DELIVERING HIV RAPID TEST RESULTS: Experiences from the field

VIDEO DISCUSSION GUIDE & RESOURCES

Region I Title X Family Planning Training Center JSI Research & Training Institute, Inc.



This video was a project of the Region I Federal Training Centers Collaborative (FTCC):

Region I Title X Family Planning Training Center

New England AIDS Education and Training Center

Sylvie Ratelle STD/HIV Prevention Training Center of New England

New England Addiction Technology Transfer Center

New Jersey Medical School Global TB Institute

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Developed with funding from the U.S. Department of Health and Human Services, Office of Population Affairs, Office of Family Planning. Contents of the video and discussion guide are solely the responsibility of JSI Research & Training Institute, Inc. and do not necessarily represent the official views of the U.S. Department of Health and Human Services.

Please note that the video and discussion guide are not intended to be a substitute for HIV testing training.

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Introduction

Enhanced access to HIV testing is a crucial strategy for reducing HIV's toll, enabling those infected with HIV to be linked to life-saving medical care and to practice safer behaviors to protect their partners from infection. While fully understanding the importance and procedures for conducting HIV testing, many providers feel daunted by the prospect of communicating the news that a client has HIV.

The video *Delivering HIV Rapid Test Results: Experiences from the Field* was developed for a wide range of health care providers and counselors working in settings that provide HIV testing. The video offers personal experiences and perspectives from a diverse group of clients and providers, and demonstrates counseling approaches for effectively and compassionately delivering HIV test results. This companion guide provides discussion questions and additional resources to enable viewers of the video to learn from one another, and to build upon their past experience delivering difficult news to clients.

SCENARIO I: Antonio and Eric

22-year old **Antonio** has come in today specifically for an HIV test. While waiting for the test result, he has told the counselor, **Eric**, that he has had multiple sex partners and regularly uses club drugs.

Test result: rapid test non-reactive (negative)

Counseling Notes Client-Provider Dialog

Eric states and explains the meaning of the test result, waits for Antonio's reaction and is willing to take a moment to celebrate the good news with Antonio.

Eric gives important information about the "window period" without ordering Antonio to retest. He wants retesting to be Antonio's decision, based on Antonio's self-perception of risk.

A gentle, almost rhetorical, question that respectfully reminds Antonio of what has already been shared.

Once more, Eric is very supportive in approach, and discusses prevention in a encouraging rather than directive manner. He elicits Antonio's ideas about protection before giving his own.

Eric then summarizes Antonio's plans and leaves the door open for further interaction.

Eric: Antonio, the test has finished. The result is negative, which means that you are most likely not infected with HIV. *Antonio:* Negative?? Wow!!! You sure?

Eric: (smiling and nodding) Great news, huh?

Antonio: You know, I really did think it was gonna be bad...

So, I'm okay, huh?

Eric: Here's what this negative result tells you — at this time you are not showing signs of HIV infection. But here's something that's important for you to know: For the particular HIV rapid test that we used today, if you were exposed to HIV within the last 3 months, this test might not pick that up.

Antonio: Well, but it's still good news...I mean I don't have it, right?

Eric: Antonio, you've really been up front with me about what's been going on in your life, about the partying and all..... Have you been in any situations in the past 3 months that might have put you at risk for HIV?

Antonio: (Pauses, looks down, then up) Yeah, well I guess I'll be back for another test in three months.....(shrugs and smiles a little sheepishly)...and then I'll be okay!

Eric: I sure hope so!.... Hey, Antonio, next time you come back, it would be great if you got another negative result.

Antonio: You got that right!

Eric: If you want to get another negative result next time, and know that it really means you are not infected with HIV – then you'll want to be sure you are protecting yourself...So, how could you do that?

Antonio: Well, I guess...try all the stuff we've been talking about – use condoms every time, take it easy with the drugs...

Eric: (Nods and smiles) So—vou're gonna come back in three

months for another test... And here's some condoms you can take with you. In the meantime, if you wanna talk about any of this some more, I'm here.

Antonio: Hey, brother, thanks, really, thanks.

Discussion Questions for Scenario I: Antonio and Eric

- 1. Does this scenario "ring true"? What parts of the scenario seem more realistic/less realistic based on your experience with clients?
- 2. For each of the following aspects of the visit—What do you think the counselor (Eric) did well? What could he have done differently?
 - Stating and explaining the meaning of the test result
 - Explaining the "window period"
 - Using the "teachable moment"
 - Being supportive and non-judgmental
- 3. What are some approaches you yourself have found helpful when delivering non-reactive (negative) HIV rapid test results?
- 4. What do you find most difficult/worry most about in talking with clients about their negative HIV test results? What kinds of support or training do you need to help you feel better prepared to do this work?
- 5. In what ways can your clinic or program support you and make it easier for you to deliver HIV rapid test results to clients in an effective and compassionate way?

SCENARIO II: Keith and Carolyn

Keith has come to the STD clinic because of symptoms, and has agreed to be tested for HIV along with testing for other STDs. **Keith** has disclosed to the provider, **Carolyn**, that he has had sex with both women and men in the past, and has been going to a Narcotics Anonymous group for the past year.

Test result: rapid test reactive (preliminary positive)

Counseling Notes

Carolyn immediately and clearly states the test result, and also stresses the importance of the confirmatory test.

Carolyn gently asks for time, and then articulates the feelings she sees expressed in Keith's behavior.

After asking an open-ended question to invite Keith to talk more, Carolyn gives him control and tells him how she can be of help.

Carolyn does not try to take away Keith's fears. Her respectful acknowledgement of his perspective may facilitate his willingness to hear more from her.

Client-Provider Dialog

Keith: Okay, let's get this over with. What's it show? **Carolyn:** Keith, the preliminary test result is positive, but we won't know for sure if you are infected with HIV until we get the results from a confirmatory test.

Keith: (Slumps down in his seat, shaking his head, then pounds one fist into the palm of his other hand, seems to be talking to himself) I knew it...This time, I just knew it...(looks up) Okay, listen, I just gotta get out of here. I'll be okay, alright? (Starts to get up to go)

Carolyn: Could you stay for just a few minutes, Keith? I just gave you a really difficult piece of news... (Carolyn pauses and waits, Keith sits back down resignedly) It sounds like you were expecting this result?

Keith: Yeah...no...I dunno. You know...I guess I knew it could happen...I messed around...what did I think was going to happen? ... Listen, miss, I know about HIV, I don't think there's anything you can tell me. I just screwed up.

Carolyn: I know this is not easy to think about or talk about... but what's first on your mind right now?

Keith: (looks at Carolyn as if she's crazy) Look, I know you mean well (suddenly puts his head in his hands)

Carolyn: Keith, you don't have to talk with me – of course you don't. But there's some information I'd like to give you. If I bring up something you don't want to discuss, or ask a question you don't want to answer that's OK.

Keith: (looks at Carolyn, then takes a deep breath and begins to talk, in a flat, resigned tone) You asked what I'm thinking...
I'm thinking HIV caught up with me and I'm gonna be sick....
If I want to live, I'll have to take those medications and probably still feel sick. And how I'll ever pay for it all?...I have no idea....
Carolyn: You're right – some people who take the medications do have a hard time with them; but many people don't. And you may not even need medication right away. You

Counseling Notes

Carolyn demonstrates her depth of knowledge about local HIV services, and her familiarity with and confidence in the referrals she is offering.

Carolyn takes the risk of asking about Keith's NA involvement, which Keith revealed earlier in the visit. This gives Carolyn a chance to capitalize on an already-existing and potentially powerful source of support in Keith's life.

Carolyn asks about Keith's immediate plans.

Carolyn goes beyond just checking on the presence of support to explore how genuine that support is likely to be.

Carolyn lets Keith know he can check in with her if he needs to, closing the session but not the door.

Client-Provider Dialog

Keith: (interrupts) So what do you want me to do?
Carolyn: As a first step, we need to get the results of the confirmatory test... And I can connect you with Dr Lyman, a specialist in HIV treatment, who can see how you're doing and work with you to find the best ways to fight the virus and keep you healthy....If she decides you do need to be on medications, the clinic there has a social worker who can set you up with a program that helps to pay for HIV medications..... I know these people—they provide excellent treatment and they really care.

Keith: Uh huh. (Sounds skeptical but continues to look at Carolyn as if waiting for more information)
Carolyn: Keith, you told me you recently started a recovery program...was it Narcotics Anonymous you mentioned?

Keith: Yeah, for all the good that's gonna do me! **Carolyn:** You know, there are NA groups in town that are specifically for people who have HIV. (Hands him a brochure with the program information)

Keith: Yeah? Well, maybe one of these days, I'll check that out. Not right now.

Carolyn: (Nods) OK. Well, what will you do when you leave here today?

Keith: I dunno...maybe I'll call my sponsor.

Carolyn: (Nods again) How do you think your sponsor will react to your news?

Keith: He's handled everything else I've handed him so far. He's cool...he's there for me.

Carolyn: If you'd like to call him before you leave here, I can find a private space for you to do that....Otherwise, please just know that you can call me back anytime—if you have any questions at all, or just need to talk. Here's my number—I'll be here. (Hands him her card)

Discussion Questions for Scenario II: Keith and Carolyn

- 1. Does this scenario "ring true"? What parts of the scenario seem more realistic/less realistic based on your experience with clients?
- 2. For each of the following aspects of the visit—What do you think the counselor (Carolyn) did well? What could she have done differently?
 - Stating and explaining the meaning of the test result
 - Dealing with Keith's emotional reactions to the news
 - Making referrals to medical care and other services
 - Assessing Keith's potential support system
- 3. What are some approaches you yourself have found helpful when delivering reactive (preliminary positive) HIV rapid test results?
- 4. What do you find most difficult/worry most about in delivering a positive HIV test result? What kinds of support or training do you need to help you feel better prepared to do this work?
- 5. In what ways can your clinic or program support you and make it easier for you to deliver HIV rapid test results to clients in an effective and compassionate way?
- 6. Delivering HIV test results can be hard on the provider. What are some ways providers can get support, let off steam and take care of themselves, so they don't burn out?

SCENARIO III: Nicole and Angela

Nicole is a young mother of two children, ages 6 and 3. In discussing her medical history with the nurse practitioner, **Angela**, she has revealed no risk factors for HIV infection. She has come in today for a check-up and Pap test, and has agreed to a rapid HIV test, which is offered routinely at the community health center.

Test result: rapid test reactive (preliminary positive)

Counseling Notes	Client-Provider Dialog	
Angela does not delay or evade sharing the result. Her willingness to be direct is important.	Angela: Nicole, I have the results of your tests. Your rapid HIV test result is preliminary positive, which means you most likely have been infected with HIV. We won't(gets interrupted by Nicole as she is about to talk about confirmatory test) Nicole: What?? What did you say?? Wait, wait (She stands up. She's clearly agitated, turns around, then sits back down again.) Are you telling me I've got the virus — I've got HIV?? Listen, you gotta run that test again. This has got to be a mistake!!	
Angela refrains from offering "false hope" while being clear about the need for confirmatory testing.	Angela: We do need to do another test to confirm this result. At the same time, I don't want to mislead you – this test is very accurate, and it's likely that the confirmatory test will also be positive. Nicole: But, wait, wait (Her anger is beginning to dissolve into fear and tears) Oh, no, no, what does this mean? I mean I've got kids – oh, God, what does this mean about my kids?	
Angela's request for permission is an attempt to give control to her client.	Angela: Nicole, I want to answer all your questions; whatever questions you have. (pauses) May I do that? (Nicole nods, wipes tears from her cheeks, seems to momentarily focus on Angela. Angela pauses allowing space for Nicole to speak. When she doesn't after a moment, Angela speaks again)	
Her use of the open-ended question, "What's concerning you the most" keeps Angela from assuming she knows the client's chief concerns.	Angela: You've asked about your kids. What's concerning you the most about your kids? Nicole: If I've got it, do they? If I've got it, what's gonna happen to them?	
Angela normalizes Nicole's concerns and offers to facilitate testing.	Angela: I think a lot of mothers like you feel so worried about their children when they hear this news — they want to get their children tested. I can help you to do that, if you want. Nicole: Yeah okayButBut what will happen to them if I get sick and die? (She stumbles over her words at this thought, and puts her face in her hands)	

Counseling Notes

Angela's use of Nicole's name at this point is a way to bring her back to the moment, to "ground" her. She offers real hope, made all the more credible because of her own experience working with HIV+patients.

Rather than directly answering Nicole's first question, "How could this happen to me?" Angela hears and responds to the emotions of disbelief and fear underlying the question. She outlines next steps, and again asks for permission.

Angela tries to identify support for Nicole.

Angela is straightforward about the importance and challenge of seeking support. She then facilitates a referral to a counselor who can help Nicole take the next steps.

Client-Provider Dialog

Angela: Nicole, please listen if you can. (Nicole looks up very tentatively. Angela leans toward her and speaks kindly) You can live with this, Nicole. (pauses) People are living a long time with HIV now, as long as they get into care and follow the advice of their doctors. Finding this out today gives you the best chance to be here for your kids....I take care of several patients with HIV—and I can help take care of you, too.

Nicole: But...How could this happen to me? What do I do now?? Angela: This is such hard news to hear...and it must feel just overwhelming to you right now. (pauses to leave room for Nicole to speak — Nicole shrugs helplessly)...Let's take it a step at a time — Let's try to focus on getting you the help and care you need today. Why don't I give the lab a call so that we can get the confirmatory test done, right after we finish here. Is that OK with you? (Nicole nods).

Angela: Nicole, who knew you were coming in today for your check up?

Nicole: My mom has the baby...and she'll get my son from the bus...oh, my mom! This is gonna kill her!

Angela: She loves you a lot ...

Nicole: Uh huh...and I put her through a lot.

Angela: It's really important to have someone you can talk to about this — If you think your mom can handle this news and be there for you, that's great. But you may want to wait until you have the confirmatory test done and you're sure... Once you have told someone you cannot "un-tell" them...so you have to think about who in your life will be supportive... Nicole: (shaking her head) I don't know, I just don't know... Angela: Nicole, there is a counselor here at the clinic right now, someone you can talk to, who'll support you until you're ready to tell your family...Would you like me to take you to her now?

Discussion Questions for Scenario III: Nicole and Angela

- 1. Does this scenario "ring true"? What parts of the scenario seem more realistic/less realistic based on your experience with clients?
- 2. For each of the following aspects of the visit—What do you think the counselor (Angela) did well? What could she have done differently?
 - Stating and explaining the meaning of the test result
 - Listening to Nicole's emotions and fears
 - Helping Nicole to understand that HIV is a treatable chronic illness
 - Assessing Nicole's potential support system
- 3. What are some approaches you yourself have found helpful when delivering reactive (preliminary positive) HIV rapid test results?
- 4. What do you find most difficult/worry most about in delivering a positive HIV test result? What kinds of support or training do you need to help you feel better prepared to do this work?
- 5. In what ways can your clinic or program support you and make it easier for you to deliver HIV rapid test results to clients in an effective and compassionate way?
- 6. Delivering HIV test results can be hard on the provider. What are some ways providers can get support, let off steam and take care of themselves, so they don't burn out?

Delivering HIV Rapid Test Results: Helpful Statements and Questions

Here are examples of "what to say and how to say it" for five key aspects of the visit.

1) Stating and explaining the test result:

- "Your rapid test result is preliminary positive. This means that you are likely to be infected with HIV, but we need to do a confirmatory test to be sure of this result".
- "Your rapid test result is negative—at this time you are not showing signs of HIV infection. It's important to know, though, that if you were infected within the last 3 months, it may not show up on this test. You may want to test again 3 months after the last time you may have been exposed to HIV."

2) Responding to the client's immediate emotional reaction:

- "How are you feeling about this result?"
- "What questions do you have about this result?"
- "What is your biggest concern right now?"
- "What's first on your mind right now?"
- "I can see that this is very upsetting to you. Take your time, we have plenty of time to talk about the result."
- "You seem to have been expecting this result. I'm wondering what is going on for you now."

3) Assessing the client's support network and short term plan:

- "Who can be supportive of you in dealing with this?"
- "It's important to take care of yourself emotionally now. Have you thought about who you can discuss your result with?"
- "How have you handled stressful situations like this in the past? How could that work for you now?"
- What will you do after you leave here? Who will you talk to about this news?"

4) Making referrals:

- "It's very important that you receive regular medical follow-up, even if you are feeling healthy."
- It's very important for you to connect with a medical care provider who can see how you're doing and what the best ways are to keep you healthy."
- "There are a lot of options for people living with HIV. Let's talk about how we can get you into medical care and also other services you may want to consider."
- "If you like, I can take you there now or make an appointment for you."

5) Ending the visit:

- "I'm available if you want to talk more. If you like we can set up a visit right now to check in in a few days."
- "You may have other questions or concerns after you leave today.
 Please feel free to call me. Here's a number where you can reach me."
- "Let me know how to reach you so we can be sure you get the confirmatory test result and get connected with services you may need."

Responding to Difficult Emotions

Learning the result of their HIV test may evoke strong reactions and feelings in your client—anger, sadness, shock, fear, anxiety, grief, uncertainty, confusion, hope and more. When responding to such emotions, resist the powerful temptation to pursue clinical details. Instead, show that you've noticed the client's strong feelings by responding with a **PEARLS** statement, rather than with more questions or information.

P=Partnership

Function: Joint problem solving.

Statements: "I want to help you with this."

E=Empathy

Function: Show understanding. Put feelings

into words. Show compassion.

Statements: "This is so hard." "You look scared." "What is worrying you the most about this?"

A=Apology

Function: Show concern for errors, hurts. **Statements:** "I'm sorry if I (or others) hurt/frightened/upset you."

R=Respect

Function: Value client's choices, traits, behaviors, and special qualities.

Statements: "I appreciate and respect your (courage, decision, action)." "You were

brave to tell me this."

L=Legitimation

Function: Let the client know that his or her response is normal and expected. Validate his or her feelings and choices. **Statements:** "Anyone would be (scared, sad, angry) in this situation."

S=Support

Function: Offer ongoing support

(non-abandonment).

Statements: "I'll stick with you as long as I can." "We'll work together on this." "I'll be there for you."

P=Partnership

E=Empathy

A=Apology

R=Respect

L=Legitimation

S=Support

Adapted from materials developed by the American Academy on Physician and Client Courses Committee, http://nyumacy.edu/facultydev/cards/badnews.html

Tips from Region I Clients Who Have Received

- Tell the client the result right away. (Don't ask them a question that makes them assume the result, i.e., "Would you like me to call in a counselor?").
- Don't read from a file look at the person when you give the result.
- Have empathy and be compassionate.
- Let the client have an emotional response whatever the emotion may be and accept it.
- It's OK for the provider to have an emotional response with the person.
- When receiving a positive test result, clients need support, not education. Schedule another appointment and ask the client to bring a list of questions.
- Help the client think through a support system, someone they can talk to and depend on. Offer to connect the client with a counselor, mental health professional or support group.
- Be available to answer questions when they arise after the visit.
- Many people get depressed in the days after a positive result. Warn the client of this, normalize it, and provide a contact person if they need to talk to someone.
- Give the client hope. Explain that the HIV is longer a death sentence, and that a healthy life is possible.

Tips from Region I Providers Who Have Delivered HIV Test Results

- Don't prejudge what result someone will have. Anyone can be HIV positive.
- Be ready for the full range of possible client reactions.
- Recognize that while many clients will be relieved to receive a negative test result, some will have mixed feelings, including guilt and anxiety.
- Don't assume that a positive result is always completely "bad news". Some clients may be almost relieved to get the result they have been worrying about for years. Others may feel solidarity with their HIV-positive partner.
- Have comprehensive up-to-date referral information at your fingertips.
 Have everything you need to make good referrals on the spot.
- Know "cold" your agency's forms and protocols for dealing with a preliminary positive result. The client needs to feel that you know what you are doing.
- Help the client to understand that HIV is not a death sentence, but a treatable, manageable chronic illness.
- When receiving a negative test result, people are often more open to learning about risk reduction. See the encounter as a "teachable moment".

TIPS FROM REGION I PROVIDERS WHO HAVE DELIVERED HIV TEST RESULTS

- Know your agency's population—what are the common beliefs, perceptions and misperceptions your clients may have about HIV and HIV testing.
- Be aware of the limits of your role—i.e. to give the result, provide some immediate support and give referrals—you can't solve everything. AND remind yourself of the importance of this role—people need to know so they can get care and not spread the virus.
- Realize that this will be hard on you at times—seek support from your colleagues and supervisor.
- Delivering HIV test results does get a bit easier with experience.

What Clinic/Program Administrators Can Do to Support Delivery of HIV Rapid Test Results

SUGGESTIONS FROM PROVIDERS IN REGION I

- Managers should understand that delivering a reactive (preliminary positive) test result requires additional time. Managers should have back-up clinic flow plans.
- Make sure there is always another clinician or counselor on site when HIV rapid testing is being done.
- Every few months check and update the agency's referral directories/ networks for HIV medical care and related services.
- Have regular check-ins with staff who are delivering HIV test results to see how they are doing, and provide support.
- Schedule periodic updates/trainings at staff meetings or other times to ensure that everyone has the latest information on HIV/AIDS, testing best practices, clinic protocols around HIV testing, referral resources, etc.
- Periodically ask staff what would help them to do this job better, i.e. what other support they need from the organization.

Making Effective Referrals

When delivering HIV test results, you will feel more confident and able to help the client if you know that you are well prepared with good referral resources. Most important for clients testing positive is prompt linkage to HIV treatment. Follow your agency's protocols for connecting HIV positive clients with HIV medical care. You should also be prepared to refer your client to other services he or she may need to become better informed, find support, reduce risk, prevent transmission and improve quality of life with HIV.

Staff who deliver HIV test results should have ready access to a comprehensive directory of providers, agencies and programs to which clients can be referred. In addition to listing local sources for primary and specialty HIV medical care, this directory should include the following types of services:

- HIV information lines
- HIV Drug Assistance Programs (HDAP)
- HIV counseling and testing sites
- HIV/AIDS service organizations
- State and city HIV/AIDS programs
- HIV partner services (Partner Counseling and Referral Services)
- Substance abuse treatment programs
- Mental health services
- Domestic violence services
- STD screening and treatment programs
- Hepatitis screening and treatment programs
- TB testing services
- Emergency assistance programs (food, shelter)
- Other services (e.g. health insurance, legal services, housing programs)

Tips for Making Effective Referrals

Here are some tips to help ensure that the referrals you make will meet your client's needs.

- Be familiar with the agencies and programs to which clients are referred. Know the range of services provided, eligibility requirements, hours, location, accessibility by public transportation, availability of child care, financial requirements, etc. as well as the agency's capacity to provide services appropriate to the client's cultural and linguistic background.
- Have a working relationship with a staff person at the key referral agencies. Know a person you can call with questions, or who can act as an advocate for the client at the agency. Clients may be more likely to complete the referral if you can give them a specific person's name.
- Assure the client that his/her confidentiality will be protected. Clients' fears about possible disclosure of their status may make them reluctant to seek needed services. Assure the client of your own and your agency's commitment to protecting the client's confidentiality. It may help to explain that your agency has signed confidentiality agreements with referral agencies.
- Strategize with your client around follow-through. Talk with the client about what would help him or her to make and keep the appointment. If indicated, you can provide direct assistance like scheduling the appointment, or helping to fill out forms.

HIV Referral Guides for New England

The Region I Title X Family Planning Training Center has developed state-specific booklets entitled *I Just Found Out...* for clients newly diagnosed with HIV, and state-specific *Referral Guides* to facilitate the provision of high-quality referrals for HIV-positive clients. Contact the Region I Training Center or visit the website, www.famplan.org, to order or download these materials.

Information and Referral Resources

State Health Departments' HIV/AIDS Programs

Contact your state health department's HIV/AIDS program for information about HIV rapid testing in your state, training opportunities, referral resources, and HIV partner services.

Federal Training Centers in Region I (New England)

The Federal Training Centers also provide information, tools and training around HIV testing and treatment. The Region I Training Centers serve the six New England States.

Region I Title X Family Planning Training Center

www.famplan.org

New England AIDS Education Training Center

www.neaetc.org

Sylvie Ratelle STD/HIV Prevention Training Center

www.ratelleptc.org

New England Addiction Technology Transfer Center

www.attcnetwork.org/regcenters/index_newengland.asp

New Jersey Medical School Global TB Institute

www.umdnj.edu/globaltb/home.htm

For HIV Testing Guidelines

Centers for Disease Control and Prevention

www.cdc.gov/hiv

Helpful Websites for Clients/Patients

The Body: HIV/AIDS resource site for people living with HIV

www.thebodv.com

Federal HIV/AIDS information and resources

www.aids.gov

Medline Plus (look for AIDS under Health Topics tab)

http://medlineplus.gov

AIDSinfo (U.S. Dept. of Health and Human Services)

www.aidsinfo.nih.gov

To share your thoughts and feedback on the video and discussion guide, please contact the Region I Family Planning Training Center: https://www.surveymonkey.com/s/deliveringhivresults





