



*François-Xavier Bagnoud Center*  
University of Medicine & Dentistry of New Jersey

# **Trainer Manual**

*for Community Advisory Boards*

**Module 8**  
Community Assessment

Version 1.0 – May 2007



## MODULE 8: COMMUNITY ASSESSMENT

### Proposed Agenda\*

**Opening Activity: Community Linkages** *(30 minutes)*

**Slides and Discussion** *(60 minutes)*

**Activity: CAB Work Plan** *(60 minutes)*

**Participant Evaluation** *(20 minutes)*

\* *Suggested time frames for sessions are ideal and may be adjusted to meet the time available and the needs of the site*



# OPENING ACTIVITY

## Module 8

### Community Linkages

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Time frame **(30 minutes)**

#### Purpose

To begin creating a referral list for families with HIV

#### Introduction

Every CAB should have a referral list that includes all of the places and people in the community that families might go to for any type of service related to HIV care (eg, health care; nutrition information; social, spiritual, and psychological support; education about HIV; housing; general financial assistance; food banks).

#### Materials needed

- One copy of each of the participant worksheets: **Healthcare Resources, Community-based Programs, and Other Programs.**

#### Instructions

- **Please note:** This exercise will be enhanced by providing (if possible) participants with instructions and forms *in advance of the training.*
- Explain that a complete referral list has several purposes:
  - Anyone on the CAB who has contact with HIV-affected families will know where they can send families to get the help they need.
  - When exchanging information about resources, CAB members will be creating and maintaining key linkages to groups in the community.
  - The CAB can use the list as a resource for finding out more about their community; and for getting to know other groups that can help with community assessment.

**Example:** if you discover there are many churches providing spiritual and financial support to families with HIV, the churches would be a good place to meet affected families and learn about their concerns, needs, knowledge of research, etc.

- Divide participants into 3 groups.
- Give each group a different participant worksheet: the first group will get **Healthcare Resources**; the second, **Community-based Resources**, and the third, **Other Resources.**
- Have each group choose a recorder, who will write the list, and a reporter, who will present the list to the group as a whole.

- Explain that each group will work together to create a list of the resources — services, agencies, and programs in their communities — that families affected by HIV need for comprehensive care.
- Tell participants that this list as must be very specific about the type of service provided and who should be using the service (who is eligible) so as to avoid inappropriate referrals.
- Tell participants they will have 20 to write their lists.
- At the end of 20 minutes, ask that the groups stop their work.
- Ask for a volunteer to be the first reporter to read their group's list to the group as a whole.\*
- After the first group finishes reporting, ask participants if they have additional resources to suggest so that the entire group can contribute all they know to each list.
- Because participants may not have all the information they need to complete the resource list (unless you were able to give them the list in advance of the training), you may want to schedule follow up finalization of the list for the next CAB meeting. This will give participants an opportunity to bring more information to include on the list.

### Debriefing

- Although the list will be useful for CAB members as they work and live in the community, it should also be shared with the clinicians and researchers at the site so that everyone is knowledgeable about where to send people for help.
- Emphasize that CAB members, the clinical and research teams, and families with HIV need to communicate often to keep the list accurate and up-to-date. Keeping the list comprehensive and current must be an ongoing project. The CAB may want to consider asking for administrative help with this referral resource list.

## PARTICIPANT INSTRUCTIONS

### COMMUNITY RESOURCES AND LINKAGES

**Instructions:** For this activity, first create a list that includes the services, agencies, and programs families affected by HIV need for comprehensive care (For example: dental care, food and nutrition support, support groups, legal help, etc.). Then work with your colleagues to create a referral list of specific agencies and groups that CAB members and clinicians can use to help patients obtain needed services.

**Note:** Before using this list as a resource for families, make sure the list is *very specific* about the service provided and for whom the service is intended (who is eligible).

#### Examples of Healthcare Resources

- Family planning services
- Pediatric HIV healthcare professionals and clinics
- Adult HIV healthcare professionals and clinics
- Agencies and programs that provide care for all family members when a parent or child has HIV
- Dental care
- Addiction treatment services

#### Examples of Community-Based Programs

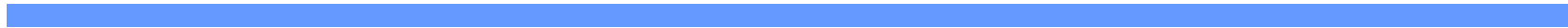
- Faith-based services (AIDS ministries, family support activities)
- Other family support services
- Financial aid
- Legal services
- Nutrition support services
- Housing services

## PARTICIPANT WORKSHEETS

### Healthcare Resources

Type of Service	Who can receive services?	Name, Address	Contact Information
<p><b>EXAMPLE:</b> Family planning</p>	<p>Girls, women of childbearing age and their partners</p>	<p>UNICEF #3 Street Town</p>	<p>Name: Mrs. Rachel Abraham  Telephone numbers: 509-123-4567 (office) 509-765-4321 (cell)  Email address: abrahamra@yahoo.com</p>
			<p>Name:  Telephone number:  Email address:</p>
			<p>Name:  Telephone number:  Email address:</p>
			<p>Name:  Telephone number:  Email address:</p>

## Healthcare Resources



Type of Service	Who can receive services?	Name, Address	Contact Information
			Name: Telephone number: Email address:
			Name: Telephone number: Email address:
			Name: Telephone number: Email address:

## Community-Based Programs



Type of Service	Who can receive services?	Name, Address	Contact Information
			Name: Telephone number: Email address:
			Name: Telephone number: Email address:
			Name: Telephone number: Email address:

## Community-Based Programs



Type of Service	Who can receive services?	Name, Address	Contact Information
			Name: Telephone number: Email address:
			Name: Telephone number: Email address:
			Name: Telephone number: Email address:

## Other Programs



Type of Service	Who can receive services?	Name, Address	Contact Information
			Name: Telephone number: Email address:
			Name: Telephone number: Email address:
			Name: Telephone number: Email address:



## **Module 8**

**Slides - Insert Here**






Slide 1




## Slide 2

This teaching tool was developed by the François-Xavier Bagnoud Center at the University of Medicine and Dentistry of New Jersey, with the support of the International Maternal Pediatric and Adolescent Clinical Trials (IMPAACT) network.

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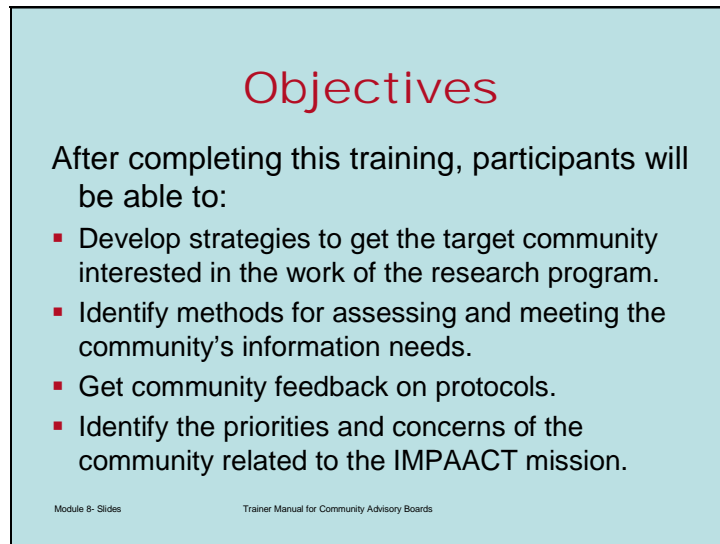
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## Slide 3



## Objectives

After completing this training, participants will be able to:

- Develop strategies to get the target community interested in the work of the research program.
- Identify methods for assessing and meeting the community's information needs.
- Get community feedback on protocols.
- Identify the priorities and concerns of the community related to the IMPAACT mission.

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This slide lists the objectives (or goals) for this training module. The slides we will show and the activities planned for this training all relate to the following questions:

- What strategies can CABs use to involve the community in the research program?
- How can the CAB assess the community's learning needs related to IMPAACT research?
- Once the needs are identified, how can the CAB help meet these needs?
- How can the CAB collect information about the community's concerns and priorities regarding the research projects planned by the IMPAACT network?

## Slide 4

## Community assessment: steps

1. Identify goals.
2. Choose target community.
3. Determine what information is desired.
4. Select questions to ask.
5. Find links to community.
6. Talk to people.
7. Identify what information is not available.
8. Share results and make a plan.



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While every community and every CAB is unique, the steps for community assessment are basically the same, wherever it is done. We will talk about each of these steps as we go through the rest of the slides.

- Identify goals.
- Choose target community.
- Determine what information is desired.
- Identify what information is not available.
- Select questions to ask.
- Find links to community.
- Talk to people.
- Share results and make a plan.

## Slide 5



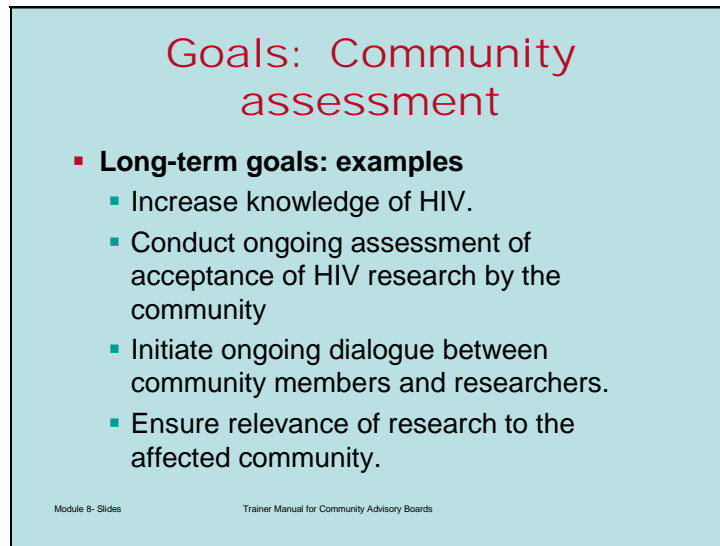
**Goals: Community  
assessment**

- **Short-term goals: examples**
  - Assess the community's
    - Knowledge of research
    - Priorities for research
    - Concerns about research
  - Find out about community's knowledge of HIV.
  - Prepare a foundation for ongoing dialogue.

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- The short-term goals of community assessment may focus on finding out how much community members know about research and how they feel about it. If there is a lot of distrust about research, or they have heard about a study that found a beneficial treatment, it's important for you to know that. .
- You probably will also want to find out what the community's priorities are for research. Is there a problem with HIV treatment they feel is especially important to address?
- The community may need basic information about HIV before even beginning to learn about research. So another piece of the puzzle is finding out what the community knows and what it doesn't know.
- These conversations with community members have an additional goal, one that is just as important as the others. While talking with community members, CAB members are building a foundation for an ongoing dialogue.

## Slide 6



**Goals: Community  
assessment**

- **Long-term goals: examples**
  - Increase knowledge of HIV.
  - Conduct ongoing assessment of acceptance of HIV research by the community
  - Initiate ongoing dialogue between community members and researchers.
  - Ensure relevance of research to the affected community.

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- The long-term goals are based on the information gathered from the community in the earlier stages of the assessment. Now that you have some information about the community “baseline” knowledge and feelings about HIV and research, and about problems or questions people have, what are the next steps?
- At this point, you may want to develop a work plan to help achieve the goals. For example, if you found that people had very little knowledge of research, how might the CAB address the need for information? Are there groups or people in the community who might help you with providing education?

## Slide 7



**Goals: Community  
assessment**

- **Long-term goals: examples**
  - How do participants in the research feel about the experience?
  - What are the reasons why some people choose not to participate?
  - How do participants feel about the informed consent process?
  - Do people feel free to decline to participate?

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When the research is underway, CAB members may want to assess how things are going. For example:

- How do participants feel about the research team? Do they feel informed? Free to ask questions?
- What problems are participants experiencing? Do some people find participating a burden?
- Are people who decline to participate fearful? What are other reasons for people choosing not to participate? Are there issues that the CAB, or the research team, should address?
- How did the informed consent process go? Do participants feel they really understood everything about the study before they gave their consent? Did they feel free to say no, or pressured to say yes?

## Slide 8

Module 8 - Slides

Trainer Manual for Community Advisory Boards

**Discussion:** What do we need to know about the community to plan our work?

**Trainer:** Try to get suggestions from the participants about what they need to know about their community. Tell the participants that there are no “right” or “wrong” answers.

Give participants time to think and offer suggestions. If they have none, you may want to begin with one or two of the suggestions below.

**Suggestions:**

- What does the community know about research?
- What are their concerns about it?
- What common myths or misinformation do they have about research?
- Do people have experience with research? Were these experiences good or bad?
- What is the impact of HIV in this community? Do people talk about it much?
- How much knowledge do people in the community have about mother-to-child transmission of HIV (or pediatric HIV or adolescent HIV)?
- What access to HIV treatment is available to this community -- other than participating in research?

## Slide 9

**Choosing a short-term goal**

- Assess the community's knowledge of and concerns about research.

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As a case study (or example), let's say that for your first short-term goal you have decided to assess the community's general knowledge of and concerns about HIV. The next series of slides will walk you through the steps in that process.

## Slide 10

**Choosing the target community**

- Who will be the target population in this trial?



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**Discussion:** Who might be your target audience?

Ask participants to respond before offering suggestions.

**Suggestions:**

- If your site is doing PMTCT studies, would you want to look specifically at what pregnant women, and women of childbearing age know and think about research?
- What If you are doing an adolescent study—who would be your target audience?


**Discussion:**

- Most IMPAACT studies are oriented toward families (because they study pregnant women and children). Why would it be important to find out what other members of the family know and think about research? Do fathers have an important say in health care decisions?

## Slide 11

## Identifying links to the community

- What do other people or groups know this population?
  - HIV service organizations, NGOs
  - Support groups
  - Members of the research and healthcare teams
  - Teachers or others involved with children and teenagers



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Once you know what to ask, the next step will be to decide who, in addition to people who are HIV-infected and -affected, will be resources for information. There are groups in the community that will be able to give you valuable feedback. These groups include HIV service organizations; nongovernmental organizations; HIV support groups; clinical care and research team members; and teachers, youth workers, and youth leaders.

**Trainer:** Ask the participants if they can think of other groups or individuals who would be valuable resources for information about their community. Give participants time to think and offer suggestions. If they have none, you may want to begin with one or two of the suggestions below.

**Suggestions:** Clergy, tribal and other community leaders, teachers, shop owners

## Slide 12




- How the CAB collects information depends on the nature of the community you represent and the cultural norms at your location. Commonly, a good place to start asking questions is in the clinic. HIV-affected or -infected people waiting their turn at the clinic are some of the very people the CAB is trying to serve, so connecting with people on site is an important start.
- Some CABs give informational talks at places where people from the community gather, such as churches, social events, and schools. These are important places to not only provide information, but also to gather information.

**Trainer:** Ask the participants if they can think of one or two examples of different places where they might meet people to include in the community assessment.

## Slide 13

## Talking to people

- You may use the same or similar questions as a general guide (rather than a script) to start discussions with community members.
- When all members use similar questions, it's easier to compare answers when you come together to share what members have learned.



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- When you have the list of questions, make sure each CAB member has a copy of them. When you talk with community members, you can use these questions to get the conversation started. When the conversation begins to slow down and there are pauses, you can ask another question on the list to get the conversation started again.
- There is another reason to hand out this list of questions. When each CAB member asks similar questions, it will be easier to compare the answers when you meet as a group after the community assessment.

## Slide 14

## Identifying missing information

- Where are the gaps in our knowledge?

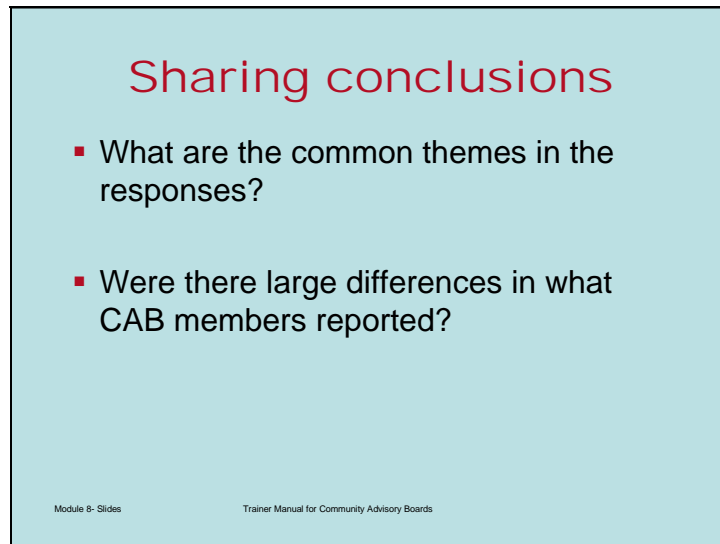
Module 8- Slides  
Trainer Manual for Community Advisory Boards

Once the CAB members have shared all the information they have collected by asking the community assessment questions, it's time to think about whether there is missing information. For example, you may lack **epidemiologic** information, such as:

- The percentage of pregnant women in antenatal care who are HIV-infected
- The percentage of these women receiving ART for PMTCT
- The estimated number of teenagers infected with HIV in your community.

After you determine what you don't know, you can make a plan for gathering that information.

## Slide 15



**Sharing conclusions**

- What are the common themes in the responses?
- Were there large differences in what CAB members reported?

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- When you share your answers with each other at a CAB meeting, listen for the topics that get mentioned again and again. This will help you learn about common themes community members spoke about. Maybe several of you learned that community members have little or no experience with research. Or you learned that community members are very suspicious and distrustful of researchers.
- It is also possible that you will find large differences in what CAB members learned. For example, one CAB member may have learned that parents are eager to get the best care for their children so they are interested in volunteering for a study. Another CAB member may have found that parents do not want to participate in research because they are afraid of what will happen if the medicine doesn't work.

It is important to know about these different experiences and feelings, because you will use that information to select the topics you will talk about in the next discussions you have with community groups or with individuals.

## Slide 16

### Sample work plan

Goal	Activities and assignments	Date due
1. Assess knowledge of research	<ul style="list-style-type: none"><li>▪ List questions.</li><li>▪ Identify participants.</li><li>▪ Assign CAB members.</li></ul>	5 May
2. Identify learning needs.	<ul style="list-style-type: none"><li>▪ Do community assessment.</li><li>▪ Report back.</li></ul>	20 June
	<ul style="list-style-type: none"><li>▪ Discuss results.</li><li>▪ Determine next steps.</li></ul>	10 July

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Now that you have collected from the community the information you need to move forward, it is time to write a plan for achieving your goals. Here and on the next slide is a sample work plan. Having a plan will keep you focused on your goal, and on the steps you need to take to reach it.

**Trainer:** Review slide.

## Slide 17

**Sample Work Plan cont.**

<b>Goal</b>	<b>Activities and assignments</b>	<b>Date due</b>
3. Create plan to address learning needs.	<ul style="list-style-type: none"> <li>▪ Plan time, place, participants, methods.</li> <li>▪ Work with team to develop teaching tool.</li> </ul>	12 August
		10 September
4. Increase knowledge of research.	<ul style="list-style-type: none"> <li>▪ Implement plan.</li> <li>▪ Evaluate results by interviewing participants.</li> <li>▪ Report back to CAB.</li> </ul>	1 October
		30 October
		15 November

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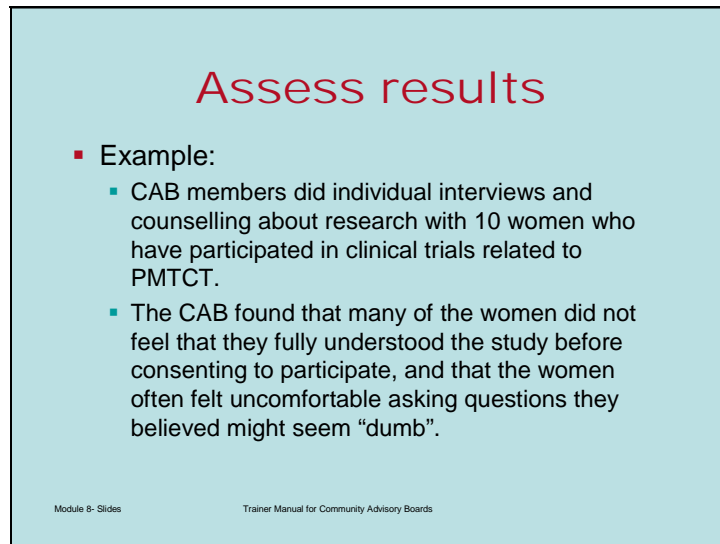
And when you have a plan, it is necessary to remember that you can change it as your work progresses. Maybe your CAB needs more time to do the community assessment, so you move the due date forward a week.

**Trainer:** Review Slide

**Discussion:** Ask participants what events or situations may make it necessary to revise their work plan.

**Trainer:** Maybe there is a community-wide event that is scheduled after you set your due dates, and the event interferes with your assessment. Or maybe some of the CAB members cannot devote the time they thought they could to participating in the assessment. Whatever the change is, you will find a way to rework the schedule.

## Slide 18



**Assess results**

- Example:
  - CAB members did individual interviews and counselling about research with 10 women who have participated in clinical trials related to PMTCT.
  - The CAB found that many of the women did not feel that they fully understood the study before consenting to participate, and that the women often felt uncomfortable asking questions they believed might seem “dumb”.

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- This slide shows a *summary* of the results of a community assessment. The CAB members in this case interviewed 10 women who had participated in a PMTCT study. The CAB members based their interviews using the same questions, took note of what they women told them, and then compared the information and summarized it.
- In this case, the CAB gained very important information. The informed consent process at the site is inadequate, because women are not getting enough information, and they are reluctant to press for more information by asking a lot of questions that might make them look less intelligent.

## Slide 19

**Assess results**

- Example:
  - The CAB shared the results of these interviews with the research team in order to make them aware of some problems participants identified related to research.
  - The CAB worked with the research team to identify ways to better communicate and support research participants to address these problems.

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- The CAB shared the results of these interviews with the research team in order to make them aware of the problems participants with the informed consent process, and worked with the research team to develop an intervention. The intervention included changing the informed consent process, including adding a “peer educator” to the research team, and formalizing a comprehensive review of the informed consent form by the CAB.
- In this case, then, the community assessment done by the CAB resulted in gaining important information that had a positive impact on the way the research team performed its work.

## Slide 20



**Discussion question:** Once the changes to the informed consent process are implemented, is the work of the CAB related to informed consent finished?

- No! The CAB does not yet know whether the interventions to the process are effective or not.
- The CAB will want to follow up after the changes to the informed consent process are implemented in order to see if the changes are having the desired effect. Do women enrolling in PMTCT protocols after the changes to the informed consent process feel more confident that they understood the study before consenting? Do they feel comfortable asking questions? Does the availability of a peer educator make it more likely that women will ask questions? Has enrollment improved because women now feel more comfortable working with the research team?
- The CAB will want to plan to do similar interviews with more research participants to see if the changes are having the desired impact on participant understanding of the research.
- This follow up is important, and is illustrated on this slide. The process of listening to the community is ongoing. It is not a one-time event. Community assessment is an ongoing and never-ending process. While the CAB cannot do everything, even small assessments and interventions like the one we've just described make an important impact in the lives of people with HIV, their families, and on the quality of the research program.

## Slide 21

### Summary

- The purpose of conducting an assessment is to learn about the community's information needs and their concerns about research.
- Another important goal of community assessment is building the foundation for an ongoing dialogue between CAB members and the community about the research.
- The results of a community assessment should be shared with the research team so that the team can incorporate this information into the research program.

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- The purpose of conducting an assessment is for CAB members to learn about the community's information needs and concerns related to research.
- Based on the assessment's results, CAB members will make a plan to explain the IMPAACT's mission, answer questions, and address community members' concerns about research.
- Another important goal of community assessment is building a foundation for an ongoing dialogue between CAB members and the community about the research. With this ongoing conversation, the CAB members will be aware of any new concerns and the need for any additional during the course of the research.



# TRAINER INSTRUCTIONS: WORK PLAN DEVELOPMENT

## Module 8

Time frame **(60 minutes)**

### Purpose

To give participants an opportunity to practice the information from the slide presentation by working together to create a work plan related to community assessment.

### Materials needed

- Worksheets (for all participants): CAB Community Assessment Planning
- Copies of Module 8 slide handout (for all participants)
- Flip chart or blackboard (*optional*)

### Instructions

- Explain to participants that each group is going to create a work plan that addresses one goal for the CAB related to community assessment.
- Divide participants into groups of 4-5 people each. (If there are only 4-5 participants in the training, they may still work together as one group).
- Instruct participants to discuss the plan first by referring to the slide titled “Community Assessment Steps”. Their task is to start a community assessment work plan by accomplishing the first 5 steps listed on the slide:
  1. Identify goals
  2. Choose a target community
  3. Determine what information is desired
  4. Select questions to ask
  5. Identify links to the community
- The goal chosen by each group can be a short-term or a long-term goal. For less experienced CABs, it may be easier to work with short-term goals. Samples of possible goals to identify are included on the slides.
- The target community should be a community related to the research being done at the site (For example, the target community might be pregnant women if the site is actively recruiting pregnant women for a study).
- Groups may limit the questions that they expect to ask to 5 or fewer questions (although groups may do more if they would like to).
- Identifying links to the community essentially means “Where will you find and speak to the target community”. There may be more than one location to list.

## Debrief

- Facilitate discussion as each group reports on the work plan they have created.
- Ask the CAB to consider how to prioritize the work plans. Will the CAB actually complete the community assessment steps identified on one or more of the work plans? Discuss ways that this might be accomplished, how to move to the next step, etc. so that the CAB can complete at least one full assessment and report on it.
- Assist the CAB in identifying where they can get support and help with the assessment as needed.

Thank the group for their hard work!

## WORKSHEET

### CAB COMMUNITY ASSESSMENT PLANNING

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Goal	Population	Linkages	Questions	Plan

## PARTICIPANT WORKSHEET - PAGE 2

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Goal	Population	Linkages	Questions	Plan

# Participant Evaluation Form

## Module 8

### Community Assessment

#### INSTRUCTIONS:

- Your opinion is important to us.
- There are no RIGHT or WRONG answers.
- Your answers are private. You do not need to put your name on this form.
- Please answer ALL the questions to help us improve this training.
- For questions 1–4, please rate the *effect* the training has had on your understanding of the following:

0= No effect, 1= Some effect, 2= Much effect	No Effect	Some Effect	Much Effect
1. Engaging the target community in the work of the research program	0	1	2
2. Assessing and meeting community's information needs	0	1	2
3. Getting the community's feedback about research protocols	0	1	2
4. Identifying the priorities and concerns of the community related to the IMPAACT mission	0	1	2
For the last 2 questions, 0= not useful, 1= useful, 2= very useful			
The materials in the training manual	0	1	2
This training as a whole	0	1	2

*Please answer the following questions to the best of your ability:*

After this training, what help might you need to apply this information?

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What changes would you suggest to make the training more useful?

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What part of this training did you find the **most useful**?

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What other training programs do you feel are important for CAB members?

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Other comments:

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***Thank you for your comments!***

# TRAINERS' ASSESSMENT: POST-TRAINING

## Module 8

### Community Assessment

*Please help us evaluate the training for this module by telling us about the level of improvement you observed in the participants' knowledge of Community Assessment.*

	NO IMPROVEMENT	SOME IMPROVEMENT	MAJOR IMPROVEMENT
1. Getting the target community interested in the work of the research program	0	1	2
2. Assessing and meeting the community's information needs	0	1	2
3. Getting the community's feedback about research protocols	0	1	2
4. Identifying the community's priorities for and concerns about IMPAACT's mission	0	1	2

What changes would you suggest to make the training more useful?

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What part of this training did you find the **most useful**?

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Trainer Name:	Signature:	Date:
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***Please use the back of this form for additional comments and suggestions***