Viral Load Monitoring and Enhanced Adherence Counseling Flipchart

Adolescents
The purpose of this flipchart is to provide information about viral load monitoring to adolescents who know their HIV status and are receiving ARVs in order to explain the meaning of viral load results, and to help with adherence assessment and counseling especially among those adolescents 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.

Consider who should be involved in counselling taking into account any regulations regarding parental rights or age of consent that may apply in your setting. Include the adolescent and any family member who may be helping him or her take ARVs if appropriate.

Each card, or set of cards, focuses on a specific topic important to the care and support of adolescents who are 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 7-20 and should be included in patient’s file.
• Card 21 should be repeated at each of the scheduled follow-up enhanced adherence counseling sessions.
• Use cards 22-23 when a patient has a low viral load test result following enhanced adherence counseling.
• Use card 24 when a patient has a high viral load test result following enhanced adherence counseling. Cards 7-20 can then be used for repeated enhanced adherence counseling sessions.
**Card Topic (also shown to patient)**

**KEY MESSAGES:**
» Also shown to the patients

**Let’s Review:**
• Points to guide review with the patients

**TALKING POINTS:**
• Some instructions for providers
• Notes to prompt and guide discussion
• Key points are bolded

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

**Provider Instructions**
Gives providers specific instructions about their interaction and conversation with the patients
Good counseling and communication skills

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

**Facts about Adolescent Development:** The brain’s ability to think about how today’s actions will affect the future (e.g., taking medicine now will keep a person healthy and well in the future) develops slowly with the brain developing into the mid-20s. It is normal for adolescents to feel as if nothing can hurt them and to think more about immediate problems (“I don’t want to take pills”) than later problems (“If I don’t take pills now, I could get sick or die”). Therefore, we are asking adolescents to be wise beyond their years with their health.

**Ask more than Tell:** Adolescents do not respond well to “You will die if you don’t take this”. It rarely helps change their behavior and, likely, they will not feel as if you are listening or care. Stay nonjudgmental and focus on immediate benefits that matter to the person.

1. Find out what is important to him or her: “What do you like to do in your free time?”
2. Be interested in the responses: “I’d like to hear more about that.”
3. Before giving advice, make sure you are clear about what information would be helpful and ask if they want information. After giving the information, check with the person about what they heard. Example:
   - **Ask:** “A lot of people struggle taking ARVs, what do you find most difficult?”
   - **Confirm:** you’re listening. “I bet that is really frustrating. People keep telling you to do something you don’t like, is hard to remember, and doesn’t feel important.”
   - **Ask:** “Would you like more information about why taking ARVs keeps you healthy?”
   - **Inform:** Focus on immediate benefits like keeping partners healthy, fewer medical visits, keeping body and brain healthy, and fewer medications.
   - **Ask:** “What questions do you have about that information?” “Did any of those benefits seem important to you?” “With that information, how does it change how you think about ARVs?”
Good counseling and communication skills (continued)

**OARS techniques for improving motivation to change:**

**O: Open Ended Questions (avoid questions that are answered as Yes/No):**
- What makes it difficult to take your ARVs every day?
- What have you already done to try and take your ARVs every day?
- What do you think is likely to happen if you keep taking your ARVs as you are now?

**A: Affirmations**
- *Open-ended questions*
  - I appreciate that you are able to be honest about the way you take your ARVs.
  - You are clearly a resourceful person to manage so many challenges.
  - You've really worked hard to take your medications despite these challenges.

**R: Reflective Listening**
- *Affirmation*
  - So you said you feel angry when you think about taking your medicine and that makes it really hard.
  - What I hear you saying is that you so overwhelmed, your health is the least of your problems right now.

**S: Summary Statements**
- *Reflective listening*
  - Let me see if I understand so far. You are struggling to take your medications because you want to be well and healthy, but you also have other problems in your life that make it difficult to focus on your health.
  - Here’s what I’ve heard you say, let me know if it is right. You feel fine when you miss a dose and are feeling really uncertain about whether medications are necessary to keep you healthy.
Flipchart Card Topics

How to use the viral load monitoring and enhanced adherence counseling flipchart

1. You’re starting ARVs
2. What is a viral load?
3. Why is a low viral load good?
4. The viral load is LOW
5. Keeping your virus low
6. The viral load is HIGH
7. How are you taking ARVs?
8. Why is it hard for you to take ARVs? (1 of 3)
9. Why is it hard for you to take ARVs? (2 of 3)
10. Why is it hard for you to take ARVs? (3 of 3)
11. Tips to improve taking ARVs (1 of 3)
12. Tips to improve taking ARVs (2 of 3)
13. Tips to improve taking ARVs (3 of 3)
14. Additional help to take ARVs
15. Remembering to take ARVs
16. Understanding your ARVs
17. Making it easier
18. Tips for pill swallowing
19. Who and why to tell
20. Taking charge of your ARVs
21. Follow up on how you are taking ARVs
22. You’ve successfully reduced your viral load
23. Keeping your virus low
24. ARVs are not working well
1. You’re starting ARVs

- ARVs stop HIV from making more virus, allowing you to become healthier.
- It is important to take ARVs every day as prescribed.
- In six months, we will check your viral load to see if ARVs are working well.
1. You’re starting ARVs

KEY MESSAGES:
» ARVs stops HIV from making more virus, allowing you to become healthier.
» It is important to take ARVs every day as prescribed.
» In six months, we will check your viral load to see if ARVs are working well.

TALKING POINTS:
• What do you know about ARVs?
• It sounds like you know some things about ARVs, now I’m going to help you learn even more.
  » When HIV is active in the body it makes a lot of virus which can make you sick and more likely to spread to sex partners and from mother to baby (MTCT) during pregnancy and breastfeeding.
  » ARVs stop HIV from making more virus and help prevent you from getting sick.
  » It is important to take ARVs every day as prescribed to make sure they work well and keep HIV from harming you.
  » ARVs do not cure HIV, which is why you must continue taking them.
  » We will do a test called viral load in six months to see if ARVs are working well. If you are taking ARVs every day and they are working well, the viral load will usually be low (less than 1000) after six months.
  » A late dose is better than a missed dose.
• Taking ARVs regularly and keeping the virus low in your body has many benefits:
  » Keeps your mind healthy. Having a low viral load prevents HIV from hurting your brain and keeps your memory, intelligence, and ability to solve problems strong.
  » Prevents other serious illnesses from developing. A low viral load will help your disease-fighting cells, called CD4s, increase and keep you from getting sick.
  » Keeps you from having extra visits to the clinic.
  » Keeps you physically and emotionally strong. Low virus can help you grow well and prevent mood problems such as depression and anxiety.
  » Keeps your sexual partners healthy. A low viral load can reduce the risk of transmitting HIV to a sexual partner.

Let’s Review:
• What do you think will be hard about taking 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?

Provider Instructions
Here are some tips on how to introduce yourself to the adolescent patient.
• Find out what is important to him or her: “What do you like to do in your free time?”
• Be interested in the responses: “I’d like to hear more about that.”
2. What is a viral load?

» ARVs stop HIV from making more virus. This keeps the virus from harming you and allows you to be healthier.

» Viral load measures how much HIV is in your blood and if ARVs are working well.

» It is very important to know your viral load results, so make sure to come back and ask for your viral load results.
Let's Review:

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

Provider Instructions

Tip: Adolescents don’t want to be ‘lectured’. It is important to have them to be part of the decision to learn new information. For example:

- Ask: “What do you know about viral load?”
- Confirm you’re listening: “It sounds like people talk about it a lot, but you aren’t sure what it means, is that right?”
- Ask: “Would you like more information about this test and why we think it is important to keep you healthy?”
- Ask: “What questions do you have about that information?” “Did any of those benefits seem important to you?” “With that information, how does it change how you think about ARVs?”

KEY MESSAGES:

» ARVs stop HIV from making more virus. This keeps the virus from harming you and allows you to be healthier.

» Viral load measures how much HIV is in your blood and if ARVs are working well.

» It is very important to know your viral load results, so make sure to come back and ask for your 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 you have a high viral load, you may not look sick, but the virus is harming your 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 you must continue taking them.
- If ARVs are working well, and you are taking ARVs every day, the viral load will usually be low (less than 1000) after six months.
- Please come back in ____ weeks for viral load results.

2. What is a viral load?

• 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 you have a high viral load, you may not look sick, but the virus is harming your 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 you must continue taking them.

• If ARVs are working well, and you are taking ARVs every day, the viral load will usually be low (less than 1000) after six months.

• Please come back in ____ weeks for viral load results.
3. Why is a low viral load good?

People often feel well for a time, even when the viral load is high, so why do we want a low viral load?
3. Why is a low viral load good?

KEY MESSAGES:
» People often feel well for a time, even when the viral load is high, so why do we want a low viral load?

Let’s Review:
• What other benefits do you see from taking your ARVs and keeping your viral load low?
• Are there any of these that surprised you or that you have questions about?

TALKING POINTS:
• What would be better for you if you had a low viral load?
  » Allow the person to respond. This should be a conversation. Remember, use reflective and summary statements to make sure you understand what they are saying.
  » Example: “I hear you really care about keeping your partner healthy.” “You are saying _____ is really important to you. Taking your ARVs will allow you to keep doing this.”

• Keeping the virus low in your body has many benefits:
  » Keeps your mind healthy. Having a low viral load prevents HIV from hurting your brain and keeps your memory, intelligence, and ability to solve problems strong.
  » Prevents other serious illnesses from developing. Low viral load can help your disease-fighting cells, called CD4s, increase and keep you from getting sick.
  » Keeps you from having extra visits to the clinic.
  » Keeps you physically and emotionally strong. Low virus can help you grow well and prevent mood problems such as depression and anxiety.
  » Keeps your sexual partners healthy. A low viral load can reduce the risk of transmitting HIV to a sexual partner.
4. The viral load is LOW

» A low viral load means you are taking your ARVs well and they are working.

» This doesn’t mean you can stop ARVs.

» Continue to take your ARVs every day!

» Keep up the good work!
4. The viral load is LOW

**KEY MESSAGES:**

» A low viral load means you are taking your ARVs well and they are working.

» This doesn’t mean you can stop ARVs.

» Continue to take your ARVs every day!

» Keep up the good work!

**TALKING POINTS:**

- You have a low viral load! Many people find it difficult to take their medications. How have you been so successful? *(Smile and complement their hard work)*
  
  » A low viral load (less than 1000) *[insert patient’s result here]* is a sign that you are taking your ARVs well and that they are working.
  
  » This does not mean you can stop ARVs.
  
  » It is important to **continue** to take **ARVs** consistently every day to keep the virus from reproducing, to stay healthy, and to prevent spread of the virus to sexual partners or your baby (for pregnant adolescents).

Ask these questions to review their success:

- I can see from the test results you have been doing very well. What has helped you remember to take your ARVs?
- Are there things that have made it hard at times to take your ARVs?
- Have you had any trouble remembering to take them?
- What do you think might get in the way of taking them in the future?

**Let’s Review:**

- What does a low viral load mean?
- Why is it important to continue taking your ARVs every day?
5. Keeping your virus low

» Your virus is low so you are protecting your health, partners, and brain.

» It is hard to continue taking ARVs, even with all these benefits—this is especially true when so many things in your life are changing.
5. Keeping your virus low

KEY MESSAGES:

» Your virus is low so you are protecting your health, partners, and brain.

» It is hard to continue taking ARVs, even with all these benefits—this is especially true when so many things in your life are changing.

TALKING POINTS:

• Does anyone help you take your ARVs? Tell me how that works.
• How do you think that might change in the future?
• Who knows that you are HIV+?
• Who might be a good source of support for you as you manage your HIV?
• Are there changes going on in your life?
• How do you think [those changes] may affect you taking ARVs?
• Additional Tips:
  » Put ARVs somewhere easy to remember, near something that you use every day, and keep a bottle of water there if needed.
  » Set an alarm on your phone to remind you to take your medication.
  » Carry ARVs with you so if you forget before leaving for the day, you have a spare.
  » Use pillboxes and a calendar to mark and keep track of when medications are taken for the day.
  » Ask for extra medications if gaps between refills is a problem.
  » If someone asks to share your medications, help them find a clinic and support. If you share, the medications won't work for either of you.

Let's Review:

• Do you think ARVs will help you?
• Are you taking any other treatments for your HIV?
• Are you seeking help from anyone outside of this clinic for your HIV?

Provider Instructions
Screen for other health beliefs or difficulty with disclosure/privacy. Review card 16 (Understanding your ARVs), card 19 (Who to tell and why), or card 20 (Taking charge of your ARVs) in these areas as helpful.
6. The viral load is HIGH

- HIV is not controlled and it is harming your body and brain.
- You may be missing doses of your ARVs.
- The virus may be resistant, meaning it has changed and ARVs are no longer working.
6. The viral load is HIGH

KEY MESSAGES:
» HIV is not controlled and it is harming your body and brain.
» You may be missing doses of your ARVs.
» 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], the goal is to keep it below 1000.
• This means that HIV is making more virus in the body.
• This may be because you are not taking ARVs properly.
• With so much virus in the blood, your immune (defense) system becomes weaker and causes your CD4 cells to be lower. This can affect the brain, heart, liver and kidneys, and make you sick.
• 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.
• In order to prevent you from getting sick or spreading the virus to partners, it’s important to prevent the virus from reproducing.

Let’s Review:
• What are the possible reasons for a high viral load?
• What can happen when your viral load is high?
• What would be good about a low viral load?
• How important do you think it is for your long-term health?
• What do you think happens if you don’t take medications regularly?

Remember to use non-judgmental and respectful language - do not blame or criticize:
“I am glad you came to get your viral load test results. Now we can help you work towards a low viral load.”
7. How are you taking ARVs?

» It can be hard to take ARVs every day.

» Together we will review how often you take your ARVs and see how it can improve.

Number of missed doses last month:

- < 2 Doses
- 2 - 4 Doses
- > 4 Doses
7. How are you taking ARVs?

KEY MESSAGES:

» It can be hard to take ARVs every day.

» Together we will review how often you take your ARVs and see how it can improve.

TALKING POINTS:

• Some people find it difficult to take ARVs every day.

• Many people have problems taking their pills at some point.

• 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?

Determing Adherence

1. Ask the patient to recall the last week and how many doses they 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 patient’s adherence is good, fair or poor.

Drug Pick-Up

• Review drug pick-up information if available or ask patient when the last pick-up was.

• Having delayed or inconsistent pick-ups may indicate problems with adherence.

Provider Instructions

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).

<table>
<thead>
<tr>
<th>Number of Missed doses per month</th>
<th>Adherence category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients taking once daily regimens</td>
<td></td>
</tr>
<tr>
<td>&lt; 2 doses</td>
<td>Good</td>
</tr>
<tr>
<td>2-4 doses</td>
<td>Fair</td>
</tr>
<tr>
<td>&gt;4 doses</td>
<td>Poor</td>
</tr>
<tr>
<td>Patients taking twice daily regimens</td>
<td></td>
</tr>
<tr>
<td>&lt;4 doses</td>
<td>Good</td>
</tr>
<tr>
<td>4-8 doses</td>
<td>Fair</td>
</tr>
<tr>
<td>&gt;8 doses</td>
<td>Poor</td>
</tr>
</tbody>
</table>

Adapted from WHO, 2012, Three interlinked patient monitoring systems
8. Why is it hard for you to take ARVs?

» Together, we will review the way you take ARVs.
KEY MESSAGES:
» Together, we will review the way you take ARVs.

8. Why is it hard for you to take ARVs? (1 of 3)

TALKING POINTS:
• It is great you have come back to get your results, by coming back, you are taking steps to improve your health.
• I’d like to talk to you more about any challenges you may be facing when taking 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.
• Can you recall and describe the circumstances around the last missed dose?

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Questions to assess barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td></td>
</tr>
<tr>
<td>Stigma and discrimination</td>
<td>Are you afraid that people will find out about your HIV?</td>
</tr>
<tr>
<td></td>
<td>Does that prevent you from coming to clinic or taking ARVs?</td>
</tr>
<tr>
<td>Knowledge deficit</td>
<td>Can you tell me the names of your ARVs?</td>
</tr>
<tr>
<td></td>
<td>What is your understanding of how you are supposed to take ARVs (e.g. what time of day, how much [if liquid], how many [if pills])?</td>
</tr>
<tr>
<td></td>
<td>What is your understanding of the purpose of the ARVs?</td>
</tr>
<tr>
<td>Side effects</td>
<td>Have the ARVs affected the way you feel?</td>
</tr>
<tr>
<td></td>
<td>Do you think the ARVs have made you feel ill in any way?</td>
</tr>
<tr>
<td></td>
<td>If yes, please describe what problems they cause (e.g. nausea, diarrhea, sleep disturbance).</td>
</tr>
<tr>
<td>Forgot</td>
<td>Have you ever forgotten or do you often forget to take ARVs?</td>
</tr>
<tr>
<td></td>
<td>Do you take them at a set time of day(s)?</td>
</tr>
<tr>
<td></td>
<td>What is your method of remembering/reminding yourself to take ARVs?</td>
</tr>
<tr>
<td>Feeling better</td>
<td>Do you take ARVs even when you are feeling well?</td>
</tr>
<tr>
<td>Physical illness</td>
<td>Have you had illnesses that have prevented you from taking ARVs?</td>
</tr>
<tr>
<td>Alcohol or drug use</td>
<td>Do you use alcohol?</td>
</tr>
<tr>
<td></td>
<td>Do you use drugs?</td>
</tr>
<tr>
<td></td>
<td>Do you feel this affects your ability to take ARVs?</td>
</tr>
<tr>
<td>Emotional issues/ depression</td>
<td>How is your mood in general?</td>
</tr>
<tr>
<td></td>
<td>Have you been feeling sad or confused?</td>
</tr>
<tr>
<td></td>
<td>If yes, has this affected your ability to take ARVs?</td>
</tr>
</tbody>
</table>

Explore with the patient barriers and challenges.

O: Open Ended Questions (Avoid questions that are answered as Yes/No), for example:
• What makes it difficult to take your ARVs every day?
• What have you already done to try and take your ARVs every day?
• What do you think is likely to happen if you keep taking your ARVs as you are now?

Document the specific barriers you identify with the patient on the Enhanced Adherence Plan Tool.
9. Why is it hard for you to take ARVs?

» Together, we will review the way you take ARVs.
9. Why is it hard for you to take ARVs? (2 of 3)

KEY MESSAGES:
» Together, we will review the way you take ARVs.

Provider Instructions

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

A: Affirmations, for example:
• I appreciate that you are able to be honest about the way you take your ARVs.
• You are clearly a resourceful person to manage so many challenges.
• You’ve really worked hard to take your medications despite the challenges.

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 taking ARVs (individual and household level barriers).

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Questions to assess barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual (continued)</td>
<td></td>
</tr>
<tr>
<td>Pill burden</td>
<td>Is the number of pills or amount of liquid a challenge for you?</td>
</tr>
<tr>
<td>Lost/ran out of pills</td>
<td>Have you ever lost or ran out of ARVs?</td>
</tr>
<tr>
<td>Transportation problems</td>
<td>Do you have difficulty getting to the health center to collect ARVs?</td>
</tr>
<tr>
<td></td>
<td>• If yes, what are the reasons? (e.g. long distance, expense, job)</td>
</tr>
<tr>
<td></td>
<td>• Do you know how to get to the clinic?</td>
</tr>
<tr>
<td></td>
<td>• What help do you need to get to the clinic?</td>
</tr>
<tr>
<td>Health beliefs</td>
<td>Do you believe that taking ARVs every day is beneficial for your health?</td>
</tr>
<tr>
<td></td>
<td>• What do you think is the best way to treat HIV?</td>
</tr>
<tr>
<td></td>
<td>• Have you tried other remedies for treating HIV?</td>
</tr>
<tr>
<td>Scheduling difficulty</td>
<td>Have you ever been too busy or faced a schedule change that has made it difficult to take ARVs?</td>
</tr>
<tr>
<td></td>
<td>• Who is responsible for making your appointments and keeping track of when they are?</td>
</tr>
<tr>
<td></td>
<td>• Do you feel like you know how to make an appointment? What number would you call? Who might you ask for?</td>
</tr>
<tr>
<td>Household</td>
<td></td>
</tr>
<tr>
<td>Share with others</td>
<td>Have you ever shared your ARVs with others?</td>
</tr>
<tr>
<td>Fear of disclosure</td>
<td>Have you disclosed your HIV status to your family? Your partner?</td>
</tr>
<tr>
<td>Family/partner relationships</td>
<td>Has your family or your partner been non-supportive or kept you from taking ARVs?</td>
</tr>
<tr>
<td>Inability to pay</td>
<td>Have clinic or other fees kept you from taking ARVs?</td>
</tr>
<tr>
<td>Food insecurity</td>
<td>Has a lack of adequate food ever been a problem for taking ARVs?</td>
</tr>
</tbody>
</table>
10. Why is it hard for you to take ARVs?

 Together we will review the way you take ARVs.
10. Why is it hard for you to take ARVs?

KEY MESSAGES:
» Together we will review the way you take ARVs.

TALKING POINTS:
• Let’s continue to explore any challenges you may be facing when taking ARVs (institutional and community level barriers).

Provider Instructions
Summarize what was learned from the patient about any specific barriers identified on this card using Reflective Listening or Summary Statements. For example:
• So you said feel angry when you think about taking your medicine and that makes it really hard.
• Let me see if I understand so far. Because of the distance you have to travel and long wait times at the clinic it’s hard to make all of your appointments.

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

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Questions to assess barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institutional/Community</td>
<td></td>
</tr>
<tr>
<td>Drug stock out</td>
<td>- Have you ever come to the health facility and found that there were no ARVs available?</td>
</tr>
<tr>
<td></td>
<td>- Have you ever come to the health facility and been given only a small supply of ARVs?</td>
</tr>
<tr>
<td>Long wait times</td>
<td>- Have you ever left the health facility before receiving your ARVs because of long wait times?</td>
</tr>
<tr>
<td>Political crisis/ war/ natural disaster</td>
<td>- Is it ever unsafe for you to pick up ARVs from the health facility?</td>
</tr>
</tbody>
</table>
11. Tips to improve taking ARVs

Together we will find ways to make taking ARVs better for you.
11. Tips to improve taking ARVs (1 of 3)

**KEY MESSAGES:**
» Together we will find ways to make taking ARVs better for you.

**TALKING POINTS:**
• I appreciate that you are able to be honest about challenges of taking ARVs.
• What I hear you saying is ... [summarize main challenges and barriers].
• Let's explore ways in which we can make it better for you to take ARVs.
• Do you have ideas how to make it better to take ARVs in response to each barrier we discussed?
• Missing more than 2-3 doses in a month can lead to medications not working well.

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Interventions to address barriers and improve adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individual</strong></td>
<td></td>
</tr>
<tr>
<td>Knowledge deficit</td>
<td>Individual counseling for basic HIV/ARV education</td>
</tr>
<tr>
<td></td>
<td>Group counseling/Peer support group</td>
</tr>
<tr>
<td></td>
<td>Written instructions</td>
</tr>
<tr>
<td>Side effects</td>
<td>Nausea → take with food, anti-emetic</td>
</tr>
<tr>
<td></td>
<td>Diarrhea → anti-diarrheal once infections ruled out,</td>
</tr>
<tr>
<td></td>
<td>hydration</td>
</tr>
<tr>
<td></td>
<td>Anxiety/Depression → take before bed</td>
</tr>
<tr>
<td></td>
<td>Headache → paracetamol, evaluate for meningitis</td>
</tr>
<tr>
<td></td>
<td>Fatigue → check Hgb, consider substitution if on AZT</td>
</tr>
<tr>
<td>Forgot</td>
<td>Medication organizer (e.g. pillbox)</td>
</tr>
<tr>
<td></td>
<td>Visual medication schedule (e.g., calendar, journal/log)</td>
</tr>
<tr>
<td></td>
<td>Reminder devices (e.g., phone calls, SMS, watch alarm)</td>
</tr>
<tr>
<td></td>
<td>Treatment buddy or supporter</td>
</tr>
<tr>
<td></td>
<td>Directly Observed Therapy</td>
</tr>
<tr>
<td></td>
<td>Announced pill count at next session</td>
</tr>
<tr>
<td></td>
<td>Take pills late, do not skip dose</td>
</tr>
<tr>
<td>Feeling better</td>
<td>Basic HIV/ARV education</td>
</tr>
<tr>
<td>Physical illness</td>
<td>Clinical care to address comorbidities</td>
</tr>
<tr>
<td></td>
<td>Directly Observed Therapy</td>
</tr>
<tr>
<td></td>
<td>Treatment buddy</td>
</tr>
<tr>
<td>Alcohol or drug use</td>
<td>Opioid substitution therapy</td>
</tr>
<tr>
<td></td>
<td>Directly Observed Therapy</td>
</tr>
<tr>
<td></td>
<td>Peer support group</td>
</tr>
<tr>
<td></td>
<td>Individual counseling</td>
</tr>
<tr>
<td>Depression</td>
<td>Screening for and management of depression</td>
</tr>
<tr>
<td></td>
<td>Individual counseling</td>
</tr>
<tr>
<td></td>
<td>Peer support group</td>
</tr>
<tr>
<td></td>
<td>Treatment buddy</td>
</tr>
</tbody>
</table>

*Provider Instructions*

After giving a tip, ask if it seems helpful or if there are questions:
• “How likely do you think it is that this will help you?”
• “How likely are you to try...?”
• “What questions do you have about...?”

Document interventions planned to address barriers identified by patient on the Enhanced Adherence Plan Tool.
12. Tips to improve taking ARVs

» Together we will find ways to make taking ARVs better for you.
### Key Messages:

» Together we will find ways to make taking ARVs better for you.

### Provider Instructions

Collaborate to come up with solutions, for example:

- “What have you already tried?”
- “You have thought a lot about this, what are other ways to solve this problem?”

### Document

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

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Interventions to address barriers and improve adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individual (continued)</strong></td>
<td></td>
</tr>
<tr>
<td>Pill burden</td>
<td>Change to fixed-dose combination or once daily dosing if possible</td>
</tr>
<tr>
<td>Lost or ran out of pills</td>
<td>Extra supply of pills</td>
</tr>
<tr>
<td></td>
<td>Drug pick-up group</td>
</tr>
<tr>
<td></td>
<td>Educate patient to alert facility if occurs</td>
</tr>
<tr>
<td>Transportation problems</td>
<td>Drug pick up group</td>
</tr>
<tr>
<td></td>
<td>Three month supply when feasible</td>
</tr>
<tr>
<td></td>
<td>ART group</td>
</tr>
<tr>
<td>Health beliefs</td>
<td>Individual counseling for basic HIV/ARV education</td>
</tr>
<tr>
<td></td>
<td>Group counseling</td>
</tr>
<tr>
<td></td>
<td>Peer support group</td>
</tr>
<tr>
<td>Scheduling difficulty</td>
<td>Education (e.g., combine with daily routine such as bedtime or brushing teeth)</td>
</tr>
<tr>
<td></td>
<td>Reminder devices (e.g., phone calls, SMS, watch alarm)</td>
</tr>
<tr>
<td></td>
<td>Treatment buddy</td>
</tr>
<tr>
<td></td>
<td>Three month supply when feasible</td>
</tr>
<tr>
<td></td>
<td>ART group</td>
</tr>
<tr>
<td>Household</td>
<td>Individual counseling for basic HIV/ARV education</td>
</tr>
<tr>
<td></td>
<td>Group counseling</td>
</tr>
<tr>
<td></td>
<td>Facilitate enrollment into care/PrEP for family members</td>
</tr>
<tr>
<td>Fear of disclosure</td>
<td>Individual counseling</td>
</tr>
<tr>
<td></td>
<td>Group counseling</td>
</tr>
<tr>
<td></td>
<td>Peer support group</td>
</tr>
<tr>
<td></td>
<td>Treatment buddy</td>
</tr>
<tr>
<td></td>
<td>Unmarked pill bottle</td>
</tr>
<tr>
<td></td>
<td>ART group</td>
</tr>
<tr>
<td></td>
<td>Couples counseling and testing</td>
</tr>
<tr>
<td>Family/partner relationships</td>
<td>Group counseling</td>
</tr>
<tr>
<td>Inability to pay</td>
<td>Refer to social worker, peer worker, or NGO</td>
</tr>
<tr>
<td>Food insecurity</td>
<td>Refer to social worker, peer worker, or NGO</td>
</tr>
</tbody>
</table>
13. Tips to improve taking ARVs

» Together we will find ways to make taking ARVs better for you.
13. Tips to improve taking ARVs (3 of 3)

KEY MESSAGES:

» Together we will find ways to make taking ARVs better for you.

Document

- Document interventions and any needed referrals on the Enhanced Adherence Plan Tool.
- Summarize results and plan made. Have the patient repeat back the plan.
- Tell the patient the next follow-up date and whether it is for another adherence session or for repeat viral load test.

Provider Instructions

Offer suggestions to overcome specific barriers that have been identified.

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Interventions to address barriers and improve adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institutional/Community</td>
<td>NURSE-LED OR COMMUNITY-BASED CARE</td>
</tr>
<tr>
<td>Long wait times</td>
<td>THREE MONTH SUPPLY WHERE FEASIBLE ART GROUP</td>
</tr>
<tr>
<td>Stigma and discrimination</td>
<td>INDIVIDUAL COUNSELING</td>
</tr>
<tr>
<td></td>
<td>GROUP COUNSELING</td>
</tr>
<tr>
<td></td>
<td>PEER SUPPORT GROUP</td>
</tr>
<tr>
<td></td>
<td>ART GROUP</td>
</tr>
<tr>
<td>Political crisis/war/natural disaster</td>
<td>INDIVIDUAL COUNSELING</td>
</tr>
<tr>
<td></td>
<td>CASE MANAGEMENT</td>
</tr>
</tbody>
</table>
14. Additional help to take ARVs

» Together we will find ways to make taking ARVs better for you.
14. Additional help to take ARVs

**KEY MESSAGES:**
» Together we will find ways to make taking ARVs better for you.

**TALKING POINTS:**

Let’s look closer at a few of the common barriers to taking ARVs.

- Of the areas we discussed, what is the biggest problem you have taking ARVs?
- Here’s what I’ve heard you say. Let me know if I understand correctly. [*Reflect back on identified challenges*]
  » Go to card 15 (labeled Remembering to take ARVs) for “forgets”
  » Go to card 16 (labeled Understanding your ARVs) for “knowledge”
  » Go to card 17 (labeled Making it easier) for “side effects,” “emotional issues,” or “pill burden”
  » Go to card 18 (labeled Tips for pill swallowing) for “difficulty swallowing pills”
  » Go to card 19 (labeled Who to tell and why) for “disclosure”
  » **FOR ALL ADOLESCENTS** go to card 20 (labeled Taking charge of your ARVs) after discussing other interventions.
15. Remembering to take ARVs

» Always remembering to take ARVs can be difficult.

» Missing ARV doses can be a reason for high viral load and can harm you.
15. Remembering to take ARVs

KEY MESSAGES:
» Always remembering to take ARVs can be difficult.
» Missing ARV doses can be a reason for high viral load and can harm you.

TALKING POINTS:
• What have you already tried to help you remember?
• Let me make sure I understand. What I hear you saying is [circumstance for missing doses]. Here are some things that others have found helpful:
  » Put ARVs somewhere easy to remember, near something that you use every day, and keep a bottle of water there if needed.
  » Set an alarm on your phone to remind you to take your ARVs.
    * Help the adolescent put a reminder in the phone and show them how to do this if they don’t know.
  » Carry ARVs with you so if you forget before leaving for the day, you have a spare.
  » Use pillboxes and a calendar to mark and keep track of when medications are taken for the day.
  » Ask for extra medications if gaps between refills is a problem.
  » Ask: “Is there someone who can help you remember to take your ARVs?”

Let’s Review:
Remembering to take ARVs can be challenging, I’d like to check with you about a few things we discussed.
• What changes do you plan to make to help you remember to take your ARVs?
• How do you track whether you have taken your medications?
16. Understanding your ARVs

To be successful with ARVs it is important that you learn how they work, how best to take them daily, and how to avoid or manage side effects.
16. Understanding your ARVs

**KEY MESSAGES:**

» To be successful with ARVs it is important that you learn how they work, how best to take them daily, and how to avoid or manage side effects.

**TALKING POINTS:**

Which area is the patient having the most difficulty with?

» **Names and Frequency of Medications:**
  » Provide education and fact sheets.

» **How Medications Work:**
  » Review earlier cards from prior visits or answer questions.

» **Health Beliefs**
  » Instruct patient to take ARVs whether they feel healthy or sick, unless otherwise specified by a doctor.
  » Probe for specific beliefs about ARVs and health (e.g. Have you heard others say negative things about ARVs? Are there other remedies that you think are better than ARVs?)

Let's Review:

- Let's go over these instructions again to see if you have any questions.
- Can you tell me how you understand what ARVs are and how you are supposed to take them, and tips to avoid side effects?
- Provide patient with written resources if available.

**Document**

Document planned interventions to address barriers identified by patient on the Enhanced Adherence Plan Tool.
Taking ARVs is difficult because all the good things come in “the future”.

Sometimes there are things that are tough about taking ARVs that happen today—like side effects.

Let’s discuss ways to make taking ARVs better for you.
17. Making it easier

KEY MESSAGES:

» Taking ARVs is difficult because all the good things come in “the future”.

» Sometimes there are things that are tough about taking ARVs that happen today—like side effects.

» Let’s discuss ways to make taking ARVs better for you.

TALKING POINTS:

Managing Side Effects:
- Take with food (nausea/headache).
- Take at night (drowsiness/mood).

Managing Emotions:
- Many people feel angry, sad, or afraid of being HIV+.
- Feeling upset by ARVs can make it hard to take them every day. Sometimes when taking a dose, people have thoughts like “I hate that I have to take this.” Does this happen to you?

Difficulty Taking Pills:
- Eat strong, pleasant-flavored food immediately after dose to mask taste (like a mint or sweet candy).
- Practice pill swallowing training tips (see card 18).
- Put pill in a small amount of a soft food (like honey or jam) on a spoon, and take medicine from the spoon.

Other Tips:
- Pair taking medications with something happy or good.
- Take medications with a treat.
- Think thoughts like “I’m keeping myself healthy” or “I’m taking care of my body”.
- Talk and share with trusted friends and/or family to get support.

Document planned interventions to address barriers identified by patient on the Enhanced Adherence Plan Tool.
18. Tips for pill swallowing

Place the pill on the back of your tongue.

Use a water bottle with a small opening that you can cover with your mouth.

Tip your head back as far as you can while swallowing the pill and water.

Tipping your head back makes swallowing much easier.

» Using a water bottle is a good way to help swallow pills.
18. Tips for pill swallowing

KEY MESSAGES:

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

» Place the pill on the back of your tongue.

» Use a water bottle with a small opening that you can cover with your mouth.

» Tip your head back as far as you can while swallowing the pill and water.

» Tipping your head back makes swallowing much easier.
19. Who and why to tell

» Sharing your status with someone you trust can help you take your ARVs every day.
19. Who to tell and why

KEY MESSAGES:

» Sharing your status with someone you trust can help you take your ARVs every day.

TALKING POINTS:

Ways to protect privacy:
• Use an unmarked pill bottle.
• Use pill boxes rather than bottles.
• Brainstorm places where the patient can keep ARVs out of the sight of others, but that are easily visible/accessible to the patient.

Discuss ways to decide who to share their diagnosis with and how to share:
• What characteristics do you think make a good choice for someone to share your status?
• What are benefits of someone knowing your status?
• How do you decide whether you can trust someone?
• Are you concerned that harm might come to you if you disclose your HIV status?

If patient is in a relationship:
• What might be beneficial for your partner if you were taking your ARVs every day?
• How do you think your partner might support you to take your ARVs?

Document planned interventions to address barriers identified by patient on the Enhanced Adherence Plan Tool.
20. Taking charge of your ARVs

» By being in charge of your ARVs, you are setting yourself up to lead a healthy life.

» Most people still find support helpful, even if you are in charge.
20. Taking charge of your ARVs

**KEY MESSAGES:**

» By being in charge of your ARVs, you are setting yourself up to lead a healthy life.

» Most people still find support helpful, even if you are in charge.

**TALKING POINTS:**

- You are the only one living in your body—it is your job to make sure you take your ARVs to protect it.
- Many people have support in taking ARVs, but ultimately it is your job.
- Where are you living? Who lives with you? How might this affect you taking your ARVs?
- Who currently helps you take your medications? How do you think that might change in the future?
- Who knows that you are HIV+?
- Who might be a good source of support for you as you manage your HIV?
- I hear you saying you have lots of changes in your life right now, how do you think this might affect you taking ARVs?
- It sounds like you have a busy schedule! I hear it is important to you to stay healthy to keep this up. How do you think taking your ARVs can fit into your schedule?

**Let’s Review:**

- Do you think ARVs will help you?
- Are you taking any other treatments for your HIV?
- Are you seeking help from anyone outside of this clinic for your HIV?
21. Follow up on how you are taking ARVs

Together we’ll review the plan made last time to see how you are taking ARVs.

Number of missed doses last month:

- < 2 Doses
- 2–4 Doses
- > 4 Doses
21. Follow up on how you are taking ARVs

KEY MESSAGES:
» Together we'll review the plan made last time to see how you are taking ARVs.

Provider Instructions

- For patient whose prior viral load was high, viral load will be repeated after three months of “good adherence.” Advise care recipient of when repeat viral load will be done.
- If adherence is fair or poor, continue monthly adherence sessions using cards in this flip chart and additional pages of the Enhanced Adherence Treatment Plan tool until the adherence is good.

TALKING POINTS:
- Last time we met, we planned ________ (interventions decided upon at last adherence session) to help you take ARVs.
  » How has that been going?
  » Are there any new challenges taking ARVs?
  » Can you recall and describe the circumstances around the last missed dose during the passed month?
- 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?
- 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 take your ARVs?
  » Use adherence assessment tables on prior cards as needed to look for new barriers.

<table>
<thead>
<tr>
<th>Number of Missed doses per month</th>
<th>Adherence category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients taking once daily regimens</td>
<td></td>
</tr>
<tr>
<td>&lt; 2 doses</td>
<td>Good</td>
</tr>
<tr>
<td>2-4 doses</td>
<td>Fair</td>
</tr>
<tr>
<td>&gt;4 doses</td>
<td>Poor</td>
</tr>
<tr>
<td>Patients taking twice daily regimens</td>
<td></td>
</tr>
<tr>
<td>&lt;4 doses</td>
<td>Good</td>
</tr>
<tr>
<td>4-8 doses</td>
<td>Fair</td>
</tr>
<tr>
<td>&gt;8 doses</td>
<td>Poor</td>
</tr>
</tbody>
</table>

Adapted from WHO, 2012, Three interlinked patient monitoring systems

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.
22. You’ve successfully reduced your viral load

- The repeat viral load is low!
- You have taken your ARVs consistently, the medications are working, and you are keeping yourself well.
KEY MESSAGES:
» You have taken your ARVs consistently, the ARVs are working, and you are keeping yourself well.

Let's Review:
Let's briefly review what a low viral load means and plans for continuing to take your ARVs:
• In your own words, what does having a low viral load mean?
• Why is it important to continue ARVs?
• What has helped you remember to take your ARVs?
• Are there new things or do you expect there to be things that will make it hard at times to take your ARVs?

TALKING POINTS:
• A low viral load (less than 1000) [insert patient's result here] is a sign that you are taking ARVs well and the medications are working.
• Your changes in _______ have been successful and you are getting the ARVs you need to stay well.
• It is important that you continue to take your ARVs every day to keep HIV from making more virus and to stay healthy.
• It’s 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 six months if there are no new problems or problems taking ARVs.
• Please let your provider know if there are any problems taking ARVs in the future, so that he/she can help you to address them.

Document
• Document results of repeat viral load on Enhanced Adherence Plan Tool.

Provider Instructions
• Use cards 22 & 23 for patients whose repeat viral load result is ≤ 1,000.
• Can also review cards cards 2 & 3 for basic viral load information.
23. Keeping your virus low

» Your virus is low so you are protecting your health, partners, and brain.

» It is hard to continue taking ARVs, even with all these benefits—this is especially true when so many things in your life are changing.
23. Keeping your virus low

**KEY MESSAGES:**

» Your virus is low so you are protecting your health, partners, and brain.

» It is hard to continue taking ARVs, even with all these benefits—this is especially true when so many things in your life are changing.

**Let’s Review:**

- Do you think ARVs will help you?
- Are you taking any other treatments for your HIV?
- Are you seeking help from anyone outside of this clinic for your HIV?

**TALKING POINTS:**

- Does anyone help you take your ARVs? Tell me how that works.
- How do you think that might change in the future?
- Who knows that you are HIV+?
- Who might be a good source of support for you as you manage your HIV?
- Are there changes going on in your life?
- How do you think [those changes] may affect you taking ARVs?

**Additional Tips:**

- Put ARVs somewhere easy to remember, near something that you use every day, and keep a bottle of water there if needed.
- Set an alarm on your phone to remind you to take ARVs.
- Carry ARVs with you so if you forget before leaving for the day, you have a spare.
- Use pillboxes and a calendar to mark and keep track of when medications are taken for the day.

**Let’s Review:**

- Do you think ARVs will help you?
- Are you taking any other treatments for your HIV?
- Are you seeking help from anyone outside of this clinic for your HIV?

**Provider Instructions**

Screen for other health beliefs or difficulty with disclosure/privacy. Review card 16 (Understanding your ARVs), card 19 (Who to tell and why), or card 20 (Taking charge of your ARVs) in these areas as helpful.
24. ARVs are not working well

» It is likely that the virus is resistant, meaning that it has changed and ARVs are no longer working.

» Changing ARVs is recommended.
**KEY MESSAGES:**

» It is likely that the virus is resistant, meaning that it has changed and ARVs are no longer working.

» Changing ARVs is recommended.

**TALKING POINTS:**

- I appreciate the effort that it has taken to get to good adherence.
- Even though you are taking the ARVS consistently, your repeat viral load result is still high.
- It is likely that ARVs are not working well due to the virus being resistant.
- I understand this might feel disappointing.
- We expect that now that you are able to take ARVs every day, the new medication will reduce the viral load and keep you well.
- We recommend to change ARVs to ____________.
  » Provide detail instructions on new regimen.
  » Discuss possible side effects and how to avoid/manage.
  » Provide written instructions.
- It is extremely important to take your new ARVs properly.
- Please let a provider know if you have any trouble so that you can get assistance.
- If you start other medications, such as TB medications, please let your provider know right away.
- Your next appointment is ____________.

**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?
- In your own words, what does resistance mean?
- What are the new ARVs and how will you take them?
- What has helped you to take your ARVs? It will be important to do these things now too to take new ARVs exactly as prescribed.
- When is your next appointment?
- If you have any problems taking your ARVs before then, come to the clinic.
- We will check your viral load again in _____ months to see how the new ARVs are working.
- Do you have questions?

**Document**

Document new ARVs on the Enhanced Adherence Plan Tool.

**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 after ARV switch, use the cards beginning with “How Are You Taking Your ARVs?” (Card 7) to assess adherence to new regimen and provide counseling. Can also review cards 2 & 3 for basic viral load information.
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 icap.columbia.edu