5

Identify and Describe Stakeholders
Introduction

As you outline the broad context of your trial, you have probably begun to identify potential stakeholders and to collect relevant information about them. This step will help you create a comprehensive list of individuals and organizations that have a stake in your project, compile background details about them and organize these data in a useful way. Taking the time to identify and compose descriptive profiles of key stakeholders will provide an invaluable resource to you throughout the project.

Many nonprofit organizations and research teams tend to collect this information informally. They often rely on a single, well-connected individual to develop relationships with partners. This informal style makes the institution vulnerable should that person leave the organization or not be available at a critical moment. It could also limit the diversity of the stakeholders that might be identified. You can avoid that pitfall by acting as a team. Act as a group when you identify whom to contact, document the results of contacts, and have mechanisms to share successes, challenges and lessons learned.

Learning what you can about your stakeholders will also help you to develop relationships with them. Begin this work early, and continue it throughout the project. Taking the time to identify and describe stakeholders will also provide an important foundation when translating findings into intervention programs.1

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Goals of Step Five

- Compile a thorough list of key local, regional, national and global stakeholders.
- Collect relevant data about these individuals and organizations using information-collection sheets.
- Create a system for organizing this information.
- Contact stakeholders.
- Secure the active involvement of a core group of stakeholders.
- Maintain a stakeholder database, and update the profiles throughout the life of the project.

Why you need to identify and describe stakeholders

A systematic approach in Step Five will make it much easier for your team to:

- Identify the organizations and individuals who are relevant to your project.
- Decide who to contact and how to contact them.
- Create a database that will be useful for this project and for future research.
- Obtain suggestions for other stakeholders whose involvement may be critical to the success of your research.
- Use stakeholder information throughout the project to conduct meaningful preliminary research in the community, explain trial goals and make accurate statements about the generalizability of your trial’s conclusions.
1. **Host an in-house brainstorming session.**

   **Action:** Get the team together and make a list of everyone that you can think of who might be interested in, benefit from, apprehensive about or alienated by your project.

   **Result:** You will have a great starting point for identifying stakeholders for your project without having to do any external research.

   **Explanation:** The first step in identifying stakeholders is using the resources that are right in front of you. People who are part of your trial team may already have good connections to or knowledge of individuals and organizations that have a stake in your project. By using those connections as a starting point, you'll be well on your way to developing a comprehensive list. Be mindful, however, that your team may have a limited scope. For example, your team may know many researchers but no advocates, or many health service providers but no one in the target population. It's important to realize that this is just a first step toward developing an inclusive list of stakeholders. Use the Stakeholder Identification Sheet (Tool 5A) to help you organize this initial list.

2. **Develop stakeholder descriptions.**

   **Action:** Now that you have a list of stakeholders, collect some information about them.

   **Result:** You will have an annotated list that includes contact information, background details, and selection criteria to make it easier for you to prioritize whom to contact, when and why.

   **Explanation:** Although the first part of this step is relatively informal, making sure that you systematically decide whom to contact can help you to control the process. Be sure to collect contact information, including email addresses and phone numbers. It is also helpful to collect background information such as press releases, white papers and statements released by the organizations. Make notes about potential referrals that you may receive.
from these individuals or organization.\footnote{Schmeer K. Guidelines for conducting a stakeholder analysis. Bethesda, MD: Partnerships for Health Reform, Abt Associates Inc.; 1999 Nov.} Tool 5B: Stakeholder data collection sheet and Tool 5C: Identification of stakeholder roles can be modified to suit the needs of your project, and they will help you collect this information in a systematic way.

### General guidelines for identifying stakeholders

- Identify the individuals and organizations that will be directly or indirectly affected by the research.
- Identify the individuals or organizations that will support the research. Determine what they might contribute to the research and what they might gain from it.
- Identify individuals or organizations that will oppose the research. Determine why they are opposing it and how you might address their resistance to the research.
- Determine the best way to leverage insights or address objections and concerns.
- Itemize your objectives for engaging each stakeholder on your list.


3. **Refine your list.**

**Action:** Based on the information you gathered in Task 2 above, reduce your list of stakeholders to a more manageable size, making sure that all the relevant groups are represented.

**Result:** You will have a targeted list of people to contact as partners for your project.
Possible secondary sources of information

- Newspapers
- Institutional reports and publications
- Speeches
- Political platforms
- Annual reports (staff size and number of offices)
- Websites and Internet searches
- Expenditure data
- Other studies and opinion polls


**Explanation:** It is a good idea to start with an exhaustive list of every person and organization that might have a stake in your project. But this list will not be useful unless it has been carefully edited to suit your purposes. Do you have adequate representation of the relevant groups? Advocates? People living with HIV or AIDS? Is your list culturally diverse? Do you have representatives from the target population? If not, how will you make sure they are included? You will need to answer these questions before you take the next step.

Your team should prioritize the list of potential stakeholders to include only those individuals or organizations that have a direct interest in the trial and could impact its implementation.³ Use **Tool 5A: Stakeholder identification tool** to organize this information.

4 Create an electronic database.

**Action:** Create a shared database where you can store contact information and other relevant details about the stakeholders.

**Result:** By keeping all this information in a single location that the team can access, you will make communications and follow-up more efficient. This database should also make it easier for your team to contact stakeholders for future studies and initiatives.

**Explanation:** Develop a system that works for your team. For example, some of these data may need to be confidential, particularly if you are including participants or people who are HIV positive. But it is also important that members of the team can access contact information when they need to. Determine who will manage the database, and come up with a protocol for how to access it. Update the database regularly when contact information changes, if a person or organization drops out or if a new stakeholder comes on board.

Note how often organizations wish to be involved, and include some notes about past interactions.

For an in-depth discussion on how to work with the media, please refer to the *Communications Handbook for Clinical Trials.*

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*Start as early as possible! There’s a constant tension between the community and scientists coming up with a research idea. What we often hear from the community is, “Yes, we can help if you bring a study to us midway through the development process, but it would have been more helpful if we could have given our input from the beginning.”*

– Sam Griffith, Operations Manager, HPTN 061

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5 Approach the individuals and organizations on your list.

**Action:** Call or email the people on your list and invite them to participate in the project.

**Result:** You will have a preliminary idea of who will participate in your process.

**Explanation:** Identify the best person on your team to approach each stakeholder. Might it be someone who knows them? Should you get an introduction from a mutual acquaintance? If the person is busy, would it be best to approach them by email or by telephone? Would a letter be better? What is your plan for following up if the individual does not respond to initial overtures? And how will you extend the invitation? Once you ask them to participate, make sure they feel that they are part of the process. For example, you may invite them to join the CAB or attend an open house to find out more about the project. Use Tool 5D to plan and track initial contact with new stakeholders.

6 Conduct interviews and record notes.

**Action:** Once you have made the initial contact with stakeholders, schedule a short interview with them.

**Result:** Taking the time to gather in-depth information will help you develop a more accurate description of the people you have identified.

Identifying stakeholders is something you do throughout your project; maintain relationships and get new relationships, pulling in new stakeholders as you realize that they should be involved. It’s something that you have to keep in mind, throughout the project.

— David Jolly, N.C. Central University
Building relationships in LinCS 2 Durham

Randy C. Rogers, M.S., Durham County Health Department and LinCS 2 Durham HIV Prevention Project, Durham, North Carolina

For the LinCS2 Durham study, the research team created a list of people to contact. Given my role in the community, I began to identify folks who were active in HIV work: folks from AIDS service organizations, the Durham Housing Authority and college students. We also identified stakeholders through word of mouth, and we had them refer us to others. It was important to connect with people we already had an established relationship with, who lived in Durham and who were cognizant of research in general. These people could then spread the word and raise awareness about the study.

Initially we invited members of the community to open houses in different areas of the city. We invited people who had different roles — faith-community leaders, those who lived in housing development communities, clinicians and providers who worked with individuals with HIV.

I collected their contact information and age, and tracked their stakeholder role, as I perceived it. If they became involved more intimately, we had them identify their role — for example, grassroots, research enterprise, program or target population. I continue to manage the database in terms of updating the information, and I’m the only one who can edit. We have a Wiki website, and the database is on there so that staff can access it whenever they need to. If there are referrals for potential stakeholders, usually they will be fed through me.

Part of being successful in identifying stakeholders is talking with a community member who is influential and asking him or her about the best way to connect in a way that’s respectful, genuine and shows that you want this to be a partnership and cooperative effort. That’s the baseline. If you don’t know folks directly who can be of assistance, be able to ask, “Whom do I need to talk to? What is the most respectful and appropriate way to approach the community?” Building relationships can be labor intensive, but the most important thing is establishing relationships that are built on trust. It will take some time.

Randy C. Rogers is a health education specialist with the Durham County Health Department and serves as the collaborative council coordinator for the LinCS 2 Durham study.
Explanation: The interviewers should follow the protocol established by the group, with one person as the lead interviewer. Four major attributes are important for describing stakeholders: their position on the issue, the level of influence they hold, the level of interest they have in the trial and the group or coalition to which they belong or can reasonably be associated with. Review any background literature about the group or coalition before you start to collect the data. Do your homework and show up prepared.

If your team is fairly knowledgeable about one of the groups or individuals on the list, you may not need to interview them. Your goal is to make sure you know enough details to adequately engage each stakeholder.

7 Get referrals.

Action: When you contact stakeholders, be sure to ask them to recommend other potential stakeholders, even if they decline to participate.

Result: You will have a richer pool of stakeholders. And you may get recommendations of stakeholders that you might have overlooked. Some names will come up repeatedly, which will help you understand who the “prime movers” are.

Explanation: Aside from gathering a more comprehensive list of stakeholders, taking the time to ask for recommendations shows that you are sincere about building partnerships and drawing on the expertise of everyone you contact.

8 Classify stakeholders according to type.

Action: Using the information gleaned from your experience, the interviews and the background information, classify each stakeholder according to broad groups. Record their views of your trial.

Result: You will have an easy-to-use index of the stakeholder groups (and their interest in the trial) that you can use for focus groups, communications, media and other situations where you might need stakeholder feedback.

Getting the target population to the table

David H. Jolly, Ph.D., N.C. Central University, Durham, North Carolina

With the LinCS 2 Durham project, I don’t think there was anything magical or formal about identifying stakeholders. It was a matter of pulling various people together and brainstorming; it’s a known community. We drew on personal contacts, and that gave us a great list of people who work on HIV in Durham. Our target population consists of 18- to 30-year-old black adults in Durham, and we wanted to make sure the target population was represented well in our collaborative council. But we’ve been much less successful in getting our target population to the table.

One thing that made it difficult is that our collaborative council has regular two-hour meetings. We meet monthly, which involves a higher level of commitment than is usually asked of a community advisory board. This structure works for older people and professionals who are used to meetings with an agenda. That is not a model that appeals to young people. We have had young people come to a meeting or two, and then they just disappear. And we have not had much success with our social networking attempts through our website, Facebook or Twitter.

So we have devised another model. It’s called the “target advisory board.” It does not involve the level of commitment required by the collaborative council. It involves a series of meetings in which we discuss the project and get feedback from young black adults. But there is no expectation that they need to come to more than one meeting. The agenda is structured so that we can gather information or ideas about an issue or problem in a single meeting. It is led by research team members who are themselves 18- to 30-year-old black adults.

With any of these projects, it is going to be easy to identify policymakers, service providers and others. But just because you come up with a good list of these folks, don’t feel too smug. It is critical to get key community people, and that can be a labor-intensive process — you need to identify those people, engage them, gain their trust and get their commitment. That takes a long time. If you are not from that community, it’s going to take a lot longer. Identify some bridge people, and work with them.

Associate Professor David Jolly chairs the Department of Public Health Education at N.C. Central University.
**Explanation:** Different kinds of stakeholders will have different concerns relative to the research and are likely to require different engagement strategies. Five broad groups of stakeholders need to be included in your efforts. By categorizing your list of stakeholders into these five groups, you can quickly see major gaps. These are the five major stakeholder groups:

- Trial participants and their families, partners, neighbors and co-workers
- Local community members
- Health care programs and service providers
- Researchers, funding agencies and regulatory bodies
- HIV and AIDS policymakers and advocates

You may also wish to create descriptive subcategories to further document stakeholders encompassed in these broad groups. For example, under local community members, you might have people living with HIV or AIDS, faith leaders, nonprofit workers and brothel owners; under health care programs and service providers, you might have private physicians and family planning clinics; under HIV and AIDS policymakers and advocates, you might have

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**Pitfalls to avoid**

- Inviting only stakeholders who agree with a proposed plan
- Selecting only stakeholders from the organizations that are directly involved in the trial
- Omitting certain groups of stakeholders
- Inviting stakeholders to a preliminary briefing but not including them in decision making, problem solving or trial design
- Including stakeholders who may not be able to contribute or make decisions because they do not have that power in the community or the organization
- Creating expectations about the project at the beginning, but doing little or no follow-up about the results of the initiative

ministry-level officials and civil society organizations. You should use the level of detail that is most helpful for your trial and context.

Having gathered information about the stakeholders, their interests and their capacity to oppose or support the trial, the research team can decide how to best integrate the stakeholders’ concerns into the research.6

Other tips:

- Organize your list of stakeholders according to their relative power (influence), so that you can better understand their potential effect on the trial.
- Consider using a matrix to organize and classify the information. Such a matrix can provide an at-a-glance grouping of the stakeholders into those that have something to gain or lose from the trial and whether they can significantly affect the process.7
- Use Tool 5C: Identification of stakeholder roles to organize this information.

9 Secure active involvement from the partners.

Action: Invite stakeholders to an event or a meeting where you can outline the ways they can be involved.

Result: The stakeholders will be actively involved and can make a commitment to the project.

Explanation: Once you have made the contacts, you are ready to secure their active involvement. Will you invite them to participate in a CAB? Will they volunteer at a community outreach project? Will they provide constructive comments on your research? How often will you meet with them? What time and energy commitment do you require? You may want to offer the stakeholders a variety of options on how they might participate — they will have various levels of desire, ability and time to dedicate to your trial. Having different options provides assurance that the stakeholders will be involved in different ways at a variety of levels. Keep track of this information.

10 Update the database regularly.

Action: Add to or edit the database as needed throughout the project.

Result: You will have a list that your team will use for many different aspects of your project, and possibly for future research as well.

Explanation: The stakeholder information list is a living document that must be current to be useful. Although some of the information must be kept confidential, you should try to make the database or selected parts of it accessible to those who need it. One idea is to create a secure internet space, where people can access and edit the background information. Be careful to manage access in a way that ensures accuracy and maintains confidentiality!

Checklist: Step Five

Use this checklist to make sure that you accomplished all the tasks required in Step Five.

- List all key stakeholders.
- Collect information about individuals and organizations.
- Enter information into an electronic database.
- Create expanded profiles.
- Clearly define stakeholder groups.
- Secure active involvement.
- Update database throughout the project.
Appendix

Tools: Step Five

(No tools are included for Step Four)

Tool 5A: Stakeholder identification sheet
Tool 5B: Stakeholder data collection sheet
Tool 5C: Identification of stakeholder roles
Tool 5D: Stakeholder contact record
Tool 5A: Stakeholder identification sheet

Use this tool at your brainstorming session. Review and adjust each of the headings and subheadings in Column A to suit the country or regional context in which the trial will take place. If necessary, rephrase the headings in Column A so that they are compatible with the national and regional contexts. Categorize each of the listed stakeholders according to one of the main headings in Column A and one of the subgroups in Column B. For institutions, list a point person if possible. You do not need to fill in all of the subgroup cells in Column B; rather, use them as a guide to help you think about the possible stakeholders. Add new subgroups where appropriate for your context.

## Tool 5A: Stakeholder identification sheet

<table>
<thead>
<tr>
<th>(A) Stakeholder Groups</th>
<th>(B) Stakeholder Subgroups</th>
<th>(C) Stakeholder’s Name (Institutions/Individuals)</th>
<th>(D) Institution Point Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Trial participants, their families, partners, neighbors and co-workers</td>
<td>Trial participants target population</td>
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<td></td>
<td>Immediate families of trial participants</td>
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<td></td>
<td>Partners of trial participants</td>
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<td>2. Local community members</td>
<td>Formal community leaders</td>
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<td>Informal community leaders</td>
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<td>Community advisory boards</td>
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<td>Local community health partnerships</td>
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<td></td>
<td>Businesses</td>
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<td></td>
<td>Religious institutions (churches, mosques, synagogues, etc.)</td>
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<td>Schools</td>
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<td>Other educational institutions</td>
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<td>Youth representatives</td>
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<td>Local political leaders</td>
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<td>(A) Stakeholder Groups</td>
<td>(B) Stakeholder Subgroups</td>
<td>(C) Stakeholder’s Name (Institutions/Individuals)</td>
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<td>2. Local community members (continued)</td>
<td>Community theater</td>
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<td></td>
<td>Other local media (e.g., local singers and poets)</td>
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<td></td>
<td>People living with HIV or AIDS</td>
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<td></td>
<td>Racial and ethnic representatives</td>
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<td></td>
<td>Gender representatives (e.g., women, GLBT)</td>
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<td>3. Researchers, funding agencies and regulatory bodies</td>
<td>Leadership of national research institutions</td>
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<td>Leadership of international research institutions</td>
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<td></td>
<td>Principal funders</td>
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<td>Other sources of funds/resources</td>
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<td>Principal investigators</td>
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<td></td>
<td>Co-investigators</td>
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<td></td>
<td>Other scientific staff</td>
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<td>Trial managers</td>
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<td>Behavioral and social scientists</td>
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<td>Ethicists</td>
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<td>Stakeholder engagement specialists</td>
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<td>Site identification and development</td>
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<td></td>
<td>Trainers</td>
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<td>Instructional design specialists</td>
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<td>In-house communications specialists</td>
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<td>In-country investigators</td>
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<td>Internal publications staff</td>
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<td></td>
<td>Scientific spokespersons (often big names in the field)</td>
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<td>Other international research organizations</td>
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<td>The broad scientific community</td>
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<td>(A) Stakeholder Groups</td>
<td>(B) Stakeholder Subgroups</td>
<td>(C) Stakeholder’s Name (Institutions/Individuals)</td>
<td>(D) Institution Point Person</td>
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<td>4. HIV and AIDS policymakers and advocates</td>
<td>National advocacy groups</td>
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<td></td>
<td>Party leadership</td>
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<td>International advocacy groups</td>
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<td>Civil society organizations</td>
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<td>Regulatory agencies (national)</td>
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<td>Regulatory agencies (bilateral, multinational)</td>
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<td>5. Health care programs and service providers</td>
<td>Senior technical staff (regional/national)</td>
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<td>Health facility staff</td>
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<td>Community health workers</td>
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<td></td>
<td>Traditional birth attendants</td>
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<td>Community-based distributors</td>
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<td>Physicians</td>
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<td>Health educators</td>
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<td>Nurses and clinical officers</td>
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<td>Other clinic staff</td>
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<td>Outreach workers</td>
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<td>Program directors</td>
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</tbody>
</table>

Completed by: _________________________________
Date: ______________________________________

Updated by: __________________________________
Date: _______________________________________
Tool 5B: Stakeholder data collection sheet

Use this sheet to collect information about the stakeholders that you wish to approach. Modify the sheet to suit your purposes.

Name:
Position(s)/Role(s):
Organization(s):
Community/neighborhood:
Contact information:
Stakeholder category:
Other relevant information about this stakeholder:

Interests of this stakeholder in (a) HIV and AIDS prevention research and (b) the specific research project that is being discussed:
1. 
2. 
3. 

Interests of researchers in relation to this stakeholder:
1. 
2. 
3. 

History of working relationships with this stakeholder:
1. 
2. 
3. 

Ideas and strategies for clarifying and strengthening our working relationships with this stakeholder:
1. 
2. 
3. 

Ways in which this stakeholder can potentially be a “champion” of HIV and AIDS prevention research:
1. 
2. 
3. 

Additional information about this stakeholder:

Entered by: _______________________
Date: __________________________
Updated by: _____________________
Date: __________________________
Example — Completed Tool 5B: Stakeholder data collection sheet

Name: Mr. Big Tibbs  
Position(s)/Role(s): Bar owner  
Organization(s): Tibbs’ Big Bar  
Community/Neighborhood: Marwani district  
Contact information: btibbs@mybar.com  
Stakeholder category: local community member  
Other relevant information about this stakeholder: none

Interests of this stakeholder in (a) HIV/AIDS prevention research in general and (b) the specific research project that is being discussed:
1. Serves community that is at high risk for HIV
2. Project is about preventing HIV in commercial sex workers, and many CSWs find clients at Mr. Tibbs’ bar.
3. Interests of researchers in relation to this stakeholder:
4. Good place to recruit participants
5. Important to build a relationship with the bar owner so that he will be an ally in the project

History of working relationships with this stakeholder:
1. No history of working with him, but we have worked with other business owners in the area
2. Ideas and strategies for clarifying and strengthening our working relationships with this stakeholder:
3. Make sure to get permission from Mr. Tibbs before recruiting participants on his property
4. Invite him to participate in a stakeholders meeting; ask him for his ideas about how to prevent HIV among these clients
5. Be careful not to stigmatize the business or alienate him by disrespecting his business

Ways in which this stakeholder can potentially be a “champion” of HIV/AIDS prevention research:
1. By speaking favorably about the project to his customers
2. By reassuring clients that he is not watching them

Additional information about this stakeholder: none

Entered by: Ms. Research Assistant  
Date: 06/29/2011  
Updated by:  
Date:
Tool 5C: Identification of stakeholder roles

Use this sheet to identify and prioritize which potential stakeholders can fill needed roles for your trial. Could they be part of the CAB? Will you invite them to review your materials? Are they information gatekeepers who should receive newsletters and announcements about community events? Once again, modify this sheet to personalize it for your trial. It is important to complete this step before you convene a meeting with your stakeholders.

**Tool 5C: Identification of stakeholder roles**

<table>
<thead>
<tr>
<th>(A) Activity area</th>
<th>(B) Description of roles needed</th>
<th>(C) Suggested stakeholders to fill roles</th>
<th>(D) Preliminary actions required</th>
<th>(E) By whom?</th>
<th>(F) By when?</th>
<th>(G) Status</th>
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<tbody>
<tr>
<td>Consultation</td>
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<td>Deliberation</td>
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<td>Advocating</td>
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<td>Community outreach</td>
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<td>Community organizing</td>
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<td>Championing the trial</td>
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<td>Disseminating information</td>
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<td>Providing resources</td>
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<td>Oversight and monitoring</td>
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<td>Evaluating</td>
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<td>Training</td>
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<td>Observing and reflecting</td>
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<td>Translating and interpreting</td>
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Completed by: ___________________________ Date: ___________________________

Updated by: ___________________________ Date: ___________________________

Updated by: ___________________________ Date: ___________________________

Updated by: ___________________________ Date: ___________________________
Tool 5D: Stakeholder contact record

Use this sheet to plan and track initial contact with new stakeholders. You can use this form as a task assignment sheet for research team members, filling out the contact information for each person or organization that you would like that team member to contact. Once again, modify this sheet to personalize it for your trial.

### Tool 5D: Stakeholder contact record

<table>
<thead>
<tr>
<th>Purpose of contact:</th>
<th>Person making contact:</th>
<th>Name of organization &amp; contact person</th>
<th>Email</th>
<th>Phone number</th>
<th>Comments</th>
<th>Contacted (date/notes/follow-up needed?)</th>
</tr>
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<td>To introduce our research organization to these stakeholders and let them know about our proposed work on HIV prevention trials.</td>
<td>Sam Staffman</td>
<td>County Health Dept., Ms. Carla Smith, VCT Coordinator</td>
<td><a href="mailto:csmith@state.gov">csmith@state.gov</a></td>
<td>O: 999-999-9999 C: 999-888-8888</td>
<td>Could be helpful source for recruitment strategy. Our screening data could be of interest to her office.</td>
<td>09/06/2011: emailed to introduce study; call scheduled for the 10th at 9:30am</td>
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<td>AIDS Volunteers, Mr. Ben Brown, Health Educ.</td>
<td><a href="mailto:Bbrowan@group.org">Bbrowan@group.org</a></td>
<td>O: 999-111-1111 C: 999-111-2222</td>
<td>Long-time treatment advocate</td>
<td>09/06/2011: called him at 2:15pm; scheduled to meet on the 7th. 09/07/2011: Met at his office. He is concerned about ensuring good referral for care for positive screens. Wants more info on referral plan.</td>
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Example — Completed Tool 5D: Stakeholder contact record

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