

CHIVA Annex

Characteristics of participants – parents and caregivers of children receiving ART

		Number of participants	%
Sex	Female	46	97.90%
	Male	1	2.10%
Age (years)	18–24	7	14.90%
	25–34	11	23.40%
	35–44	14	29.80%
	45–54	9	19.10%
	55+	6	12.80%
Live in	City	1	2.10%
	Suburb	1	2.10%
	Township	24	51.10%
	Rural area	21	44.70%
Parent or caregiver	Parent	19	40.40%
	Caregiver	28	59.60%
Age of child	0–11 months	4	8.50%
	1–3 years	7	14.90%
	4–6 years	14	29.80%
	7–9 years	9	19.10%
	10–12 years	13	27.70%
Does the child live with you?	Always	40	85.10%
	Sometimes	5	10.60%
	Not often	2	4.30%
Child's treatment duration	Less than 6 months	6	12.80%
	6 months – 1 year	8	17.00%
	1–2 years	4	8.50%
	2–4 years	10	21.30%
	Longer than 4 years	19	40.40%
Treatment regimen	d4T, 3TC, efavirenz	7	14.90%
	d4T, 3TC, Kaletra [®]	7	14.90%
	ABC, 3TC, efavirenz	6	12.80%
	ABC, 3TC, Kaletra [®]	6	12.80%
	Nevirapine	2	4.20%
	Don't know	19	40.40%
Switched treatment?	Yes	17	36.20%
	No	30	63.80%
Distance to clinic	0–15 minutes	8	17.00%
	15–30 minutes	16	34.00%
	30 minutes – 1 hour	17	36.20%
	Over 1 hour	6	12.80%

Characteristics of participants – pregnant women living with HIV

		Number of participants	Percentage %
Age (years)	18–24	7	15.20%
	25–34	27	58.70%
	35–44	12	26.10%
	45–54	0	0
	55+	0	0
Live in	City	1	2.20%
	Suburb	3	6.50%
	Township	36	78.30%
	Rural area	6	13.00%
Number of pregnancies	First	11	24%
	Second	13	28.30%
	Third	15	32.50%
	Fourth	6	13.00%
	>four	1	2.20%
Tested HIV positive	Before I became pregnant	19	41.30%
	During this pregnancy	21	45.70%
	During a previous pregnancy	4	8.70%
	During this delivery	2	4.30%
On ARV treatment	For own health	19	41.30%
	For PMTCT	27	58.70%
Started on ARV treatment	Before pregnancy	11	24%
	During this pregnancy	29	63%
	During a previous pregnancy	6	13.00%
	During this delivery	0	0
Appointment attendance	All appointments	41	89.20%
	Some of them	3	6.50%
	Only a few	2	4.30%
	No appointments	0	0
Feeding choice	Breastfeeding	24	52.20%
	Formula	18	39.10%
	Combination	4	8.70%
Distance to clinic	0–15 minutes	5	10.90%
	15–30 minutes	17	36.90%
	30 minutes – 1 hour	19	41.30%
	Over 1 hour	5	10.90%

Themes and subthemes

Parent and caregivers of children receiving ART	
Theme	Subtheme
Challenging factors	
Medication	Taste Strict 12-hourly timings Side effects, especially on starting ART Number of tablets Changing formulations
Disclosure	Child not understanding the need for medication Caregiver anxieties over telling the truth
Financial difficulties	Transport money Food to take medication Complications with proof of legal guardianship
Health service factors	Distance to the clinic Medication stock-outs No provision of ART at primary health care clinics Frequent appointments Staff attitudes Lack of confidentiality
Impact on the parent or caregiver	Having to quit work to attend appointments Inability to keep up with the demands Not understanding ART Feeling of guilt if child became unwell
Supportive factors	
Support	Family Health care workers Neighbours and friends
Observed benefit of ART	Dramatic improvements in their child's health
Disclosure	Openness with the child regarding their status Continuing discussions after disclosure Ensure understanding why they are taking their ART
Increased caregiver understanding	Treatment classes Discussions with others Health care worker input
Independence with taking ART	Encouraging autonomy Joint effort with children in remembering
Health service factors	Less frequent appointments Increased duration of medication supply Free transport to clinic
Suggested strategies for improving adherence	
Financial or economic assistance	Income-generating projects

	<ul style="list-style-type: none"> Free transport to clinic Improved grant structure Food provision
Health service changes	<ul style="list-style-type: none"> Decentralization of ART to improve access Less frequent appointments People living with HIV as health care workers Family clinics Improved appointment structure Delivery of ART
Increased support	<ul style="list-style-type: none"> Parent and caregiver support groups Improved access to counselling Social worker involvement
When to start?	<ul style="list-style-type: none"> Start earlier and younger to assist children in getting used to taking ART Start treatment at diagnosis to maintain the child's health Start even if they are well to prevent them from ever becoming sick
What to start on?	<ul style="list-style-type: none"> Once a day Can be taken in the evening Taste better Do not require refrigeration

Pregnant women living with HIV	
Theme	Subtheme
Challenging factors	
Diagnosis	<ul style="list-style-type: none"> Shock Coping with HIV and pregnancy Struggling with acceptance Upsetting disclosure experience
Disclosure	<ul style="list-style-type: none"> Difficulty disclosing to family and partners Fear Not wanting to buddy, since it means disclosing
Lack of support	<ul style="list-style-type: none"> Isolated Rejection from family Stigma from community Partners not accepting diagnosis
Understanding ART	<ul style="list-style-type: none"> Limited understanding of the importance of ART Many questions, especially around how ART affects their unborn baby Confusion around feeding choices
Medication	<ul style="list-style-type: none"> Side effects, especially nausea Number of pills
Health service	<ul style="list-style-type: none"> Frequent appointments Travel costs to clinic Staff attitudes

	<p>Waiting times</p> <p>ART availability</p> <p>Pre-engaging in care postpartum</p>
Supportive factors	
Support and acceptance	<p>From clinic</p> <p>Counselling</p> <p>Discussions with others</p> <p>Support group</p> <p>Family and partners</p>
Benefit of ART	<p>Own health</p> <p>Health of their baby</p>
Disclosure	To others for support
Understanding ART	<p>Information from counselling</p> <p>Treatment classes</p> <p>Support groups</p>
Reminders	<p>Alarms</p> <p>Diary</p> <p>Friends and partners</p>
Suggested strategies for improving adherence	
Early diagnosis and acceptance	Including partner's acceptance
Health service changes	<p>Decentralization of ART to improve access, including mobile clinics</p> <p>Less frequent appointments</p> <p>After-work clinics</p> <p>Training of health care workers</p> <p>More private counselling areas</p> <p>Family clinic (mother and child's ART and care available in the same clinic)</p>
Support groups	<p>Ones that include partners and encourage the involvement of men</p> <p>Discussions with other mothers</p>
More information	<p>To improve understanding</p> <p>For families and communities</p> <p>On positive living</p>
Responses to option B+	
For option B+	<p>Benefits for their own health</p> <p>Increases the likelihood of having a HIV-negative baby</p> <p>Be less confusing and more straightforward</p> <p>Encourage ongoing engagement in care</p>
Against option B+	<p>Creates extra strain on current clinics and government finances</p> <p>Would be too much to cope with</p> <p>Causes further problems with adherence, especially if the person is not unwell</p> <p>Increases the chances of having medication side effects</p> <p>Causes anxieties about having a lifetime commitment to ART</p>
Additional considerations	Requirement of further information and advice on the options and consequences of each

Potential added benefit of being counselled by women and mothers living with HIV
The need for time to decide – with some suggesting a week
Ultimately, the decision between options should be theirs
Going to clinics different to those of their children for medication would decrease acceptability
A warning that pressure to choose B+ could result in defaulting

Workgroup discussion guide

Values and preferences of parents and caregivers of children living with HIV receiving ARV treatment

Task 1. Current experiences

- What has it been like for you and your child in starting and keeping them on treatment?
 - Prompt: What is your experience in relation to: storage, timing of doses, formulation and amount, getting your child to take the medication, adjusting doses with growth, dividing pills into smaller doses, collection of medication etc.
- Draw, write down or explain your experiences and views and present them.

Task 2. Identification of current support or hindrances

- What has assisted or made it difficult for you and your child in starting and keeping them on treatment?
 - Prompt: What makes it easier for you? What makes it harder for you?
 - Draw, write down or explain five things that helped
 - Draw, write down or explain five things that make it harder
 - List them from the most helpful too the most difficult and explain the reasons behind your choice

Task 3. Solutions

- What would help you to support your child in starting and keeping them on treatment?
 - Prompt: What would help other caregivers to support their child starting and keeping them on treatment?
 - Draw, write down or explain your response and present it.

Task 4. Specific questions for discussion

- We understand that younger children have to take treatment twice a day. Is this hard for you? Would taking it once a day make a difference for you?
- Would you consider starting your child on treatment when they are feeling well? Or would you prefer to wait until they are unwell? Give a reason for your answer.
- At what age would you prefer to start your child on treatment? Younger than 3 years old or older? Or does it not matter? Give a reason for your answer.

Part 2) Values and preferences of pregnant women living with HIV

Task 1. Current experiences

Divide the group into two smaller groups of five people in each

- Group 1
 - What was it like for you taking ARV treatment during and after your pregnancy?
 - Prompt: What is or was your experience in relation to taking your treatment, feeding choices etc.
- Group 2
 - What was it like for engaging in care during and after your pregnancy?

- Prompt: What is or was your experience in relation to attending your appointments, including follow-up?
 - o Draw, write down or explain your experiences and views and present them.

Task 2. Identification of current support or challengers

- o Group 1
 - What has helped you in taking your ARV treatment during your pregnancy and/or breastfeeding?
 - What has made it hard for you in taking your ARV treatment during your pregnancy and/or breastfeeding?
 - Prompt: What has made it easier for you? What has made it harder for you?
- o Group 2
 - What has helped you to stay in long-term care and follow-up, including after you had your baby?
 - What has made it hard for you to stay in long-term care and follow-up, including after you had your baby?
 - Prompt: What has made it easier for you? What has made it harder for you?
 - o Draw, write down or explain five things that assisted.
 - o Draw, write down or explain five things that hindered or caused challenges.
 - o List them from the most supportive to the most hindering and present the reasons behind your choice.

Task 3. Solutions

- o Group 1
 - What would assist you to take your ARV medicines during your pregnancy and/or breastfeeding?
 - Prompt: What would help other women pregnant women living with HIV to take their ARV treatment?
- o Group 2
 - What would assist you to engage in care, including after you have had your baby?
 - Prompt: What would help other pregnant women living with HIV to engage in care?
 - o Draw, write down or explain what would have assisted you.

Task 4. Specific questions for discussion

Lifelong treatment from pregnancy even if you are feeling well

- o What do you feel the benefits would be?
- o What would be your concerns?
- o How should these options be offered to women?
- o How would you feel if you were told that you had to start taking lifelong treatment beginning in pregnancy when you are feeling well?
- o How would you feel if you were given a choice to decide between option B or option B+?
 - o What support and information would you need to make the right decision for you?
 - o How long would you need to think about this option and make a choice?
- o In order to support these new options, what changes do you think would be helpful to introduce in the community?
- o How could the community better support women in making these choices and in changing perceptions about the need for lifelong treatment?
- o What changes would need to be made at the facility level (staffing and patient flow) if more women will require lifelong treatment?

Pre-workshop survey

Parents and caregivers of children living with HIV on ART workshop questionnaire

Circle as appropriate

I am a: Female Male

I am: _____ years old

Where do you live: City Suburb Township Rural area

Other _____ (please state)



I am the: Parent Caregiver

My child is: _____ years old

Does the child live with you? Always Sometimes Not often

How long has your child been on ART for? less than 6 months 6 months – 1 year
1–2 years 2–4 years Longer than 4 years

Which ARVs does your child take? _____ Don't know

Has your child changed their ART? Yes No

How long does it take you to get to the clinic?: 0–15 minutes 15–30 minutes 30 minutes – 1 hour
Over 1 hour

Pregnant women living with HIV workshop questionnaire

Circle as appropriate

I am: _____ years old

Where do you live: City Suburb Township Rural area
Other _____ (please state)

This pregnancy is my: First Second Third Fourth More than four

I tested HIV positive: Before I become pregnant During this pregnancy
During a previous pregnancy During this delivery

I take ARVs: For my own health To prevent transmission to my baby

I started my ARVs: Before I became pregnant During this pregnancy During a previous pregnancy
During this delivery

I have attended: All of my appointments Some of my appointments
Only a few appointments No appointments

For this current pregnancy, what was or will be your feeding choice? Exclusive breastfeeding Formula/bottle
combination

How long does it take you to get to the clinic? 0–15 minutes 15–30 minutes 30 minutes – 1 hour
Over 1 hour

Informed consent

Parents and caregivers of children living with HIV on treatment consent

Date:

Hello, I am working on behalf of the World Health Organization. I am helping them **to explore the values and preferences of parents and caregivers of children living with HIV receiving ARV treatment** as part of developing international guidelines. We would like to organize two workshops of focus group discussions with 20 parents and caretakers of children living with HIV.

You are being invited to consider if you would like to be a **part of a workshop**. If you want to participate, you will spend an afternoon or morning taking part in a group workshop with about 10 parents and caregivers of children living with HIV receiving ARV treatment. The workshop will involve activities and a discussion and will be held at

The aims of the workshop are:

- to gain parents' and caregivers' perspectives on starting, switching and maintaining their child on ARV treatment;



- to have a better understanding of what aspects of starting, switching and maintaining their child on ARV treatment are important; and
- to explore issues of what would make starting, switching and maintaining their child on ARV treatment more manageable.

Being a part of this workshop is up to you. If you participate, you can change your mind at any time. You can decide how much information you would like to share. No one will be upset if you don't want to participate, if you choose to stop or if you refuse to answer some questions.

Everything in this workshop will be kept **strictly confidential**. Your names will not be used in any reports and you can even give an alias name to introduce yourself.

You may know some of the other participants in the group, but we ask that you protect their confidentiality as they should protect yours. Unfortunately, we are unable to guarantee this and therefore request that you **not disclose any sensitive or personal information** of your own.

Once the workshop is finished, we will let the World Health Organization know what we discussed. We hope that this will help to further develop **services that are appropriate and will support the needs of children living with HIV**. However, it is important to note that changes to your local services are not up to us, but participating in this workshop will ensure that your thoughts and opinions are heard.

You will not be paid for participating, but you will be given the equivalent of R30 to cover your travel costs. We will also serve snacks and some drinks at the workshop.

If you have any questions or are unsure of anything to do with the workshop, you can contact us at:
WHO Country Office
Address

Consent form for the parents and caregivers of children living with HIV receiving treatment

Yes, I want to take part in this workshop.

I _____ have been informed about the workshop entitled: **Values and Preferences of Parents and Caretakers of HIV-positive Children on Treatment.**

- I understand the workshop that has been explained to me.
- I have been given an opportunity to ask questions about the workshop and have had them answered clearly.
- I understand that my participation in this workshop is voluntary.
- I understand that I can change my mind to participate and no one will be upset at me.
- I understand that I do not have to answer any of the questions if I do not want to.
- I understand that everything I say will be kept private and that my name will not be used in any reports.
- I understand that, if I have any questions or concerns about the workshop, I can contact the facilitator at any time.
- I understand that the workshop discussions will be recorded for quality purposes.

I understand that if I have any questions or concerns about my rights as a workshop participant, or if I am worried about the workshop or the facilitators, then I may contact:

WHO Country Office

Signature of participant

Date

Signature of witness

Date

Signature of translator (where applicable)

Date



Consent form for values and preferences of pregnant women living with HIV

Date:

Hello, I am working on behalf of the World Health Organization. I am helping them **to explore the values and preferences of pregnant women living with HIV** as part of developing international guidelines. We would like to organize two workshops of focus group discussions with 20 pregnant women or those that have given birth in the past year who are living with HIV.

You are being invited to consider if you would like to be a **part of a workshop**. If you want to participate, you will spend an afternoon or morning taking part in a group workshop with about 10 pregnant women or those that have given birth in the past year who are living with HIV. The workshop will involve activities and a discussion and will be held at

The aims of this workshop are:

- to gain HIV-positive women's perspective of receiving ARV treatment during pregnancy and breastfeeding;
- to have a better understanding of what aspect of receiving ARV treatment during pregnancy and breastfeeding are important; and
- to explore issues of what would make receiving ARV short-term or lifelong treatment during pregnancy and breastfeeding more acceptable.

Being a part of this workshop is up to you. If you participate, you can change your mind at any time. You can decide how much information you would like to share. No one will be upset if you don't want to participate. If you feel that the information discussed during the workshop is upsetting you or your baby, you can choose to stop your involvement. This will not have any impact on the services you receive at the hospital. A counsellor will also be on standby if you would like to discuss things further.

Everything in this workshop will be kept **strictly confidential**. Your names will not be used in any reports and you can even give an alias name to introduce yourself. However if something is said that makes me concerned about your safety, such as someone causing you physical harm, I may have to talk to someone about it, but I will not do this without discussing it with you first.

You may know some of the other participants in the group, but we ask that you protect their confidentiality, as they should protect yours. Unfortunately, we are unable to guarantee this and therefore requested that you **not disclose any sensitive or personal information** of your own.

Once the workshop is finished, we will let the World Health Organization know what we discussed. We hope that this will help to further develop **services that are appropriate and will support the needs of pregnant women living with HIV**. However, it is important to note that changes to your local services are not up to us, but participating in this workshop will ensure that your thoughts and opinions are heard.

You will not be paid for participating, but you will be given R30 to cover your travel costs. We will also serve snacks and some drinks at the workshop.

If you have any questions or are unsure of anything to do with the workshop, you can contact us at:
WHO Country Office

Consent form for pregnant women living with HIV

Yes, I want to take part in this workshop.

I _____ have been informed about the workshop entitled: **Values and preferences of pregnant women living with HIV**

- I understand the workshop that has been explained to me.
- I have been given an opportunity to ask questions about the workshop and have had answered clearly.
- I understand that my participation in this workshop is voluntary.
- I understand that I can change my mind to participate and no one will be upset at me.
- I understand that I do not have to answer any of the questions if I do not want to.
- I understand that everything I say will be kept private and that my name will not be used in any reports.
- I understand that, if I have any questions or concerns about the workshop, I can contact the facilitator at anytime.



- I understand that the workshop discussions will be recorded for quality purposes.
- I understand that if I have any questions or concerns about my rights as a workshop participant, or if I am worried about the workshop or the facilitators, then I may contact:

WHO Country Office

Signature of participant

Date

Signature of witness

Date

Signature of translator (where applicable) Date