Viral Load Monitoring and Enhanced Adherence Counseling Flipchart

Infants and Children







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This flipchart is intended for use by health care workers in order to provide information to patients living with HIV and their families. For questions about the contents or use, please contact ICAP at icap-communications@columbia.edu

HOW TO USE THE VIRAL LOAD MONITORING AND ENHANCED ADHERENCE COUNSELING FLIPCHART

The purpose of this flipchart is to provide information to parents about their children's viral load monitoring, explain the meaning of viral load results, and to coach parents with children receiving ARVs to work with them to improve adherence, providing help with adherence assessment and counseling, especially among those with elevated viral load who warrant enhanced adherence counseling. It was developed for a range of health care workers (e.g. adherence counselors, doctors, nurses, pharmacists, community health workers) who work with patients living with HIV and their families in settings where viral load testing is being performed.

Each card, or set of cards, focuses on a specific topic important to the care and support of patients on ARVs who will have a viral load test done or who already have a viral load result. Topics are color coded for ease of use.

Directions on how to use the flip chart:

- Place flipchart on table so that the patient has a good view of the pictures while you use the side with notes.
- Key messages to convey to the patients and instructions to providers are in the left part of each card.

- On the right side, **key points** have been **bolded** to serve as reminders. There are also notes to prompt and guide discussion.
- The bottom has questions to pose to the patients to review the covered material and assess patient's understanding.
- There are certain cards for specific visits including when starting ARVs, when viral load test is being sent, and when results are available. If the result is 1000 or less there are corresponding cards to use. If the result is more than 1000 there are a series of cards to be used to explain the result and to conduct enhanced adherence counselling sessions.
- A separate document, the **Enhanced Adherence Plan** tool, is used to document findings and plan for cards 6-16 and should be included in patient's file.
- Card 17 should be repeated at each of the scheduled follow-up enhanced adherence counseling sessions.
- Use card 18 when a patient has a low viral load test result following enhanced adherence counseling.
- Use card 19 when a patient has a high viral load test result following enhanced adherence counseling. Cards 6-16 can then be used for repeated enhanced adherence counseling sessions.

Card Topic (also shown to patient)

KEY MESSAGES:

» Also shown to the patients

TALKING POINTS:

- Some instructions for providers
- Notes to prompt and guide discussion

• Key points are bolded

Let's Review:

• Points to guide review with the patients



Tells providers which forms to use to document discussions with the patients



Gives providers specific instructions about their interaction and conversation with the patients

image from card front

Good counseling and communication skills

1. Good counseling and communication skills are essential. Here are some useful tips:

- Always make **eye contact** with the patient
- Sit face to face
- Speak clearly and in a **nonthreatening voice**
- Be non-judgemental and respectful do no blame or criticize!

SOAOpen-ended questionsAAffirmationRReflective listeningSummary statements

2. To be most effective in increasing adherence to ARVs use the following OARS techniques (**O**pen ended questions, **A**ffirmation, **R**eflective listening, **S**ummary statements):

O: Open Ended Questions (avoid questions that are answered as Yes/No):

What makes it difficult for your child to take his/her ARVs every day? What have you already done to help your child try and take his/her ARVs every day? What do you think is likely to happen if your child keeps taking ARVs as s/he is now?

A: Affirmations

<u>I appreciate that you are able</u> to be honest about the way your child takes his/her ARVs. <u>You are clearly a resourceful person</u> to manage so many challenges.

You've really worked hard to help your child take his/her medications despite these challenges.

R: Reflective Listening

<u>You're not sure why</u> your child needs to take ARVs every day.

So you said you feel angry when you think about giving your child ARVs and that makes it really hard.

<u>What I hear you saying is that you have so many other important things to do, it can be difficult to give your child medications every day.</u>

S: Summary Statements

Let me see if I understand so far. You want your child to be healthy, but you are struggling to give your child ARVs because you have other problems in your life that make it difficult to focus on his/her health.

Here's what I've heard you say, let me know if it is right. Your child feels fine when s/he misses a dose and you are feeling really uncertain about whether ARVs are necessary to keep your child healthy.

Flipchart Card Topics

How To Use The Viral Load Monitoring and Enhanced Adherence Counseling Flipchart Good counseling and communication skills

- 1. Beginning your child's ARVs
- 2. Talking to your child about ARVs
- 3. What is a viral load?
- 4. The viral load is LOW
- 5. The viral load is HIGH
- 6. How are you giving your child ARVs?
- 7. What are the challenges you face giving your child ARVs?
- 8. What are the challenges you face giving your child ARVs?
- 9. What are the challenges you face giving your child ARVs?
- 10. Ways to help your child take ARVs
- 11. Sharing your child's status with others
- 12. Remembering to give ARVs
- 13. Understanding your child's ARVs
- 14. Child doesn't want to take medication
- 15. Tips for helping your child take medication
- 16. Tips for pill swallowing
- 17. Follow up: how you are giving your child ARVs?
- 18. You've successfully reduced your child's viral load
- 19. ARVs are not working well

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1. Beginning your child's ARVs



- ARVs stop HIV from making more virus, allowing your child to stay or become healthier.
- » It is important to give your child ARVs every day as prescribed.
- In six months, we will check your child's viral load to see if ARVs are working well.

1. Beginning your child's ARVs

KEY MESSAGES:

- ARVs stops HIV from making more virus, allowing your child to stay or become healthier.
- » It is important to give your child ARVs every day as prescribed.
- » In six months, we will check your child's viral load to see if ARVs are working well.



Let's Review:

- Who will be responsible for giving your child his/her ARVs?
- What do you think may be a challenge in giving ARVs every day?
- In your own words, what do ARVs do?
- Are there any benefits of a low viral load that surprised you or that you have questions about?
- What are the benefits of you or some other adult being responsible for giving your child medications?

TALKING POINTS:

- What do you know about ARVs?
- When **HIV** is **active** in the body it makes a **lot of virus** which harms your child and can make your child **sick**.
- **ARVs stop HIV** from making more virus and help prevent your child from getting sick.
- It is important to give your child ARVs every day as prescribed to make sure they work well and keep HIV from harming your child.
- **ARVs** do **not cure** HIV, which is why your child must continue taking them.
- If your child stops taking ARVs or does not take them every day your child can get sick.
- Children need to be given their ARVs and cannot manage to take them without adult supervision.
- We will do a test called viral load in 6 months to see if ARVs are working well. The viral load measures how much HIV is in the blood and will usually be low (less than 1000) after 6 months.
- A late dose is better than a missed dose.
- Taking ARVs regularly and having a low viral load has many benefits:
 - » **Keeps your child's mind healthy.** Having a low viral load prevents HIV from hurting your child's brain and allows your child to learn and develop normally.
 - » **Prevents other serious illnesses.** Low viral load means your child has more disease-fighting cells, called CD4s, which can fight serious illnesses.
 - » Keeps your child from having extra visits to the clinic.
 - » **Keeps your child physically and emotionally strong.** Low virus can help your child grow well and prevent mood problems such as depression and anxiety.
 - » Allows you and your child to focus on everyday life.



2. Talking to your child about ARVs



- » It is normal for your child to have questions about taking medications.
- It is important to give children truthful information once they start having questions so when they grow up they can learn to take care of themselves.
- What you say, including when you tell them about HIV, will depend on their age and how well they can understand.

2. Talking to your child about ARVs

KEY MESSAGES:

- » It is normal for children to be curious and have questions about taking medications.
- » It is important to give children truthful information once they start having questions so when they grow up they can learn to take care of themselves.
- What you say, including when you tell them about HIV, will depend on their age and how well they can understand.

TALKING POINTS:

- What have you told your child about his/her health?
- Does your child take other medications or know other people who take medications?
- Introducing ARVs:
 - » "Your doctor has given you medicine to keep you healthy and strong and prevents you from getting sick. It is important we take it every day."
- Common questions and answers:
 - » Q: "I don't feel sick, or I don't like it, why do I have to take medication?"
 - » A: Some medicine helps you when you feel sick to feel better. This medicine is different it keeps you healthy and strong.
 - » Q: "Why don't (peers/siblings/others) have to take medications?"
 - » A: Everyone's body is different and needs different things. This medicine is what your body needs to be healthy and strong.
 - » Q: "Can I just not take it today?"
 - » A: For this medicine to work properly, you have to take it everyday.
- The best age to tell your child about their HIV is different for each child and family.

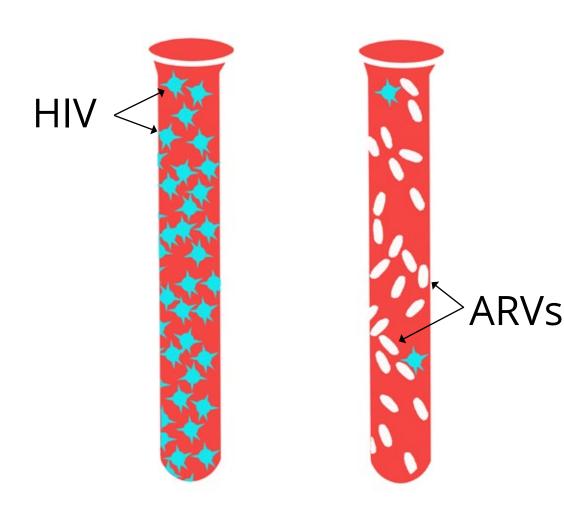
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Review:

 What do you think is hardest about talking to your child about ARVs? Is there anything that worries you about talking with your child about ARVs? • What do you plan to say to your child?



3. What is a viral load?



- ARVs stop HIV from making more virus. This keeps the virus from harming your child and allows them to grow up healthier.
- » Viral load measures how much HIV is in the blood and if ARVs are working well.
- It is very important to know your child's viral load, so make sure to come back and ask for your child's results.

3. What is a viral load?

KEY MESSAGES:

- ARVs stop HIV from making more virus. This keeps the virus from harming your child and allows them to grow up healthier.
- » Viral load measures how much HIV is in the blood and if ARVs are working well.
- It is very important to know your child's viral load, so make sure to come back and ask for your child's results.



Let's Review:

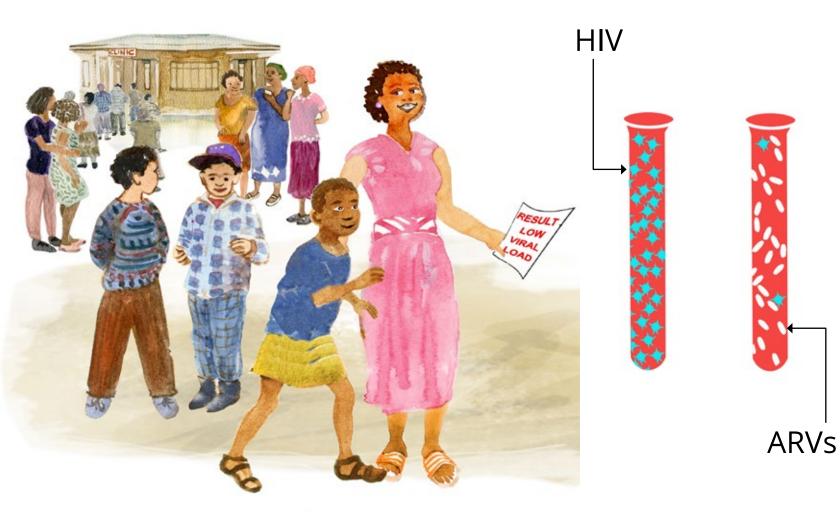
- In your own words, what is viral load?
- How does a low viral load help your child?
- When will you return for your child's viral load results?

TALKING POINTS:

- The **"viral load"** test tells us **how much virus** is in about one drop of blood.
- **ARVs stop HIV** from producing more virus and brings the viral load down.
- If your child has a high viral load, he/she may not look sick, but the virus is harming his/her body.
- The viral load test tells us whether ARVs are working to stop HIV from making more virus.
- **Remember, ARVs** do **not cure HIV,** so your child must continue taking them.
- If ARVs are working well, and your child is taking ARVs every day, the viral load will usually be low (less than 1000) after 6 months.
- A low viral load:
 - » Keeps your child's mind healthy. Having a low viral load prevents HIV from hurting your child's brain and allows your child to learn and develop normally.
 - » **Prevents other serious illnesses.** Low viral load means your child has more disease-fighting cells, called CD4s, which can fight serious illnesses.
 - » Keeps your child from having extra visits to the clinic.
 - » **Keeps your child physically and emotionally strong.** Low virus can help your child grow well and prevent mood problems such as depression and anxiety.
 - » Allows you and your child to focus on everyday life.
- CD4 count is also used to see if ARVs are working, but viral load is more accurate.
- Please come back in _____ weeks for viral load results.



4. The viral load is LOW



- A low viral load means ARVs are working well!
- This does
 not mean
 ARVs can be
 stopped.
- » Continue to give your child ARVs every day.

4. The viral load is LOW

KEY MESSAGES:

- » A low viral load means ARVs are working well!
- » This does not mean ARVs can be stopped.
- » Continue to give your child ARVs every day.

Let's Review:

- What does a low viral load mean?
- Why is it important to continue ARVs?
- How does a low viral load help your child?
- Why is it important that an adult supervise or give the ARVs?

TALKING POINTS:

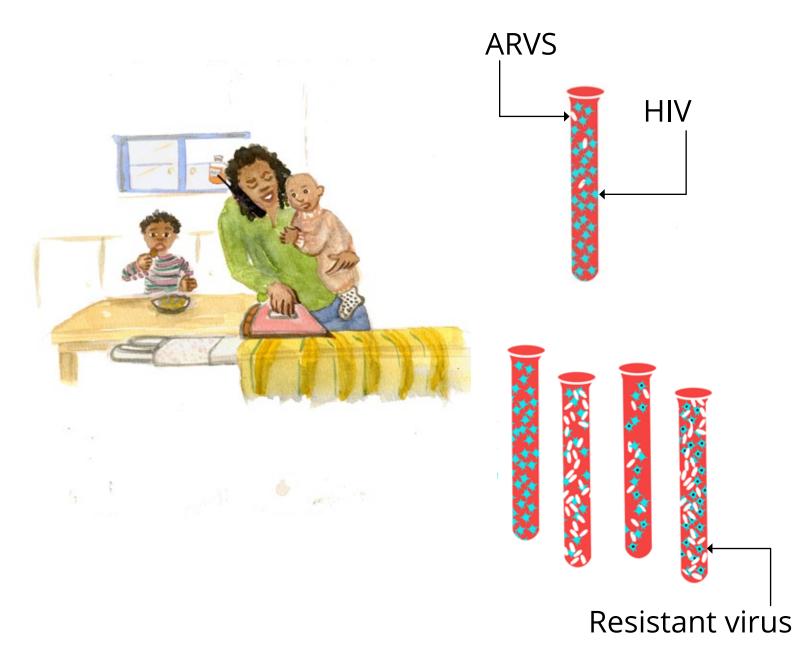
- A low viral load (less than 1000) [insert patient's results here] is a sign that your child is taking ARVs well and that ARVs are working.
- Remember this doesn't mean ARVs can be stopped.
- It is important that you continue to give your child ARVs every day to stop HIV from making more virus and to stay healthy.
- A late dose is better than a missed dose.
- I can see from the test results that you have been doing very well. What has helped you remember to give your child ARVs
- What things have made it hard at times to give your child ARVs?
- What do you think might get in the way of giving your child ARVs in the future?
- Would you like to discuss these challenges so we can help you and your child continue to take ARVs or make it even better and easier?

A few reminders:

- » It's important to keep all of your child's appointments.
- » If you are running out of ARVs come to the clinic even if you don't have an appointment.
- Unless there are any concerns, we will check the viral load again in six months.
- Please let your child's provider know if there are any problems giving ARVs in the future, so that he/she can help you to address them.



5. The viral load is HIGH



- » HIV is not controlled and it is harming your child's body and brain.
- Your child may be missing doses.
- The virus may be resistant meaning it has changed and ARVs are no longer working.

5. The viral load is HIGH

KEY MESSAGES:

- » HIV is not controlled and it is harming your child's body and brain.
- » Your child may be missing doses.
- The virus may be resistant meaning it has changed and ARVs are no longer working.

TALKING POINTS:

- The **viral load** test result is **high** [*insert patient's result here*], the goal is to keep it below 1000.
- This means that **HIV** is making more virus in the body.
- With so much virus in the blood your child is being harmed even if he/she does not appear sick.
- When the viral load is high, your child's immune (defense) system becomes weaker, and their CD4 cells decrease, so your child can become sick.
- A high viral load can be because your child is **not taking ARVs** as instructed and is missing doses.
- If ARVs are not taken properly, the **virus can change** and become "**resistant**" **to the ARVs**, meaning that even if taken properly, they will no longer work.

- What are the possible reasons for a high viral load?

Let's Review:

- What can happen when viral load is high?
- What would be good about a low viral load?
- How important do you think it is for your child's long-term health?
- What do you think happens if your child doesn't take their medications regularly?

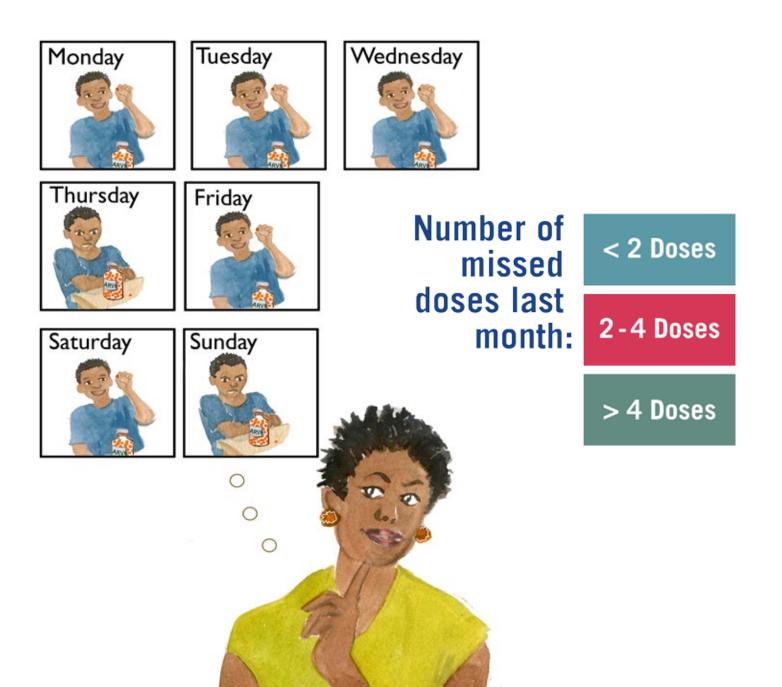


Remember to use non-judgmental and respectful language - do not blame or criticize:

"I am glad you came to get your child's viral load test results. Now we can help you work towards a low viral load for your child."



6. How are you giving your child ARVs?



- Caregivers sometimes find it hard to give their child ARVs every day.
- Together we will review how often your child takes ARVs and see how it can improve.

6. How are you giving your child ARVs?

KEY MESSAGES:

- Caregivers sometimes find it hard to give their child ARVs every day.
- Together we will review how often your child takes ARVs and see how it can improve.

TALKING POINTS:

- Some caregivers find it difficult to give their child ARVs every day.
- Problems giving their child pills can occur at any time during treatment.
- Please think back to the past WEEK, how many ARV doses (days) do you think your child missed?
 - » Was this a typical week?
 - » Now what about the past month?





1. Ask the parent to recall the last week and how many doses their child missed.

2. Ask if this is typical.

3. Determine how many doses were missed in the last month.

4. Using the table to the left, determine if the child's adherence is good, fair, or poor.

Document

Complete the first column of Enhanced adherence session 1 on the **Enhanced Adherence Plan Tool** and mark adherence as good, fair, or poor, according to the number of doses missed per month (as per table).

Number of Missed doses per month	Adherence category	
Patients taking once daily regimens		
< 2 doses	Good	
2-4 doses	Fair	
>4 doses	Poor	
Patients taking twice daily regimens		
<4 doses	Good	
4-8 doses	Fair	
>8 doses	Poor	

Adapted from WHO, 2012, Three interlinked patient monitoring systems

7. What are the challenges you face giving your child ARVs?



» Together, we will discuss some reasons it may be difficult to give your child ARVs.

7. What are the challenges you face giving your child ARVs? (1 of 3)

Forgot

Feeling better

Multiple

Caregivers

Physical illness -

Responsibility/ -

-

KEY MESSAGES:

Together, we will discuss » some reasons it may be difficult to give your child ARVs.

TALKING POINTS:

- Let's explore any **challenges** you may be facing when giving your child ARVs.
- Please feel comfortable telling me about challenges you are facing; I am asking because I want to try to find ways to make it easier.

disturbance).





Barriers	Questions to assess barriers
Individual	
Knowledge deficit	 Can you tell me the names of your child's ARVs? What is your understanding of how you are supposed to give your child ARVs (e.g. what time of day, how much [if liquid], how many [if pills]? What is your understanding of the purpose of the ARVs? What is your child's understanding of why he/she takes ARVs? Is it difficult to give the right dose (e.g. has trouble measuring liquid ARV)? Is someone else giving your child ARVs? If so do you believe they know how to give ARVs properly?
Side effects	 Have the ARVs affected the way your child feels? Do you think the ARVs have made your child feel ill in any way? If yes, please describe what problems they cause (e.g. nausea, diarrhea, sleep

Does your child forget to take his/her ARVs?

Do you give ARVs even when your child is feeling well?

take? Do you watch your child take their medication?)

Do you give them at a set time of day?

Have you ever forgotten or do you often forget to give your child ARVs?

What is your method of remembering/reminding yourself to give ARVs?

Has an illnesses prevented you from giving or your child from taking ARVs?

have disclosed who can give medication when you are sick or unavailable?

How does your child get ARV doses (Do you give? Do you ask/remind child to

Are you the only person responsible for giving/supervising the child's ARVs? If

no, who are the others? etc. If yes, are there others in the home to whom you

Provider Instructions

Explore with the patient barriers and challenges.

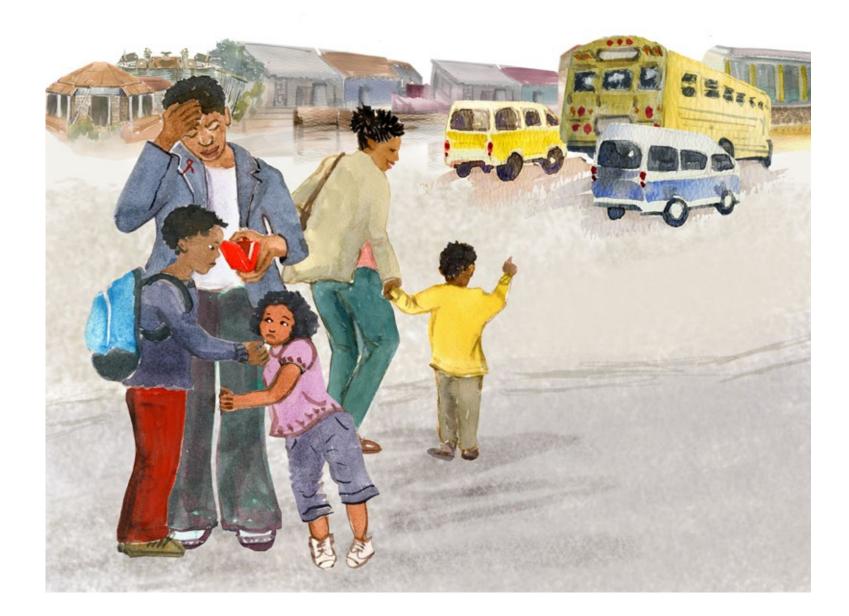
O: Open Ended Questions (Avoid guestions that are answered as Yes/No). for example:

- What makes it difficult for your child to take his/her ARVs every day?
- What have you already done to try and help your child take ARVs every day?
- What do you think is likely to happen if your child keeps taking ARVs as s/he is now?



Document the specific barriers you identify with the patient on the Enhanced Adherence Plan Tool.

8. What are the challenges you face giving your child ARVs?



 » Together, we will discuss some reasons it may be difficult to give your child ARVs.

8. What are the challenges you face giving your child ARVs? (2 of 3)

KEY MESSAGES:

 Together, we will discuss some reasons it may be difficult to give your child ARVs.



Summarize what was learned from the patient about any specific barriers identified on this card.

A: Affirmations, for example:

- *<u>Lappreciate that you are able</u>* to be honest about the way your child takes ARVs.
- <u>You are clearly a resourceful person</u> to manage so many challenges.
- <u>You've really worked hard</u> to help your child take his/her medications despite these challenges.



Document the specific barriers you identify with the patient on the **Enhanced Adherence Plan Tool.**

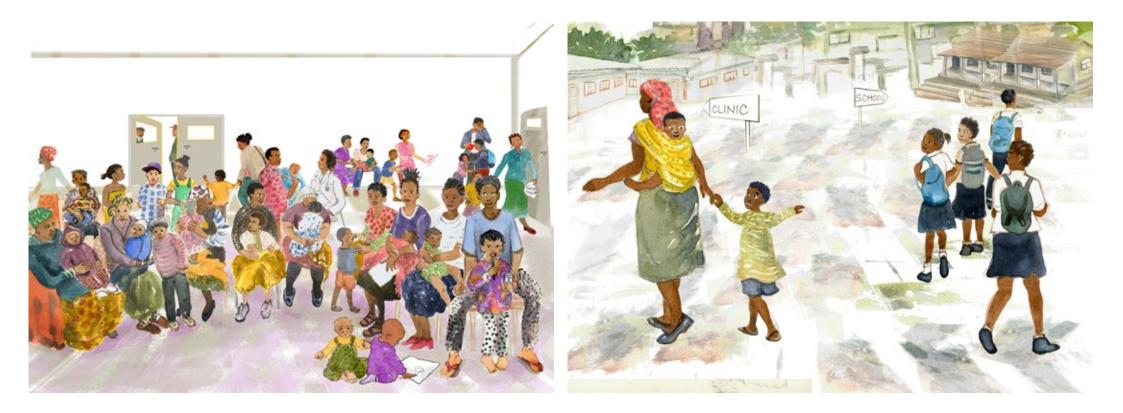
TALKING POINTS:

• Let's continue to explore any challenges you may be facing when giving your child ARVs (individual and household level barriers).



Barriers	Questions to assess barriers	
Individual (continued)		
Pill burden	 Is the number of pills or amount of liquid a challenge for your child? Is the taste of liquid/size of pills a problem for your child? 	
Lost/ran out of pills	- Have you ever lost or run out of ARVs?	
Transportation	 Is it hard to get to the health center to collect ARVs? 	
problems	- If yes, what are the reasons? (e.g. long distance, expense, job)	
Health beliefs	- Do you believe that taking ARVs every day is good for your child's health?	
	 What do you think is the best way to treat your child's HIV? 	
	 Have you tried other remedies for treating your child's HIV? 	
Scheduling difficulty	 Have you ever been too busy or faced a schedule change that has made it difficult to give your child ARVs? 	
	- Does work take you away from home for long periods of time?	
Household		
Share with others	- Have you ever shared your child's ARVs with others?	
Fear of disclosure	- Have you disclosed your child's HIV status to your family?	
	- Is your child aware of his/her HIV status?	
Family/partner	- Has your family or your partner been non-supportive or kept you	
relationships	from giving your child ARVs?	
Inability to pay	- Have clinic or other fees kept you from giving your child ARVs?	
Food insecurity	 Has a lack of adequate food ever been a problem for giving your child ARVs? 	

9. What are the challenges you face giving your child ARVs?



» Together, we will discuss some reasons it may be difficult to give your child ARVs.

9. What are the challenges you face giving your child ARVs? (3 of 3)

KEY MESSAGES:

 Together, we will discuss some reasons it may be difficult to give your child ARVs.



Summarize what was learned from the patient about any specific barriers identified on this card.

R: Reflective Listening, for example:

- <u>You're not sure why</u> your child needs to take ARVs every day.
- <u>So you said you feel</u> angry when you think about giving your child ARVs and that makes it really hard.
- <u>What I hear you saying is that you</u> have so many other important things to do, it can be dificult to give your child medication every day.

Document

Document the specific barriers you identify with the patient on the **Enhanced Adherence Plan Tool.**

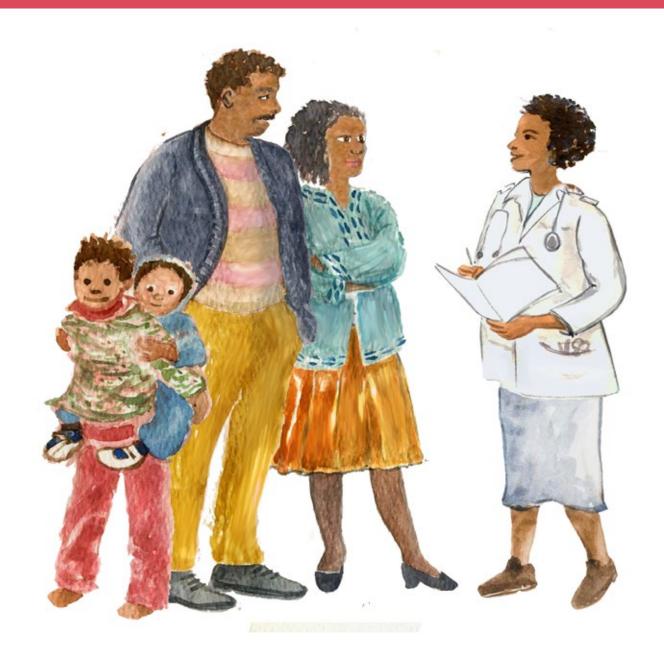
TALKING POINTS:

• Let's continue to explore any challenges you may be facing when giving your child ARVs (institutional and community level barriers).



Barriers	Questions to assess barriers	
Institutional/Commun	nity	
Drug stock out	- Have you ever come to the health facility and found that there were no ARVs available?	
	 Have you ever come to the health facility and been given only a small supply of ARVs? 	
Long wait times	 Have you ever left the health facility before receiving your child's ARVs because of long wait times? 	
Stigma and discrimination	Are you fearful that people in the community will find out about your child's HIV?	
	 Does that prevent you from coming to clinic or giving ARVs? 	
Political crisis/war/ natural disaster	Is it ever unsafe for you to pick up ARVs from the health facility?	
Parent Factors		
Alcohol or drug use	 Do you use alcohol? Do you use drugs? Do you feel this affects your ability to give your child ARVs? 	
Depression	 How is your mood in general? Have you been feeling sad or confused? If yes, has this affected your ability to give your child ARVs? 	
Behavior or other child concerns	 Do you have other concerns or struggles with your child (e.g., mood, school, behavior, anxiety, other illnesses)? Does your child refuse ARVs? Do these concerns impact your ability to give your child his/her medications? 	

10. Ways to help your child take ARVs



 » Together we will find ways to make giving ARVs to your child better.

10. Ways to help your child take ARVs

KEY MESSAGES:

» Together we will find ways to make giving ARVs to your child better.



Summarize what was learned from the patient about any specific barriers identified on this card.

S: Summary Statements, for example:

- <u>Let me see if I understand so far.</u> You want your child to be healthy, but you are struggling to give your child ARVs because you have other problems in your life that make it difficult to focus on his/her health.
- <u>Here's what I've heard you say, let me know if it is</u> <u>right.</u> Your child feels fine when he/she misses a dose and you are feeling really uncertain about whether ARVs are necessary to keep your child healthy.



Document planned interventions to address barriers identified by patient on the **Enhanced Adherence Plan Tool.**

TALKING POINTS:

- Based on the challenges we discussed, let's explore ways in which we can make it easier for you to give your child ARVs.
- Many children have trouble taking their ARVs all the time.
- Do you have ideas how to make it easier to give your child the ARVs in response to each barrier we discussed?
- Missing more than 2-3 doses in a month can lead to medications not working well.
- We want to make sure you have the information, tools, and support you need to do your difficult job well. There is some information and tools I can give to you directly, but we may find other sources of support for you as well.
- Of the areas we discussed, what is the biggest problem you have giving your child his/her medications?



- Go to Card 11 for "disclosure."
- Go to Card 12 for "forgets."
- Go to Card 13 for "knowledge" and "health beliefs."
- Go to Card 14 for "side effects," "child does not want to take ARVs," and "child behavior."
- Go to Card 15 for "help giving small child take medications."
- Go to Card 16 for "pill swallowing."



11. Sharing your child's status with others



» Sharing your child's status with someone you trust may make it easier to give your child ARVs every day.

11. Sharing your child's status with others

KEY MESSAGES:

» Sharing your child's status with someone you trust may make it easier to give your child ARVs every day.



- Identify possible treatment supporters available to help with administering the child's ARVs.
- For parents that want to disclose HIV status to others or to the child, make a plan and provide assistance (can involve other members of the care team).

Document

Document planned interventions to address barriers identified by patient on the **Enhanced Adherence Plan Tool.**

TALKING POINTS:

- Discuss ways to decide who to share your child's diagnosis with and how to share:
 - » What characteristics do you think makes a good choice for someone to share your child's status with?
 - » What are the benefits of someone knowing your child's status?
 - » How do you decide whether you can trust someone?
 - » How do you tell someone your child's status?
 - » How do you think another person might support you to give your child ARVs every day?
 - » Are you concerned that harm might come to your child if you disclose their HIV status?
- Discuss disclosing your child's HIV status to child:
 - » When do you think is a good time for your child to know their HIV status?
 - » What are the benefits of your child knowing their HIV status?
 - » Do you think knowing their status would make it easier for them to take ARVs?
 - » What concerns do you have about your child knowing their HIV status?



12. Remembering to give ARVs



- » Always remembering to give ARVs can be difficult.
- » Missing ARV doses can harm your child's health.

12. Remembering to give ARVs

KEY MESSAGES:

- Always remembering to give ARVs can be difficult.
- » Missing ARV doses can harm your child's health.



Let's Review:

Remembering to give ARVs can be a lot of work, so I'd like to check with you about a few things we discussed.

- Who is responsible for your child's medications?
- What changes do you plan to make to ensure your child gets ARVs every day?
- Where do you keep the medications?
- How do you keep track of whether you have given the medications?

TALKING POINTS:

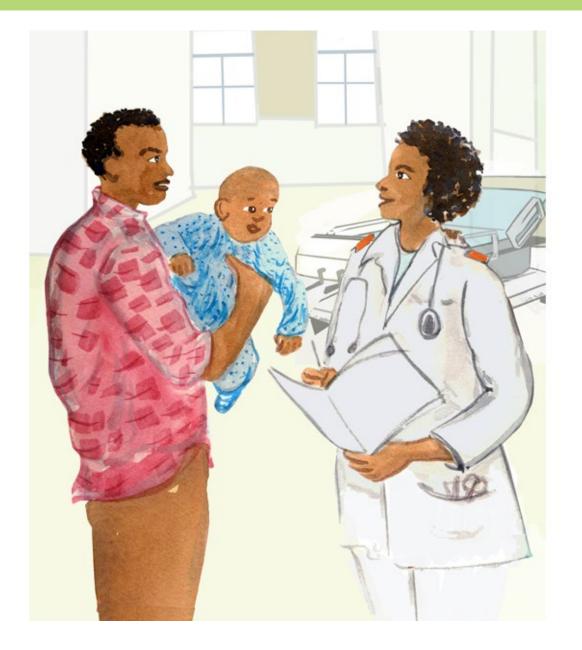
- Let me make sure I understand. What I hear you saying is [*circumstance for child missing doses*].
- Here are some things that others have found helpful:
 - » Giving ARVs is an adult job: Adult caregivers should give children their medication. Assign one person whose "job" it is to give the medication. If that adult cannot give the medication that day, it is that adult's job to find another adult to give the medication.
 - » Put medications somewhere easy to remember that you use every day.
 - » Use an incentive chart or calendar to mark/put a sticker when medications are taken for the day.
 - » Ask provider for pill boxes and/or travel packs.
 - » Ask for extra medications if gaps between refills is a problem.



Document planned interventions to address barriers identified by patient on the **Enhanced Adherence Plan Tool.**



13. Understanding your child's ARVs



 To be successful with ARVs it is important that you learn how they work and how best to give them to your child daily.

13. Understanding your child's ARVs

KEY MESSAGES:

To be successful with ARVs it is important » that you learn how they work and how best to give them to your child daily.

Let's Review:

Ask the parent questions to ensure they understand what you have discussed:

• Let's go over these instructions again to see if there are any questions. Can you tell me how you understand what ARVs do and how you are supposed to take them, and tips to avoid side effects?

Provide written resources if available.

TALKING POINTS:

Which area is the parent having the most difficulty with?

- Names and Frequency of Medications
 - » Provide education and fact sheets.
- How Medications Work
 - » Review earlier cards from last visit or answer questions.
- Health Beliefs
 - » Instruct patient to give medications whether the child feels healthy or sick, unless otherwise directed by doctor.
 - » Probe for specific beliefs about medication and health.
 - » If caregiver is using alternative remedies (e.g., herbs), explain that sometimes these can prevent the ARVs from working.



Document

Document planned interventions to address barriers identified by patient on the Enhanced Adherence Plan Tool.



14. Child doesn't want to take medication



 » Some children dislike taking ARVs.

14. Child doesn't want to take medication

KEY MESSAGES:

» Some children dislike taking ARVs.



Let's Review:

- Ask the parent questions to ensure they understand what you have discussed:
 - What I hear you saying is (add the reason), I'd like to make sure I understand how you plan to help your child take ARVs
- Provide written resources if available.

Document

Document planned interventions to address barriers identified by patient on the **Enhanced Adherence Plan Tool.**

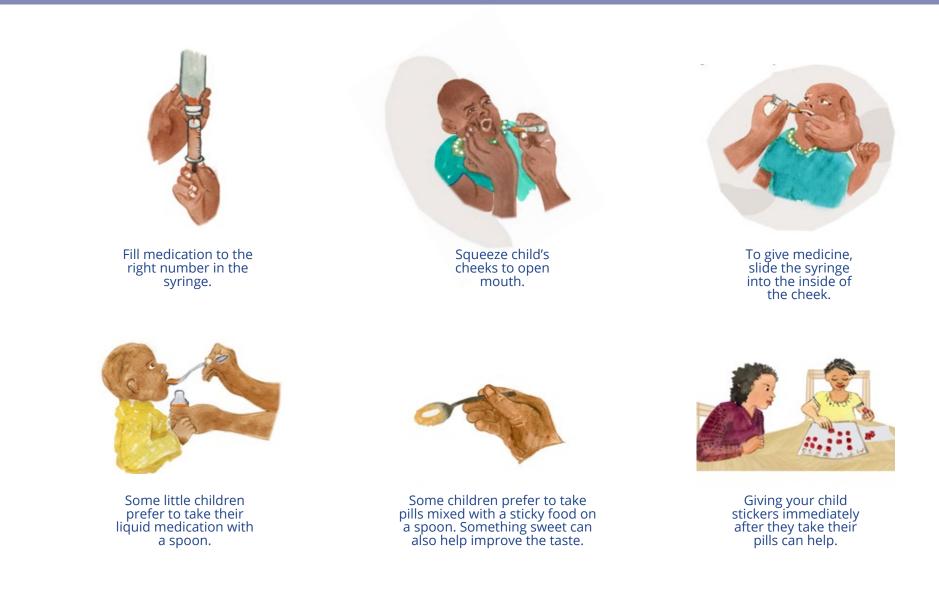
TALKING POINTS:

Sometimes it can be difficult to give children medicines. Why do you think your child is having a hard time?

- Child is experiencing side effects
 - » Give tips for managing side effects.
 - » For nausea, take pills with food.
 - » For headache/drowsiness, take pills at night.
- Child wants to do other activities and/or has a hard time agreeing to take pills every day
 - » Pills then play. No meds, no play.
 - » Make taking medications part of the daily routine, not something that is decided every day.
 - » Giving your child stickers immediately after they take their pills can help.
- Health beliefs why do I have to take them? How to talk to child about taking medications
 - » Help parent with what to say to their child: "You need this to keep you strong and healthy/ so you don't get sick," or "Medicine keeps the virus from harming you."
- For some children, bitter-tasting medications are easier to take as pills or pellets. This can be discussed with your doctor.



15. Tips for helping your child take medication



» There are several ways you can help your child take medication.

15. Tips for helping your child take medication

KEY MESSAGES:

- » There are several ways you can help your child take medication.
- » Fill medication to the right number in the syringe.
- » Squeeze child's cheeks to open mouth.
- » To give medicine, slide the syringe into the inside of the cheek.
- » Some little children prefer to take their liquid medication with a spoon.
- » Some children prefer to take pills mixed with a sticky food on a spoon. Something sweet can also help improve the taste.
- » Giving your child stickers immediately after they take their pills can help.



16. Tips for pill swallowing



» Using a water bottle is a good way to help swallow pills.

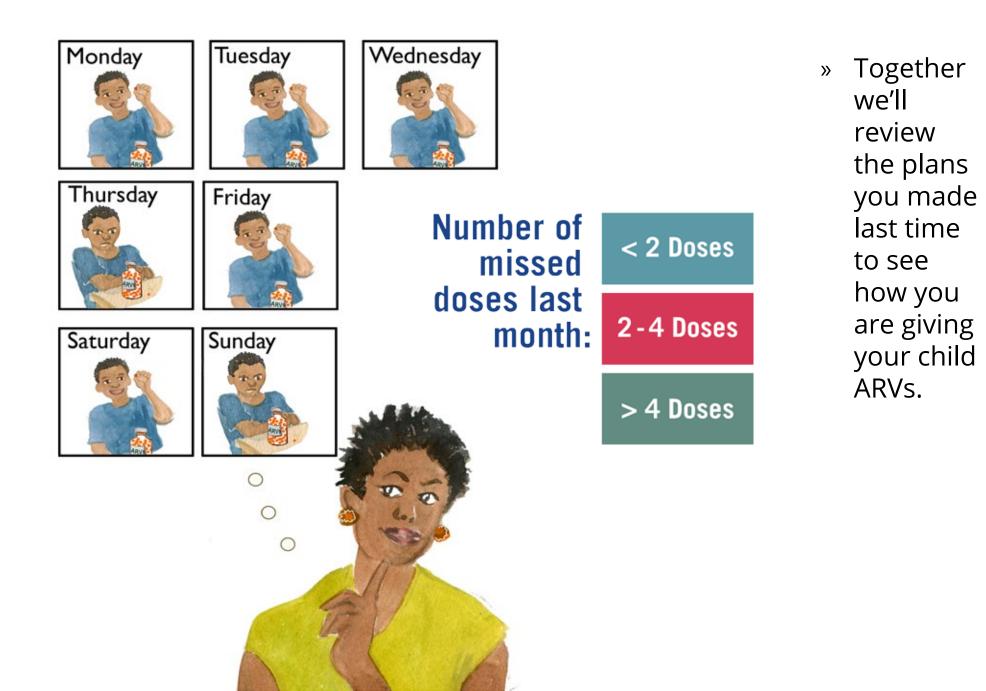
16. Tips for pill swallowing

KEY MESSAGES:

- » Using a water bottle is a good way to swallow pills.
- » Have the child place the pill on the back of their tongue.
- » Use a water bottle with a small opening that they can cover their mouth with.
- » Have your child tip their head back as far as they can while swallowing the pill and water.
- » Tipping your head back makes swallowing much easier.



17. Follow up: how you are giving your child ARVs?



17. Follow up: how you are giving your child ARVs?

KEY MESSAGES:

» Together we'll review the plans you made last time to see how you are giving your child ARVs.



- Use adherence assessment tables on prior cards as needed to look for barriers and new interventions.
- Return to prior cards to review strategies or information.
- Repeat viral load should be done after 3 months of "good adherence".
- Advise care recipient of when repeat viral load will be done.

TALKING POINTS:

- Last time we met, we planned

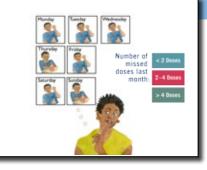
 _____(interventions decided upon at last adherence session) to help you give your child ARVs.
- How has that been going?
- Are there any new challenges giving your child ARVs?
 - » Please think back to the past WEEK, how many ARV doses (days) do you think you missed?
 - » Was this a typical week?
 - » Now what about the past month?
- Can you recall and describe the circumstances around the last missed dose?
- I can see you've been putting a lot of effort into this. Do you have any new ideas how to make it easier to give your child the ARVs?

Document

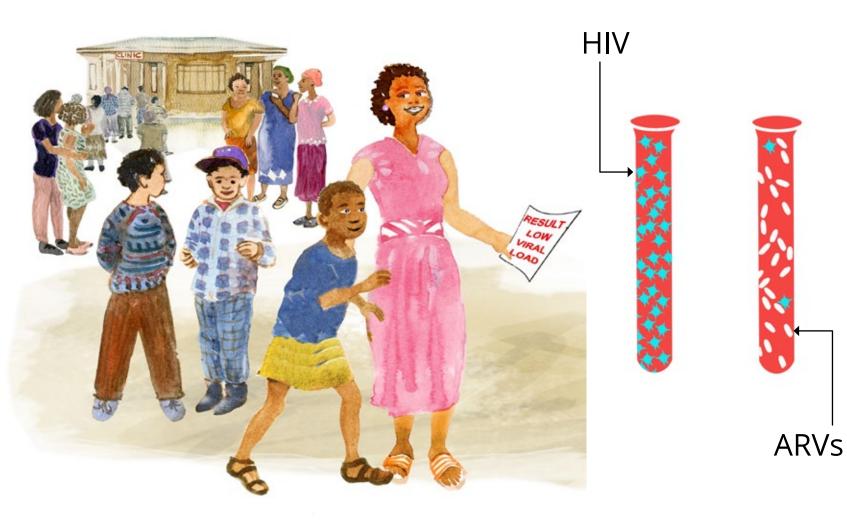
Complete the first column of session 2 or 3 on the **Enhanced Adherence Plan Tool** and mark adherence as good, fair, or poor, according to the number of doses missed per month (as per table). Complete the other two columns with any new barriers found and interventions planned.

If adherence is fair or poor, continue monthly enhanced adherence sessions using cards in this flip chart and additional pages of the **Enhanced Adherence Treatment Plan** tool until the adherence is good.

Number of Missed doses per month	Adherence category	
Patients taking once daily regimens		
< 2 doses	Good	
2-4 doses	Fair	
>4 doses	Poor	
Patients taking twice daily regimens		
<4 doses	Good	
4-8 doses	Fair	
>8 doses	Poor	



18. You've successfully reduced your child's viral load



- » The repeat viral load is low!
- You have given your child ARVs consistently, and they are working to reduce the viral load. You are keeping your child healthy.

18. You've successfully reduced your child's viral load

KEY MESSAGES:

- » The repeat viral load is low!
- » You have given your child ARVs consistently, and they are working to reduce the viral load. You are keeping your child healthy.

Let's Review:

Let's briefly review what a low viral load means and plans for continuing to give your child ARVs:

- In your words, what does it mean to have a low viral load?
- Who is responsible for remembering to give your child ARVs?
- Why is it important to continue ARVs?

Document

Document planned interventions to address barriers identified by patient on the **Enhanced Adherence Plan Tool.**

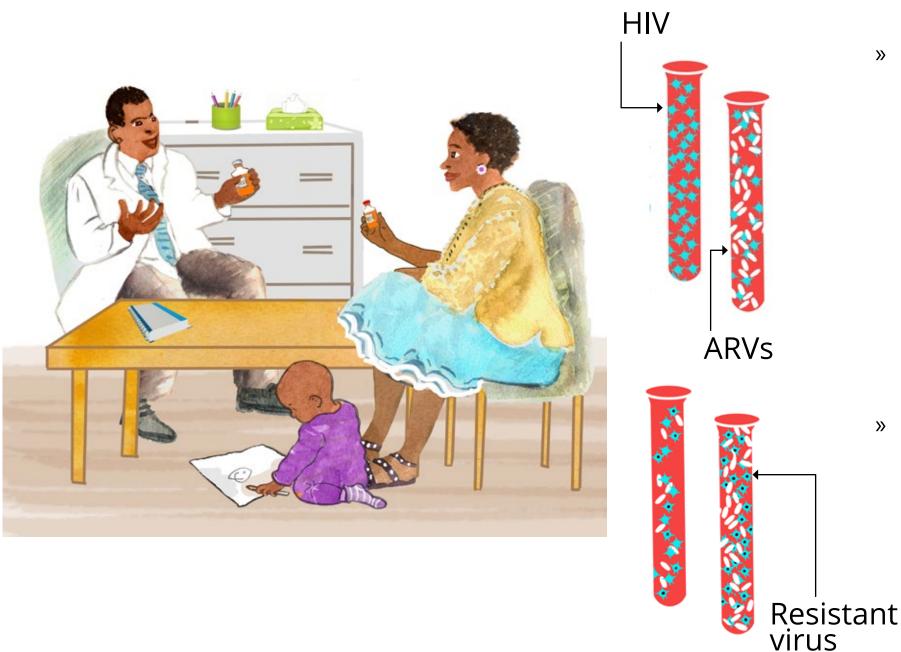
TALKING POINTS:

 A low viral load (less than 1000) [insert patient's result here] is a sign that your child is taking his/her ARVs well and that the medication is working.



- Your changes [*mention what is changed*] have been successful and your child is getting the medications he/she needs to stay well.
- Have you had any trouble remembering to give ARVs?
- It is important that you continue to give your child ARVs every day to stop HIV from making more virus and to stay healthy.
- What has helped you remember to give your child ARVs?
- Are there new things or do you expect there to be things that will make it hard at times to give your child ARVs?
- It is important to keep track of how much medication you have so that you don't run out of ARVs before the next appointment.
- If you notice that medication is running **low, come to the clinic** even if you don't have an appointment.
- We will **check** the viral load again in 6 months if there are no new problems or problems giving ARVs.
- Please let your child's provider know if there are any problems giving ARVs in the future, so that he/she can help you to address them.

19. ARVs are not working well



- » It is likely that the virus is resistant, meaning that it has changed and ARVs are no longer working.
- Your child may need different ARVs.

19. ARVs are not working well (for patients who have completed adherence sessions and repeat VL still >1000 c/ml)

KEY MESSAGES:

- » It is likely that the virus is resistant, meaning that it has changed and ARVs are no longer working.
- » Your child my need different ARVs.

Let's Review:

- We have discussed a lot of new information. I'd like to make certain that I have explained everything well and that I have answered your questions.
- Can you please tell me what you understand to be the next steps and why we advise changing ARVs?
- Do you have questions?

Document

Document new ARVs on the **Enhanced Adherence Plan Tool.**

TALKING POINTS:

- I appreciate the effort that it has taken to get to good adherence.
- Even though you are giving the medications every day, your child's repeat viral load result is still high.
- It is likely that ARVs are not working well due to the virus becoming resistant. Remember this means the virus has changed and the medicine no longer works.
- I understand this might feel discouraging but there are other ARVs that we can use.
- We expect that now that you are able to give ARVs every day, the new medications will reduce the viral load and keep your child well.
- It is extremely important to give your child ARVs properly.
- We recommend to change ARVs to ______
 - » Provide detail instructions on new regimen.
 - » Discuss possible side effects and how to avoid/manage.
 - » Provide written instructions.
- Please let a provider know if you have any trouble so that he/she can assist you.
- Your child's next appointment is ______.

Provider Instructions

At subsequent visits use relevant cards for adherence assessments and counseling, and explanation of viral load results. For example, at the first follow-up visit after ARV switch, use the cards beginning with "How are you giving your child ARVs?" (Card 6) to assess adherence to new regimen and provide counseling. Can also review cards 1 & 3 for basic viral load information.



44

ICAP was founded in 2003 at Columbia University's Mailman School of Public Health. Now a global leader in HIV and health systems strengthening, ICAP provides technical assistance and implementation support to governments and non-governmental organizations in more than 21 countries. ICAP has supported work at more than 5,200 health facilities around the world. More than 2.2 million people have received HIV care through ICAP-supported programs and over 1.3 million have begun antiretroviral therapy. Online at <u>icap.columbia.edu</u>