with someone who is not your partner when you don't want to; being raped because of your sexual orientation or gender identity ("corrective rape"); hate-motivated violence against trans women; any form of violence against sex workers by clients or strangers

**\*I have experienced violence in the community** (please **highlight** or **bold** all the answers that apply)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
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**D: Violence in a health setting** could include: rude or judgmental service providers; being asked how you came to be HIV positive; disclosing your status without your consent; making you take an HIV test without telling you or without asking for your consent; refusing to give you all the information about available services; forced/coerced abortion or sterilization; making you wait until other clients have been seen; being refused a certain type of contraceptive, even when it is available; denial of care at hospitals)

**\*I have experienced violence in health settings** (please **highlight** or **bold** all the answers that apply)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
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**E: Violence from the police / military / prison or detention services** could include: police harrassment; arrest without giving a reason, or because you are carrying condoms, lubricant or clean injection equipment; threat of or actual sexual violence or rape by police, prison/detention guards, military personnel; denial of health care in prison or detention; disclosure of HIV status; refusal to provide services

**\*I have experienced violence from the police / military / prison or detention services** (please **highlight** or **bold** all the answers that apply)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
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**F: Fear of any form of violence**

**\*I have experienced fear of violence** (please **highlight** or **bold** all the answers that apply)

Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
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**Please tell us about any of these experiences of violence in more detail if you would like to.**

**If you have experienced any of these forms of violence, were you able to access support services, and did they help you to deal with the situation/experience?**

**\* What do you think are the most important ways to address or prevent these forms of violence?** (Please choose one answer for each issue, and mark with an X)

	<b>Critical</b>	<b>Important</b>	<b>Less important</b>	<b>Don't know</b>
Remove laws which criminalize sex work				
Remove laws which criminalize drug use				
Remove laws which criminalize same sex practices				
Remove laws which criminalize HIV exposure / transmission				
Address alcohol abuse				
Increase access to employment for women, including trans women				
Increase social protection for women and children				
Increase access to harm reduction-based treatment for women who use drugs				
Strengthen laws and policies to protect the rights of people living with HIV				
Sensitize health care workers to the rights of women living with HIV				
Increase access to quality support services for women who experience gender based violence (including sexual violence)				
Provide a minimum post rape care and support package, including post-exposure prophylaxis (PEP), emergency contraception, screening for other sexually transmitted infections (STIs), and psycho-social care / counselling				
Strengthen of legal protections around all forms of violence against women / gender based violence				
Recognize and address marital rape and "date rape"				
Ensure effective complaints / redress mechanisms in case of rights violations within health services				

**Other (please specify)**

## **4: Mental health and HIV**

Many women living with HIV experience mental health problems, and this can impact on our ability to have a healthy sex life and about ability to make choices about our fertility desires and to claim our human rights. Please think about whether you have experienced any of the following for extended periods of time – i.e. more than the usual “ups and downs” of life.

\* I have experienced extended periods of: (tick any answers as apply for each issue)

	Before my HIV diagnosis	Since my HIV diagnosis	Because of my HIV diagnosis	Never	Don't know
Depression					
Shame					
Self blame					
Very low self esteem					
Feelings of rejection					
Body image issues					
A strong sense of isolation (from friends, family, partners)					
Paranoia					
Anxiety / fear / panic attacks					
Insomnia / difficulty sleeping					
Anorexia / difficulty eating					
Difficulty going out and socializing					
Spiritual isolation					
Loneliness					
Suicidal feelings					
Post traumatic stress disorder (for example, nightmares or flashbacks after a life-threatening event)					
Harmful use of drugs and/or alcohol					

**Please tell us more about the impact of these (or other mental health) experiences on your sexual and reproductive health and human rights, if you would like to:**

**What do you think is the BEST way of supporting women living with HIV to deal with mental health issues?**

## 5. Sexual and reproductive health and human rights for women living with HIV in all of our diversity

Women are not all the same. We all have multiple and interacting identities, lifestyles and circumstances. Some women have particular needs, can face additional barriers, or may experience multiple layers of discrimination which make it more challenging to access sexual and reproductive health services, and enjoy healthy pleasurable relationships.

**\* What do you think are more or less important factors to help women in all of our diversity to experience sexual and reproductive health and human rights?** (Please choose one answer for each issue and mark with an X)

	Critical	Important	Less important	Not important	Don't know
Access to methadone or buprenorphine for women living with HIV who inject drugs and are pregnant					
Sexual and reproductive health services tailored for lesbian, bisexual, trans women or other women living with HIV who have sex with women					
Comprehensive sexuality education					
Continuity of treatment access and adherence support for women in prison or detention					
Addressing HIV-related stigma and discrimination among prison staff and inmates					
Consistent implementation of up-to-date practice guidelines in relation to women living with HIV in prison (including prisons' duty of care as outlined in key performance indicators)					
Tailored access to information and services for women with disabilities					
Treatment and support for Hepatitis C and/or TB co-morbidities					
Access to sexual reassignment surgery for trans women					
Access to other gender-affirming surgeries for trans women					
Introduction of sexual and reproductive health guidelines / policy for trans women					
Interventions to halt and address violence and discrimination against sex workers					
Removal of age-restrictive policies (please give eg in box below)					

**Would you like to highlight any particular issues that you see as current gaps in clinical care, practice, policy and research regarding the sexual and reproductive health and human rights of women living with HIV from key affected populations?**

## 6. Puberty, menstrual issues and menopause

Thinking about women and girls living with HIV in your community at different stages of their life: would you like to highlight any particular issues that you see as current gaps in clinical care, practice, policy and research?

### A: Childhood, adolescence and puberty

Thinking of girl children and adolescent girls/young women living with HIV: what in your opinion or experience are current gaps in clinical care, practice, policy and research regarding their sexual and reproductive health and human rights? For example, these could be in relation to:

- Moving from children's clinic/services to adult clinic/services
- Sexual relationships counselling,
- Comprehensive sexuality education
- Impact of HIV on puberty (early / late on-set; body changes; anxiety around starting periods)

### B: Reproductive years

Thinking of women living with HIV during the main reproductive years: What in your opinion or experience are current gaps in clinical care, practice, policy and research regarding their sexual and reproductive health and human rights? For example, these could be in relation to:

- STI information, diagnosis, treatment or management (e.g. Herpes)
- Information, diagnosis and treatment about reproductive cancers (cervical, breast,)
- Menstrual irregularities: (e.g. heavy/prolonged periods)

### C: Menopause and post-menopause

Thinking of women living with HIV during and after the menopause: in your opinion or experience are current gaps in clinical care, practice, policy and research regarding the sexual and reproductive health and human rights of women living with HIV going through the menopause, or who are post-menopausal? For example, these could be in relation to:

- Menopause and support with hormone replacement treatments
- Sexual relationships counseling for older / post-menopausal women



## 7. HIV treatment and side effects

Our Sexual and Reproductive Health and Human Rights can also be affected by our experience of accessing anti-retroviral medicine (ARVs).

If we have access to ARVs when we need them, and are able to take them regularly with food, we can stay well. However, if we are forced to take ARVs before we actually need them, to protect our partner(s), some women with HIV have found that this causes violence from our partners - for example if the drugs are found, leading to disclosure of our status. Or for some of us it may mean we can no longer negotiate condom use with our partners if we have an undetectable viral load.

Alternatively, if we find that our ARVs make us feel sick or have other side effects, we may feel depressed or not feel like having sex or fear passing HIV to our children.

In this section, we ask you to reflect on some of these issues in relation to ARVs and our sexual and reproductive health and human rights.

### How often do you see your HIV service provider?

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**When was your last check on CD4 Count?** (please **highlight** or **bold** one response)

- ◆ Within the last 3 months
- ◆ 3 - 6 months ago
- ◆ 6 months - 1 year ago
- ◆ More than 1 year ago
- ◆ Never

### What is your CD4 count (if you know it)?

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### Are you taking antiretrovirals (ARVs)?

YES / NO

If yes, what is the name of your medication? (If you would like more details on any of these medications, please see <http://i-base.info/guides/category/arvs>)

Do you regularly experience any of the following? (Please **highlight** or **bold** as many as apply):

- ◆ Fatigue / tiredness
- ◆ Loss of libido / sexual Desire
- ◆ Vomiting
- ◆ Diarrhea
- ◆ Constipation
- ◆ Headaches
- ◆ Rashes
- ◆ Changes of mood
- ◆ Changes of body shape
- ◆ Hair loss
- ◆ Loss of appetite

- ◆ Strange dreams
- ◆ Menstrual disorders (e.g.) heavy bleeding, very long or painful periods)
- ◆ I have no side effects
- ◆ Other (please specify)

**How do these experiences impact on your sexual and reproductive health and human rights?**

**When was your last check on viral load?** (please **highlight** or **bold** one response)

- ◆ Within the last 3 months
- ◆ 3 - 6 months ago
- ◆ 6 months - 1 year ago
- ◆ More than 1 year ago
- ◆ Never

**What is your latest viral load (in copies/mL)?**

>

**Are there any problems with having an undetectable Viral Load? If so, please explain in your own words what these are or could be?**

## 8. Financial issues affecting access to services

Which of these issues has the biggest impact on you or other women living with HIV in your community to access quality sexual and reproductive health care and well-being? (please highlight or bold any that apply)

- ◆ Cost of sexual and reproductive health care at point of delivery
- ◆ Cost of travel / childcare to access health services
- ◆ Unequal inheritance and property Rights
- ◆ Divorce, widowhood, separation
- ◆ Cost and burden of care for others (eg children, family members with HIV)
- ◆ Lack of family support
- ◆ Lack of economic opportunities for women
- ◆ HIV-related stigma and discrimination in the workplace

**Other issues related to your livelihood (please specify)**

**What are the priority changes in policy and practice that you would like to see, to help address these financial issues:**

## Final Comments

Please use this space to give more detail on any of the issues raised above, or any other issue, if you would like to

Thank you SO MUCH for participating

All your answers and comments will be collected, analysed and given to the World Health Organisation

Please pass survey on to others, IF SAFE

The survey will run until Friday 30th May, and the report of the findings will be published on the Salamander Trust website in September 2014 ([www.salamandertrust.net](http://www.salamandertrust.net))

If you would like to find out more about the report or the survey in the meantime, would like to receive further updates about this process, or would like further resources on any of the issues dealt with in this survey, please contact Luisa Orza on [luisa.orza@gmail.com](mailto:luisa.orza@gmail.com)

Salamander Trust is a registered UK charity, which seeks to transform the way we think about HIV. It has a strong track record in global advocacy, research and training in relation to HIV, gender and rights, including sexual and reproductive health and rights, and gender-based violence. Its Founding Director, Alice Welbourn, is also a woman living with HIV and a former international chair of the International Community of Women living with HIV. For more about the Trust, see [www.salamandertrust.net](http://www.salamandertrust.net)