

Making Sure Your HIV Care is the Best It Can Be

A Consumer Quality of Care Training Workshop

New York State Department of Health AIDS Institute
Health Resources and Services Administration HIV/AIDS Bureau



NATIONAL QUALITY CENTER

Making Sure Your HIV Care is the Best It Can Be

A Consumer Quality of Care Training Workshop Curriculum Guide for Workshop Facilitators

Developed by the
New York Department of Health
AIDS Institute
National Quality Center

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Introduction

"Making Sure Your HIV Care is the Best It Can Be" was developed to assist patient educators in the delivery of consumer training workshops. Its intent is to affirm and support the HIV health care consumer's role in treatment decision-making; to acknowledge both the rational/logical components and the personal/affective components of health care decisions; to introduce the consumer to the concepts of quality of care assessment and quality improvement.

This curriculum is designed to empower and encourage consumers to use their self-advocacy skills to gather disease-specific and quality of care information for themselves from their providers and other available resources.

Curriculum Development

The development of the Making Sure Your HIV Care is the Best It Can Be was prompted by a needs assessment process which included consumer focus groups conducted throughout the state and interviews with health care providers, key informants, and consumer advocates. In addition, a review of the relevant literature on the use of health care quality "report cards," patient-satisfaction assessment, physician/patient communication, health care decision-making, HIV advocacy training methods, functional health literacy, and the relationship between these factors and health status in people with HIV infection was conducted for the purpose of establishing a set of "best practices" in the design of HIV health care consumer-learning strategies.

The curriculum was pilot-tested twice with a diverse population of HIV health care consumers before it was made available in 2002. Since then hundreds of consumers have participated in this training across the nation to learn more about empowerment and self-advocacy. In addition to the training materials, background information, including the literature search that was conducted as part of this project can be downloaded from our website at www.hivguidelines.org.

Design of the Curriculum

The modular curriculum is highly interactive and requires little or no reading on the part of participants. Module One establishes the expectations of the workshop and introduces the participants to the group processes used throughout the workshop. Module Two introduces participants to the concept of quality of care, the use of both personal and clinical indicators of quality, and the quality improvement process. Module Three provides several opportunities for participants to combine their learning with skills development in the practice of self-advocacy techniques.

Each module is divided into a series of short, interactive “Activities” through which understandings and skills are developed. Facilitator notes and support materials, instructions for the preparation of participant training materials, templates for all written training materials, and all take-home materials are provided in each modular activity section.

The curriculum has been designed for delivery in a two and one-half hour workshop. Depending upon the training experience of the facilitator and the availability of materials, preparation for each training may require about one hour.

Workshop Facilitation

The curriculum is scripted so that facilitators, regardless of their HIV-related knowledge and their experience in consumer education and training, can deliver trainings of consistent content and quality. Of course, both HIV knowledge and training experience would be an asset. Experienced peer educators may be able to provide a level of insight that would enhance the quality of the training they deliver, though this is not considered to be a necessary qualification for facilitators. HIV case managers, treatment educators, patient educators, and patient advocates are likely to have both the skills and the experience necessary to provide high quality training workshop facilitation.

Expected Outcomes

It is expected that as a result of the consumer training workshop, participants will be able to:

- Identify what is most important to them in their HIV health care.
- Judge the quality of the HIV health care they are receiving.
- Appreciate what other people, including HIV specialists consider the most important qualities of HIV care.
- Develop an action plan that will help them improve the quality of the HIV care they receive.

Use of the Facilitators' Curriculum Guide

Modular Curriculum

The curriculum is divided into three Modules. It is intended that training workshops be conducted following the sequence of modules as they appear in the Guide. Given time constraints or preference in working with some consumer groups, it may be appropriate to conduct the training workshop as a sequential series of sessions rather than as a single training workshop covering all of the Modules.

Goals and Objectives have been developed for each of the Modules, and each Module consists of a number of Activities. The Strategies and Methods used in the Module are described, as well as Materials Needed, Preparation Needed, and Time Needed for completion of the Module curriculum.

In preparation for conducting a training workshop, facilitators may follow the directions found at the beginning of the Modules. At the beginning of each Activity there is a Rationale for that Activity followed by a listing of the Materials Needed for that Activity. It is recommended that all materials, including pre-labeled newsprint sheets and copies of all training handouts, be prepared in advance of the workshop since preparation time is lengthy and there is no time during the workshop to do preparation for the Activities. Preparation for conducting a training workshop may take 45-60 minutes.

The time estimate (Time Needed) found at the beginning of each Activity is based upon the average time required for completion of the Activity in the pilot tests of the curriculum. The time may vary with the experience of the facilitator and from one workshop to another. The estimated time for the delivery of the full curriculum is two and one half hours.

Scripted Procedure

The procedure to be followed in each Activity is described in detail in the curriculum. The Guide is intended for use by facilitators with varying degrees of training experience. The level of detail provided is included to assist facilitators with less experience in conducting consumer training workshops. The numbered directions to the facilitator were derived from the pilot test experience. The scripted text found in each Activity is what is intended to be spoken by the Facilitator. While some variation in language for clarity of presentation or to enhance the comfort level of the facilitator is encouraged, experience in pilot testing of the curriculum has shown that significant deviations from the scripted text are potentially time-consuming and often lead the discussion away from the objectives of the workshop. A common example is volunteering information about either the course of HIV infection or treatments. The facilitator might quickly find him or herself in the middle of a discussion beyond the limits of his or her competency or knowledge, being asked to make judgments about treatments, side effects of therapy, or providers, or led into areas very much unrelated to quality of care. More to the point, however, is that one of

the most important goals of the training is to help participants find ways to ask such questions of their providers. When asked questions about treatments, for example, that is a perfect opportunity for the facilitator to say, “That’s a very good question, and one you should ask your doctor about. I guarantee that by the end of this workshop you will have a plan to do that.”

Another potential problem in the workshop is the volunteering of personal experience information by either facilitator or participant. Participants often will use the discussion in an Activity as an opportunity to “tell their story.” Facilitators must judge the relevance of that information to the whole group and to the objectives of the workshop and, when necessary, sensitively but clearly bring the discussion back to the task of the Activity. Similarly, facilitators should refrain from using the workshop to share their own personal experiences. The curriculum is designed to focus the attention of the Activities on the needs, understandings, strengths, problems, and skills-acquisition of the participants. It is the facilitator’s responsibility to maintain that focus.

Notes to Facilitators

Notes to facilitators can be found in Activity sections. These notes are provided to explain procedures in more detail than can be found in the Procedures section and to relate either background information or suggestions based upon pilot test experience. These notes are not intended to be read to the participants.

The literacy level of the *Curriculum Guide* was selected to make it understandable by the majority of participants. Facilitators with knowledge and experience in working with the participants in a training workshop should adjust the language level to that which best suits the participants.

Workshop Evaluation

A workshop evaluation tool is provided for use in post-program assessment of participant satisfaction. It is recommended that participants be asked to fill out an evaluation as the last part of the closing activity of Module Three. In addition to their potential value to workshop facilitators, results of the evaluation may assist in the modification of the curriculum as well as in the creation of additional curricula to meet the changing needs of consumers.

Ordering Information

For additional free copies of this Curriculum Guide and other consumer materials, please contact the New York State Department of Health AIDS Institute Quality of Care Program by telephone at (212) 417 4730.

Electronic copies of the Making Sure Your HIV Care is the Best It Can Be guide and the literature review of key articles related to this important topic are also available online at www.hivguidelines.org.

Module One:

What To Expect From The Workshop

Goals

The Goals of this module are to:

- Introduce group members to one another, establish guidelines, and build group cohesion, comfort, and trust.
- Introduce participants to the goals of the workshop and to create a sense of personal ownership of the workshop processes.
- Permit each participant to speak and to express their thoughts in a supportive, potentially low-anxiety environment before engaging in broader group activities.

Objectives

After completing this module, participants will be able to:

- Identify the value of participating in the workshop.
- Describe the purpose of the workshop.
- Identify the value of interactive group activities in the learning process.
- Describe a range of expectations that participants have for the workshop experience.

Strategies and Methods

- Discussion Circle
- Sharing in Pairs

Materials Needed

- Clock
- Pre-labeled newsprint
- Markers
- Masking tape
- Name tags

Preparation Needed

1. Arrange chairs in a circle.
2. Hang newsprint with workshop title, facilitator's name, and time of the workshop.
3. Label newsprint with "Expectations."
4. Fill out a name tag with the name of each participant as they come in and ask them to put it on.

Time needed:

20 minutes

ACTIVITY	TIME
A. Workshop Welcome And Overview	5 minutes
B. Sharing Expectations	15 minutes

Activity A:

Workshop Welcome and Overview

Rationale:

Welcoming the participants and providing them with a general overview of the workshop can serve to foster ownership of the workshop process and outcomes. This activity tells the participants that this workshop is about them and is designed to meet their needs.

Materials Needed:

One pre-labeled newsprint:

“Making Sure Your HIV Care is the Best it Can Be”

Facilitator’s Name: _____

Workshop Time: _____

Time Needed:

5 minutes

Procedure

1. Arrange the participants’ chairs into a circle.
2. Hang the newsprint with workshop title, facilitator’s name, and workshop time in a visible location in the room.
3. Welcome the group and provide an overview of the workshop by saying:

Hello, my name is _____ and I am the facilitator for today’s workshop entitled: “Making Sure Your HIV Care is the Best it Can Be.”

I know that it may have been challenging for some of you to make the necessary arrangements to be here, but I believe that you will find today a good investment in your health.

This workshop is scheduled to run for two and one-half hours, from: _____ to _____ .

Today we will talk about your HIV health care. We will learn ways to evaluate the quality of the care you are getting and we will discover ways to improve the quality of your care to meet your needs.

This workshop was designed because we believe that you have a right to the highest quality care. And it was designed to help you make decisions about what to do if you think that you are not getting the highest quality care.

A lot of what we will do in the workshop will be in large and small group activities rather than in lectures with me doing all of the talking. As many of you will probably agree, people often learn best by “doing” instead of listening.

Are there any questions about the workshop before we begin with our first activity?

4. Answer any questions about time, bathrooms, telephone, etc., but explain that all other questions about the workshop will be answered in the later activities.
5. Establish the “ground rules” for workshop participation. You should use the following as a guide. Add or delete ground rules based upon your preference and experience.

6. Say the following:

There are just a few ground rules that I will ask that we all agree to before we begin.

There are no right or wrong answers to most questions about health care. We all may have different views on what we will be talking about today. It is important to respect and, hopefully, learn from our differences.

Only one person will speak at a time, and everyone will have an opportunity to be heard.

Much of what we will do today involves group participation. If, at any time, you don't feel like participating, that decision is up to you and no one will require you to do so.

We have a lot to cover in the workshop. I will try to keep us on time. So, please don't be offended if I interrupt you and ask the group to move on. We can talk more after the workshop is over if you'd like.

There will be a 10-minute break about half-way through the workshop.

Do you have any other suggestions for ground rules?
Let's have a good time today.

Facilitator's Note

Be aware of participants with special needs. Participants in wheelchairs or who may have difficulty walking, or who are blind or deaf, may require alternative arrangements for finding and working in pairs. In addition, some participants may need help in pairing off to form the partner groups.

Activity B:

Sharing Expectations

Rationale:

This activity serves two purposes: first, it will help to “break the ice” and to provide a structure in which people can get to meet one another and feel more comfortable within the group. Secondly, it will help participants to set realistic personal goals and expectations for the workshop.

Materials Needed:

Two or more pre-labeled newsprint sheets: “Expectations”
One pre-labeled newsprint:

“Workshop Objectives”

- Identify what is most important to you in your HIV health care.
- Judge the quality of the HIV health care you are receiving now.
- Hear what other people think are the most important qualities of HIV care.
- Describe some good measures to assess of quality HIV ambulatory care.
- Make a list of action steps that will help improve the quality of HIV care you receive.

Time Needed:

15 Minutes

Procedure:

1. Explain the procedure to the group:

In our first group activity we will work together to identify your personal expectations for the workshop.

In a moment I will ask you to partner with the person sitting next to you.

When you do, introduce yourselves to one another and then ask each other, “What is the one thing that you want to get out of this workshop?”

I will give you a couple of minutes to do that.

When the time is up I will ask you to introduce your partner to the group and tell what his/her expectation is. Please begin now.

2. After about five minutes, tell the participants:

Time is up. Let’s all come back as a group. Let’s talk about what you have learned about your partner.

Facilitator's Note

It is important to be clear about those expectations that you know will not be covered in the workshop, suggesting, if possible, other ways those expectations might be met. For example, there may be an expectation that treatment or medication information will be discussed. Let the participants know that while this will not be covered, they will learn how to talk to their doctors about whatever questions they have or information they need.

This activity is a good opportunity for you to assess the literacy level of the group you are working with (if it is not a group you are already familiar with). As you list the expectations of the group you can ask individuals for further explanation and generally how well-understood selected terms are. It is important to adjust the level of language used to enable all participants to benefit from the workshop.

3. When the group has settled and you have their attention, pick one person to start and ask:

Please introduce your partner and tell us what his/her expectations are for the workshop.

4. When participants tell the group what expectations they heard, write these on the newsprint. (For example: “To learn about other places I might go for HIV care.” Or, “How to be sure my doctor is doing all the right lab tests.”)
5. Go around the room and ask for a response from each participant. When finished, review the list with the group, saying:

Thank you all for paying such close attention to what your partners said. Let’s go over the list of expectations together.

6. Go over each expectation, asking for clarification where necessary, and help participants understand how the workshop may meet them. Put a check mark next to each expectation that you believe will be covered in the workshop

7. When finished with the list of expectations, put up the newsprint list of workshop objectives and say:

Thank you for your thoughtful participation in this important activity. With your help today, by the end of the workshop each of you will be able to:

- Identify what is most important to you in your HIV health care.
- Judge the quality of the HIV health care you are receiving now.
- Hear what other people think are the most important qualities of HIV care.
- Make a list of action steps that will help improve the quality of HIV care you receive.

8. When finished with the list of objectives, say:

Are there any questions about the goals we have set?

In our next activity we will start the work of looking at how you feel about the quality of your HIV care.

Module Two:

Assessing Quality of Care

Goals

The goals of this module are to:

- Encourage participants to evaluate the degree of their satisfaction with their HIV care.
- Explore their attitudes about factors that contribute to quality of care.
- Discuss how the quality of the HIV medical care can be evaluated.

Objectives

After completing this module, participants will be able to:

- Rank the factors that contribute to the quality of their HIV care.
- Identify the factors important in selecting health care providers.
- Discuss their attitudes about quality of care factors.
- Identify four clinical indicators of HIV care quality.

Strategies/Methods

Individual Work

Consensus Group Work

Mini-lecture

Clinical Indicators Personal Assessment Activity

Materials Needed

Tape

Markers

Pens/Pencils

Continuum of Satisfaction Signs (1-5)

Quality of Care Consensus Activity Worksheet

Your Personal Quality of Care Worksheet

Pre-labeled newsprint (for details see below in Preparation Needed)

Preparation Needed:

1. Pre-label newsprint: Continuum of Satisfaction.
2. Hang Health Care Continuum of Satisfaction Signs.
3. Arrange chairs in a semi-circle and place newsprint in a visible location.
4. Label newsprint with: "Self-Advocacy Steps."
 - Identify what your health care needs are.
 - Identify obstacles to getting your needs met.
 - Develop strategies to use your resources and overcome barriers.
 - Put your plan into place.
5. Make copies of Personal Assessment Worksheet for each participant.

Time Needed:

50 minutes

ACTIVITY	TIME
A. Quality of Care Information	5 minutes
B. The HIV Satisfaction Continuum	15 minutes
C. Consensus Activity: Force Ranking of Care Factors	15 minutes
D. Roadmap to the Consumer's Guide	15 minutes
E. Your Personal Quality of Care Factors	5 minutes

Activity A:

Quality of Care Information

Rationale:

Providing an explanation of "Quality of Care" and a framework for this session increases comfort among the participants and focuses their attention on the quality of their HIV care.

Materials Needed:

Hang newsprint: Self-Advocacy Steps

Time Needed:

5 minutes

Procedure:

1. Explain the following to the group:

As consumers of HIV health care, you may not always be happy with the care you receive. Sometimes you may be happy with your health care and your provider. At other times you may be unhappy with your health care or provider. It is important that you learn how to become your own HIV health care advocate so that you can become happy with your care more of the time. Some of you already know how to do this. Everyone can learn how.

Self-Advocacy involves four stages. *[Read these from the newsprint.]* The first stage is identifying the health problem that concern you and what factors are important to you in your health care. The second stage is identifying obstacles that you face in getting health care that meets your needs. The third stage is developing strategies to overcome the barriers and the fourth stage is implementing a plan that helps you to reach your goal.

You will learn how to move through all four of these stages during this program. For the next hour, we will focus specifically on how you rate your care and how quality of HIV ambulatory care can be measured. You will also learn how to design your own quality of care checklist.

2. Ask the participants if they have any questions so far.
3. Add the following:

You can be your own advocate. As a consumer you deserve to be satisfied with your health care. Let's spend the next hour concentrating on how to rate your care and how to become an advocate for yourself.

Facilitator's Note

Some of the participants may find the term “satisfaction” vague and they may ask for clarification. They may want you to tell them what aspect of care you want them to rate. Tell them to use whatever definition they want. While each individual may have a different idea about what satisfies them about their care, the group will work collaboratively to develop a broad understanding of the quality care.

Activity B:

The HIV Care Satisfaction Continuum

Rationale:

Providing a visual rating continuum will allow participants to see that others are satisfied with their care and help them to explore their own attitudes about their HIV health care.

Materials Needed:

HIV Satisfaction Numbered Continuum Signs (1-5)

Tape

Newsprint pre-labeled: "Continuum of Satisfaction"

Markers

Time Needed:

15 minutes

Procedure:

1. Hang HIV Care Satisfaction Continuum signs (1, 2, 3, 4, and 5) along the wall in a straight line. Space the numbers far enough apart so that each of the participants can find a place to stand near one of the numbers. Pre-label newsprint "The Continuum of Satisfaction" and hang on an easel stand or a wall that is not being used for the continuum.
2. Say the following:

This activity is a moving activity called "The Continuum of Satisfaction," so be ready to move around. In this activity, you will have the chance to decide if you are unhappy (point to card number 1), in between (point to cards 2-4) or very satisfied (point to card number 5) with your HIV care. "1" is the lowest possible rating and equals being unhappy with your care; "5" is the highest rating and equals being totally satisfied with your care. I want you to think for a minute about the quality of your HIV care and then stand near the number that best describes your satisfaction with your care. Remember that this activity is about how you perceive your care. You can stand anywhere between 1 and 5.

3. Allow the participants a few moments to find a place to stand near a sign.

Facilitator's Note

When reporting back from the Satisfaction Continuum start at the #1 end and move along the continuum, It is not necessary, particularly in the interest of saving time, to ask each participant to explain why they chose to stand where they did, but be sure to ask representatives from each area along the continuum.

4. Say the following to the group:

Let's pause for a minute to see where people are standing. As you can see, people are standing near different numbers. There is diversity in how people rate their HIV care. This means that people have different feelings or attitudes about their health care. Some people are satisfied, others are not.

[NOTE: Pause for a moment so that the group can take notice of the difference within the group.]

Look around and see if there are other people near your number or standing next to you at the next number. Talk to one another about why you have decided to stand where you did.

5. Allow the participants a few minutes to discuss with each other the reasons that they are standing under the number.
6. Ask the participants the following discussion questions:

What made you stand where you are standing?

7. Have the participants take their seats. Say the following:

There were several important factors that influenced how you rated your quality of care. Let's summarize what they were.

8. Summarize the most important reasons people gave for being satisfied or dissatisfied with their HIV care. Write these on the newsprint pre-labeled "The Continuum of Satisfaction."
9. Then ask the following question:

Can you think of any other factors that might influence how you rate your quality of care?

10. Elicit responses from several participants in the group and add them to the list.
11. Summarize by saying:

As you can see, there are many factors that determine how you rate your HIV care. Whether you have a long list of factors or a short list, the important thing is to have a list.

This will help you to focus on what is important to you in your health care. In the next activity we will see if we can be more specific about the factors that help you to determine your quality of care.

Facilitator's Note

The “Quality of Health Care Checklist Consensus Activity” and the personal checklist used later in this module, “Your Personal Quality of Health Care Checklist,” can be modified and updated as necessary to meet changing perceptions of important factors related to the assessment of quality of HIV health care.

The value of this activity is in the experience of reaching consensus and not necessarily in the actual ranking of factors. This is self-advocacy practice. Taking a position, defending it and then listening to the positions of others are essential advocacy skills. In discussing this activity, take the opportunity to talk about each of these skills and how they were used in the group activity.

Activity C:

Consensus Activity: Support Ranking of Quality of Care Factors

Rationale:

Encouraging group interaction and consensus allows the participants to verbalize their attitudes about ranking quality of care characteristics.

Materials Needed

Pens/Pencils

Quality of Care Consensus Activity Worksheet (See p. 17)

Time:

15 minutes

Procedure

1. Explain the activity by saying the following:

We have spent some time talking about what makes you satisfied with your quality of care. It is important that you think about the factors that cause you to be satisfied.

For this activity, you will be given a list of quality of health care factors and you are going to rank them from most important to the least important. To help you do this, you will work in small groups and everyone in the small group will work to agree on the ranking. First get into groups of 3 or 4 for this activity.

2. Help the group get into small groups of 3 or 4 participants. Make sure there are at least two groups so that there can be a comparison of top ranked factors between the groups.
3. Hand out the “Quality of Care Checklist Consensus Activity” Worksheet to each person in the group and read the directions aloud to the group. Ask them to read the list individually first and think about their own ranking before starting the group work.

This is the “Quality of Care Checklist Consensus Activity” Worksheet. The directions are as follows: Below is a list of important Quality of Care Factors. Talk about these factors within your group and then rank the factors from 1 (most important) to 12 (least important). Consensus means that each member of the group agrees to the ranking of each factor on the checklist. A factor can have only one ranking and each ranking can only be used once. I will give you about 10 minutes to complete this activity. When all of the groups are done, one person from each group will read their group’s top 3 rankings.

4. When the 10 minutes are up, have 1 person from each group report their top 3 rankings. You can have them check off the top 3 on a newsprint sheet with the rankings list on it.
5. When the groups have read their top 3 rankings ask the following questions:

- What did you learn from doing this activity?
- In what ways was this activity easy to do?
- In what ways was this activity hard to do?

6. Summarize by saying,

Thank you. You did really well with this activity. This activity may have been hard, but it gave you the chance to talk about your health care and the factors that are important to you. It also gave you practice negotiating with other people. That is an essential part of advocating for yourself and others. Remember these factors and the way that your group ranked them. Also remember what it is like to take a position about something and defend it, while listening to what others have to say. In our next activity we will talk about some other ways to rate your care.

Quality of Health Care Checklist

Consensus Activity

Below is a list of important Quality of Care Factors. Talk about these factors within your group and rank the factors from 1 (most important) to 12 (least important). Have one person write the rankings on one list for the group. Consensus means that each member of the group agrees to the checklist. A factor can only have one ranking and each ranking can only be used once.

How important is it to me that:

- _____ I have a good relationship with my doctor.
- _____ The clinic staff makes me feel welcome.
- _____ I have confidence in the knowledge and skills of my doctor.
- _____ There is a short waiting time to be seen by my doctor.
- _____ Many different services are provided at one clinic location.
- _____ The facility is convenient to get to.
- _____ My doctor communicates well with me and answers my questions.
- _____ Other patients rate a high quality of care.
- _____ I get regular CD4 counts, viral load tests, and drug resistance testing.
- _____ HIV - related medications are available to me and their side effects have been explained to me.
- _____ Regular pelvic exams are available for women.
- _____ The staff helps me to be involved making decisions about my health care.

Activity D:

Clinical Indicators of HIV Quality Care

Rationale:

This activity introduces the concepts of quality improvement and clinical care indicators. These concepts may be new to many of the participants, even some of those who are more well - informed. The use of small group brainstorming and discussion will model the collaborative approach to information gathering.

Materials Needed:

Newsprint Sheets
Markers for newsprint
Masking tape for hanging newsprint

Time Needed:

15 minutes

Procedure:

1. Hang five sheets of newsprint on the walls. Space them enough apart to allow small groups of participants to stand around each sheet while they brainstorm and write ideas on the sheets. You will be writing a heading on each sheet after a brief discussion.
2. Introduce this activity by saying:

We have seen that each of us views the quality of our HIV care in very personal terms and each of us has different ways of deciding how satisfied we are with our care.

There are other ways of rating the quality of HIV care delivered in a clinic or doctor's office. When an external funder, regulatory agency or directors of a clinic want to evaluate the quality of care provided to patients, they are more likely to look at the medical aspects of care. These may include the types of tests used in diagnosing illness or in monitoring how treatments are working, how regularly these tests are used, or what types of medications are prescribed by doctors to treat various diseases. These medical aspects of care are called "clinical indicators" of the quality care.

What are some specific clinical indicators that you think can or should be used to evaluate the quality of HIV medical care people receive? Let's list some of them.

3. On one of the newsprint sheets write down the ideas that participants suggest.

4. These should include some or all of the following:

- HIV Viral Load Tests
- CD4 + Cell Tests
- TB or PPD Tests
- Antiretroviral Drug Resistance Testing
- Offer of antiretroviral medications
- Treatment Adherence Education and Support
- Hepatitis C Tests
- Pelvic Exams

5. Select 4 or 5 of these clinical indicators and write one each on the top of the hanging newsprint sheets.

6. Tell the group:

Most of these terms are probably familiar to you. To be sure that we all understand what each of these important terms means, let's form small groups to brainstorm as much as we know about them.

We will form groups of 3 - 5 people. Each group will start at one of the sheets and take 2 or 3 minutes to write down everything that they know about the term at the top of the sheet. One person can do the writing but each person in the group should contribute ideas to write down. You should also write down any questions that you have about the term or things that are not yet known about it. Also write down why you think it is an important measure of quality of care you receive.

After 2 - 3 minutes I will tell you to move as a group to the next sheet. You will then have the chance to add to what was written by the group before you or to answer questions they might have asked. Every few minutes you will move to each of the next sheets until your group has had the chance to write on each of them.

We will then come back as a group to discuss all of the information that you have gathered. Are there any questions? Okay, let's begin.

7. Direct the participants in forming small groups, identifying one person to write for each group, and moving to a sheet to start. Tell them that they have 2 -3 minutes to begin writing what they know.
8. After 2 - 3 minutes ask the groups to move to the next sheet. Repeat the process until each group has had the opportunity to contribute to each of the sheets.
9. When finished, ask the groups to come back to their seats.
10. You may now read what is on each sheet (one at a time) and ask if there are any points that are not clear or that you might feel are incorrect. Ask the group for help in clarifying and correcting information. Resolve any clearly inaccurate information but encourage the group to discuss how they can get the most correct and up to date information.
11. When finished with review of the sheets, say:

Good quality HIV care should include each of these clinical indicators. If they are not part of your HIV care, it may mean that less than the best quality HIV care is being provided.

Next we will take a more personal look at these indicators.

Thank you for working together on gathering the information we need on these clinical indicators. What we did here is a good model of positive self - advocacy skills by sharing information and helping to educate one another.

Activity E:

Clinical Indicators Personal Assessment Activity

Rationale:

The participants will apply their understandings about the quality of clinical care indicators to an assessment of their own care. For some participants, this activity will help them to focus their attention on an aspect of their care that they may not think much about or pay attention to in the course of their interaction with their doctors. For others, they will know very well whether or not their doctor has provided these tests or treatments. Their contribution to this activity may help to empower the less-informed participants to become more involved in the clinical aspects of their HIV care.

Materials Needed:

Newsprint sheet: list of clinical indicators discussed in Modules Activity D.
Personal Assessment Worksheet

Time Needed:

10 minutes

Procedure

1. Hand out the Personal Assessment Worksheet to each participant. Hang the newsprint sheet with the clinical indicators list. Explain:

We are now going to look at each of the clinical quality indicators we talked about in the last activity.

When we look at each indicator in turn, I want you to think about the question as I read it to you. Then answer the question, to the best of your knowledge, by checking off the answer on your worksheet.

2. Read each question on the worksheet and ask the participants to answer each question to themselves. The Personal Assessment Worksheet can be used to allow the participants to record their answers. Some participants may not be sure of their answers. Tell them to check the “not sure” box.
3. After all of the questions have been read, ask:

Are you satisfied that you were able to answer each of these questions?

What have you learned about your HIV care from this activity?

Has your personal view of the HIV care you receive changed in any way?

4. Encourage a few participants to share what they have learned about their HIV care as a result of this activity.
5. For those participants who were “not sure” about whether or not their doctor provided one or more of the indicators, ask:

Some of you were not sure about whether or not some of these tests or treatments were done. What can you do to find out more about them?

6. If no one suggests it on their own, suggest that they might consider asking their doctors about the test or the treatment they are unsure about. Ask:

What do you think might happen if you ask your doctor or nurse about a test or treatment that you are unsure about? Have you ever done that in the past?

7. If a participant says, “yes”, ask:

Please explain what happened?

8. When that person finishes describing what happened, suggest that:

Some doctors and nurses react to questions in different ways. Many appreciate it since it may help them to figure out how much you understand your care and how much you may want to participate in making decisions about your care. Others may react differently.

How can you get the information you need if you don't get your question answered by the doctor?

Ask for one or two participants to suggest some ideas. These may include: asking the doctor to explain it in another way so that you can better understand; asking the doctor where you could find out more information; asking the nurse, treatment educator or your case manager; see if you can find information in brochure or on the internet.

9. Next, ask the group to think about other indicators that might be used to evaluate the quality of care an HIV clinic provides to its patients, saying:

Based upon your personal experience, are there any other indicators that could be used to better measure the quality of HIV care a clinic provides to its patients?

10. Thank the group for participation in the activity, closing the activity with:

Thank you for participating in this activity. I hope you have a better understanding of the clinical indicators used to rate the quality of care.

11. Close the activity with:

I also want to thank you for sharing your personal experiences in communicating with your health care providers about important issues. This serves as a model of self-advocacy for all of us. Good quality of care depends upon clear and effective communication with our health care providers. As self-advocates we need to do what we can to make that happen.

This is a good time to take a brief break.

[Suggested time: 10 minutes]

Note: It is important to be clear about how long the break will be and your expectations about starting on time.

Personal Assessment Worksheet

Next to each of the statements below check off either “Yes,” “No,” or “Not Sure,” to the best of your ability.
Each of the statements relates to a measure of Clinical Indicators that maybe used to rate the quality of HIV care.

1) HAVE I HAD A VIRAL LOAD TEST IN THE LAST 4 MONTHS?

Yes No Not Sure

2) HAVE I HAD A PPD TEST IN THE LAST YEAR?

Yes No Not Sure

3) FOR WOMEN ONLY: HAVE I HAD A PELVIC EXAM, INCLUDING A PAP SMEAR, IN THE LAST YEAR?

Yes No Not Sure

4) IF PREGNANT, HAVE I BEEN OFFERED MEDICATIONS TO PREVENT HIV INFECTION IN MY NEWBORN CHILD?

Yes No Not Sure

5) I HAVE HAD A CD4 CELL TEST IN THE LAST 4 MONTHS

Yes No Not Sure

6) I HAVE BEEN SCREENED FOR HEPATITIS C

Yes No Not Sure

7) I HAVE BEEN OFFERED HELP IN SOLVING PROBLEMS I HAVE HAD WITH ADHERENCE WITH HIV-RELATED MEDICATIONS

Yes No Not Sure

8) I HAVE DISCUSSED THE USE OF ANTIRETROVIRAL MEDICATIONS FOR HIV INFECTION WITH MY MEDICAL PROVIDER

Yes No Not Sure

Activity F:

Your Personal Quality of Care Factors

Rationale:

Deciding which quality of care factors are important and ranking their importance helps participants to examine their attitudes and explore whether or not they are receiving quality care.

Materials Needed

Pens/Pencils

Your Personal Quality of Health Care Checklist

Time Needed:

4 minutes

Procedure

1. Explain the activity by saying the following:

Earlier, you worked together in small groups to rank quality of care factors. For this activity, I will give you the same worksheet and you will work by yourselves to rank the factors of quality of your own health care. I will give you about 2 minutes to complete this list.

2. Hand out the Your Personal Quality of Care Checklist to the entire group.

3. Read the directions to the group and review each factor.

This is Your Personal Quality of Care Checklist. The directions are as follows: Below are 12 Quality of Care Factors. How important is each one to you? Read the following 12 factors and rank them from 1 (most important) to 12 (least important). A factor can only have one ranking and each ranking can only be used once. I will give you 2 minutes to complete this activity.

4. When 2 minutes is up, ask the group to finish their checklists.
5. Ask the following questions:

- How is this personal ranking different from your group consensus ranking?
- How have your feelings about these factors changed?

6. Summarize by saying,

Congratulations, you now have all of the information that you will need to be an effective self-advocate. It may be hard work, but you are worth it. Hold on to this worksheet; you can use it as another way to rate your quality of health care.

This is the end of Module Two.

Your Personal Quality of Health Care Checklist

This is Your Personal Quality of Care Checklist. The direction are as follows: Below are 12 Quality of Care Factors. How important is each one to you? Read the following 12 factors and rank them from 1 (most important) to 12 (least important). A factor can only have one ranking and each ranking can only be used once.

How important is it to me that:

- _____ I have a good relationship with my doctor.
- _____ The clinic staff makes me feel welcome.
- _____ I have confidence in the knowledge and skills of my doctor.
- _____ There is a short waiting time to be seen by my doctor.
- _____ Many different services are provided at one clinic location.
- _____ The facility is convenient to get to.
- _____ My doctor communicates well with me and answers my questions.
- _____ Other patients rate a high quality of care.
- _____ I get regular CD4 counts, viral load tests, and drug resistance testing.
- _____ HIV - related medications are available to me and their side effects have been explained to me.
- _____ Regular pelvic exams are available for women.
- _____ The staff helps me to be involved in making decisions about my health care.

Module Three:

Self - Advocacy for Improved Health

Goals

The goals of this module are to:

- Practice the skills necessary to be a successful self advocates for improved quality of care.
- Assist participants in developing strategies for addressing some of the more difficult health care decisions to be faced.
- Increase participants' confidence in advocating for themselves.
- Increase the participants' communication skills and enhance their ability to problem-solve situations that may occur with their HIV health care.

Objectives

After completing this module, participants will be able to:

- Identify strategies for overcoming the barriers confronted in trying to advocate for quality health care.
- Describe strategies for promoting self-advocacy skills

Strategies/Methods

Group Discussion

Role Plays

Materials Needed

Pens/Pencils

Markers

Tape

Options Scenario

Role Play Scenarios

Helpful Hints Handout

Preparation Needed:

Pre-label newsprint: "What are my Options?"

Time Needed:

50 minutes

ACTIVITY	TIME
A. What are my Options?	20 minutes
B. Role Plays	30 minutes

Activity A:

What Are My Options?

Rationale:

Providing options for the participants provides them with additional information so that they are able to make critical decisions about their HIV care.

Materials Needed

3 Pre-labeled newsprint: Problems, Barriers, Actions
Options Scenario

Time Needed:

20 minutes

Procedure:

1. Hang three sheets, Problems, Barriers, Actions.
2. Introduce the activity by saying:

In this activity, we are going to discuss ways of handling challenging situations. We will look at a situation that has a few different solutions. In this situation I want you to first make a list of all the problems you see. Second, list the barriers to solving the problems. And third, list some actions you could take to try to solve the problems.

1. What are some of the problems in this situation?
2. What are the barriers?
3. What are some things you could do to solve the problem?

3. Say the following:

I am going to hand out and read a short scenario to you. When I am done we will talk about what you might do in this situation to make it better.

4. Hand out the Options Scenario to each participant and read the scenario.
5. After reading the Options Scenario, say:

What are some of the problems that you found in this situation?

6. List these on the sheet labeled "Problems" then ask for the barriers and list them.
7. After listening to the participants describe the problems, ask:

What are some of the options that might help make this situation better? Which of them would you try first?

8. List the options on the "Actions" sheet and discuss.
9. Summarize by saying:

From this activity we can see that problems often have many layers to them and also several possible ways of solving them. Speaking with others about problems often helps us to get a new perspective on them. Thinking about different options helps us to feel more in control of a situation and to consider our actions carefully.

Options Scenario

You are attending a job-training program, but you have been arriving late because you can't wake up on time. The director of the program has told you that if you can't show up on time, you will be kicked out. You have told your doctor that your medication is making you sleepy, but your doctor has not changed your medication. What you haven't told your doctor is that because of oversleeping you have been missing some of the doses of your HIV medication.

What do you think you can do to advocate for yourself and improve the situation?

Activity B:

Options Role Play Practice

Rationale:

Providing participants with an opportunity to practice advocating for quality health care gives them the confidence in themselves to be self-advocates.

Materials Needed

Role Play Scenarios #1 and #2

Time Needed:

30 minutes

Procedure

1. Explain the activity by saying the following:

You have done a lot of work today. We are almost finished. When you leave here today, you will be able to use all of the information and skills you have learned to make sure your HIV care is the best it can be. Remember that you deserve the best of care at all times. We have spent a lot of time discussing which quality of care factors are important to you. We have discussed how you feel about the health care that you are receiving. Now you are going to have the chance to use all of the information that we went over today in a practice session.

2. Continue by saying:

Now we are going to do some role-plays. Role-playing is a technique that can help you practice what to do in a new or hard situation. You can use all of the information that was reviewed here today, including the information that each of the group members shared, and use it in your role-play.

For the role-plays, you will need to be in pairs, so find a partner. It would be a good idea to choose someone that you have not worked with today. I am going to hand out a role-play scenario for everyone.

Facilitator's Note

1. Some groups of participants may have no experience with the use of role play as a learning tool. If this is the case with the group in your workshop, it may be very helpful for you to model the first role play with one of the participants. For example, you might play the advocate and the participant volunteer would play the client. You could then have the participants repeat the role play in their pairs. If time does not permit this, the group could do the second role play in their pairs.

It might be helpful to instruct the advocates that their role is not to be the “problem solver.” The best way for them to help the client is to help them think through the problem, looking at each of the possible options and helping them to pick one they feel most comfort-

able with. The least helpful thing they can do is give the client “the answer,” since it may only be the “answer” that the advocate likes best and not the one that fits the client’s needs the most.

2. Time may not permit each of the pairs to answer each of the questions; try to get some of the answers from different pairs. For example, have the advocate of one pair answer the first question, and then have the client of another pair answer the second, etc.
3. An alternate role play option is to have 3 participants (triad) work together. The third participant acts as the observer and can provide a different perspective during the discussion.

Read the role-play. One of you will play the client and the other will play the advocate. Both of you are trying to solve the problem with the advocate helping the client use their problem-solving skills. You will have about 5 minutes to do this role-play. It is important for you to do your best to stay in your role until the role-play is over. Your goal in each role play is to decide on an action plan to solve the problem.

3. Hand out the Role-Play Scenarios.
4. Read the Advocate Role first; then, the Client Role.
5. Give them 5-7 minutes to practice the role-play.
6. When they are finished with the role-play ask the following questions of each of the pairs:

- How did you break down the problem?
- What possible options did you think of?
What were the risks and benefits of these options?
- Which option did you choose? Why?
- What do you think you might do if the option you chose does not work?

7. Introduce Client Role #2 by saying the following:

For the second role-play, switch roles. Whoever played the advocate will now play the client and whoever played the client will now play the advocate. The Advocate Role stays the same; the client role is different. I will give you about 5 minutes to complete this role-play.

8. Give them 5-7 minutes to practice the role-play.
9. When they are finished with the role-play ask the following questions, as you did with the first role-play:

- How did you break down the problem?
- What possible options did you think of?
- Which option did you choose? Why?
- What do you think you might do if the option you chose does not work?

10. What are some important things you learned from doing these role plays?
11. Summarize by saying:

Great job. In doing these role-plays you had a chance to practice being a self-advocate in a safe place. Now that you have practiced, you are ready to be your own self-advocate and make sure that you get quality HIV health care.

Role Play Scenarios

Client Role 1

You have been going to the same health care provider for three months and have noticed that you leave the office without really understanding what you need to know about your HIV treatment. You have tried to speak with other medical staff but the waiting room is noisy and they rush you along. There are other medical concerns that you would like to ask someone, but there doesn't seem to be anyone available. You decide to talk to a friend who goes to the same clinic you do about your problem.

Client Role 2

You have a great relationship with your doctor and you trust his/her recommendations. When you talk to some of your friends who go to another HIV clinic you find that they seem to be getting tests and treatments that you are not getting. You are concerned about this and decide to talk to a friend.

Advocate Role (Both Scenarios)

Your friend has come to talk to you about the quality of care s/he is receiving at the HIV clinic you both go to. You can help him/her break down the problem, identify possible options, and select a few actions that your friend is comfortable with.

Activity C:

Closing Activity: What Have We Learned?

Rationale:

Providing participants with strategies necessary for negotiating for quality health care gives them confidence in themselves to be self-advocates.

Materials Needed

Helpful Hints for the Self-Advocate
Consumer Workshop Take-Home Summary
Self-Assessment Worksheet
Workshop Evaluation

Time Needed:

10 minutes

Procedure

1. Say the following,

As you can see, making decisions about your HIV health care can be hard work. Although the work may be hard, you have proven that you can do it. Today, you discussed the positives and negatives about your health care. You have learned that there are resources available that will help you to get the best quality HIV health care. You can be a self-advocate.

2. Explain the following:

For our last activity, I would like for you to take a few minutes and think about what you have learned today and how has this workshop helped you. To help you do that, please fill out the Self-Assessment Worksheet. Circle the terms that best describe how prepared you now feel to do each of the things on the list. Each of these is something that we agreed we would work on in this workshop.

3. Give the participants a few minutes to fill out the worksheet and then collect them. (You can use these to evaluate how effective the workshop has been in meeting the objectives discussed in the opening module.)
4. Now ask:

Now that you have thought about the work that we have done today, would someone like to tell the group something about what you have learned in the workshop today?

5. Go around the room until each person who wants to has had a chance to speak. Thank them for their contribution.
6. Hand out the Helpful Hints for the Self-Advocate. Briefly review the handout.
7. Hand out the Consumer Workshop Take-Home Summary. Briefly review this handout.
8. Thank the participants for attending and participating in the workshop.
9. As the last activity, please can ask the participants to take a few moments to fill out the workshop evaluation form. Collect these forms as the participants finish them and leave.

Helpful Hints for the Self-Advocate

You can be an effective *self-advocate*, but you need to develop a plan for handling the obstacles that may arise. Learning how to handle obstacles makes advocating easier.

Believe In Yourself And Ask Others For Help

Believe that you are someone worthy of advocating for. The more you reach out and get the services you deserve, the better you will feel about yourself. Advocacy means taking responsibility for getting what you want and deserve. It can be tiring, so don't think you have to be an advocate alone. You can ask for help.

Be Assertive

Assertiveness shapes the way we deal with other people. Being a self-advocate means you must be persistent and knowledgeable. Remember, "The squeaky wheel gets the oil."

Manage Your Anger

Do not insult, yell at, or disrespect others while you are advocating for yourself. People will be less inclined to help you or answer questions if you make them angry, uncomfortable, or cause them trouble. Don't let people have the chance to use your anger as an excuse for not helping you. Teach yourself how to control your anger.

Educate Yourself

Take every opportunity to educate yourself. That means asking questions, getting answers, and asking more questions. That also means taking advantage of every educational opportunity. Read about services that you may be eligible for and become aware of new and different treatment options.

Consumer Workshop Take–Home Summary

Making Sure Your HIV Care is the Best It Can Be

What We Believe:

- You have a right to the highest quality HIV care possible.
- You play an important part in improving the quality of HIV care at your clinic. What you need and what you think about your care matters. If you speak, people will listen.

Factors That Contribute To The Quality Of Your Care:

- The relationships you have with your doctor and the other clinic staff.
- The location and the facilities and services provided at your clinic.
- How well your personal needs are met.
- How well your medical care is handled (Are the right tests and treatments provided when they should be?).
- When you are not satisfied with your care, someone is there to help you make improvements.
- How well you can communicate with your doctor and other health care providers.

Some Important Indicators Of The Quality Of Medical Care You Receive:

1. HIV viral load tests are done at least every 4 months and the results are discussed with you.
2. You have a TB test (PPD) every year.
3. If you are a woman, you have a pelvic exam every year.
4. If you are pregnant, you are offered antiretroviral medication to help prevent HIV infection in your newborn child.

Making Sure Your HIV Care Is The Best It Can Be

Workshop Evaluation

Please take a few moments to let us know how you felt about this workshop. Your thoughts are important to us as we prepare for future workshops. Please circle your response. The following statements are about the workshop.

	POOR	FAIR	GOOD	EXCELLENT
1) WHAT IS YOUR OVERALL RATING OF THIS WORKSHOP?	1	2	3	4
2) WHAT IS YOUR OVERALL RATING OF THE TRAINER?	1	2	3	4
3) INFORMATION WAS DELIVERED IN A WAY YOU COULD UNDERSTAND.	1	2	3	4
4) PEOPLE WERE ENCOURAGED TO EXPRESS DIFFERENT OPINIONS.	1	2	3	4
5) WAS THE TRAINING PROGRAM MEANINGFUL TO YOUR PERSONAL LIFE?	1	2	3	4
6) DID THE TRAINER APPEAR KNOWLEDGEABLE ABOUT THE INFORMATION?	1	2	3	4
7) DID THE TRAINER DELIVER THE INFORMATION CLEARLY?	1	2	3	4
8) DID THE TRAINER PROVIDE OPPORTUNITIES FOR DISCUSSION?	1	2	3	4

Other Information

HOW MUCH DID THE WORKSHOP PROVIDE USEFUL INFORMATION TO YOU?

- A great deal A lot Not much Not at all

WOULD YOU RECOMMEND THIS WORKSHOP TO OTHERS?

- Yes, definitely No I'm not sure

Please provide an explanation for your response to the following 3 questions:

What were the most important things you learned in this workshop?

What did you like the most about this workshop?

What would you like to change about this workshop?

Additional suggestions or comments:

Thank You!!!

Self - Assessment Worksheet

How well prepared do you now feel to do each of the following? Please check the term that most closely describes how prepared you feel to do each of the following.

1) TO IDENTIFY WHAT IS MOST IMPORTANT TO YOU IN YOUR HIV HEALTH CARE.

- Very well prepared Well prepared A little unprepared Not prepared

HOW IS IT DIFFERENT FROM HOW YOU FELT BEFORE THE TRAINING?

- Better prepared About the same Less well prepared

2) TO JUDGE THE QUALITY OF HIV CARE THAT YOU RECEIVE?

- Very well prepared Well prepared A little unprepared Not prepared

HOW IS IT DIFFERENT FROM HOW YOU FELT BEFORE THE TRAINING?

- Better prepared About the same Less well prepared

3) TO USE QUALITY OF CARE INFORMATION AND WHAT OTHERS MAY THINK TO HELP YOU JUDGE THE QUALITY OF HIV CARE YOU RECEIVE.

- Very well prepared Well prepared A little unprepared Not prepared

HOW IS IT DIFFERENT FROM HOW YOU FELT BEFORE THE TRAINING?

- Better prepared About the same Less well prepared

4) TO DESCRIBE THE INDICATORS USED BY THE STATE TO RATE THE QUALITY OF HIV CARE PROVIDED BY HEALTH CLINICS AND HOSPITALS

- Very well prepared Well prepared A little unprepared Not prepared

HOW IS IT DIFFERENT FROM HOW YOU FELT BEFORE THE TRAINING?

- Better prepared About the same Less well prepared

Self - Assessment Worksheet...*Continued*

5) TO COMMUNICATE EFFECTIVELY WITH HEALTH CARE PROVIDERS AND STAFF ABOUT YOUR HEALTH CARE.

- Very well prepared Well prepared A little unprepared Not prepared

HOW IS IT DIFFERENT FROM HOW YOU FELT BEFORE THE TRAINING?

- Better prepared About the same Less well prepared

6) TO USE AN ACTION PLAN TO HELP IMPROVE THE QUALITY OF CARE YOU RECEIVE.

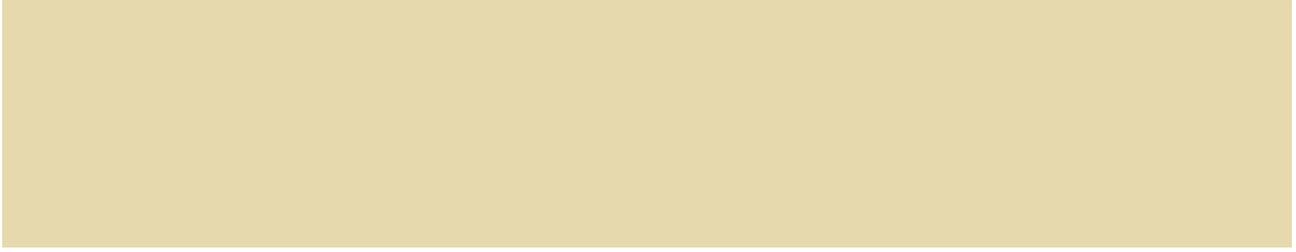
- Very well prepared Well prepared A little unprepared Not prepared

HOW IS IT DIFFERENT FROM HOW YOU FELT BEFORE THE TRAINING?

- Better prepared About the same Less well prepared



Notes



Notes

