Engage Stakeholders and Sustain Relationships
Introduction

Now that you have identified your potential stakeholders — as well as their priorities, concerns and skills — you are ready to begin building relationships. There are a number of creative approaches to stakeholder engagement, and we encourage you to approach it as a continuous learning process — modifying and adding new strategies to your expanding engagement toolbox. Step Six provides some basic strategies and tools to help you begin to develop those relationships and sustain them throughout the research process.

Forming, strengthening and maintaining good relationships between researchers, the community and other relevant stakeholders is essential to ensuring genuine stakeholder participation and engagement. In your work you will encounter different groups of stakeholders, and their level of involvement will vary. Some will be part of formal advisory structures that meet on a regular basis; others you will request meetings with to sustain relationships and provide updates. Still others — like the host community — will be more loosely defined, and you will need to engage them in a more public way. In all of your engagement activities — regardless of which stakeholders you are targeting — strive to be inclusive and responsive to local needs, and strive to provide opportunities for stakeholders to genuinely influence decisions around the research.

Remember, it is just as important to know when to engage your stakeholders as it is to know who to engage and how to engage them. Community preparedness and stakeholder engagement related to research requires a long-term investment and, ideally, should not be linked to any one trial. Instead, sites should engage stakeholders in an ongoing and sustained manner, throughout the research cycle, forming supportive relationships that extend beyond individual studies.
Goals of Step Six

- Build lasting partnerships and alliances with a range of stakeholders.
- Provide mechanisms by which stakeholders can offer input into the research process.
- Disseminate correct and accurate information about HIV and AIDS, the scientific process and your specific trial.
- Educate and update stakeholders and the community about your trial and its progress.
- Network with staff members at other HIV prevention research studies.
- Document and continue to build your toolbox for stakeholder engagement.

Why you need to engage stakeholders and sustain relationships

A systematic approach in this step will make it much easier for your team to:

- Ensure that correct and accurate information about your trial is reaching your stakeholders and the community.
- Combat misperceptions and rumors about HIV and research in the community.
- Establish trust, transparency and two-way communication with the host community and other stakeholders.
- Improve your stakeholder engagement approaches and implement better practices.
1 Build partnerships and alliances.

**Action:** Make contact with various stakeholders, set-up meetings and invite them to planned trial events.

**Result:** You will develop relationships with a diverse range of relevant stakeholders and begin to establish the necessary buy-in for the successful conduct of your trial.

**Explanation:** The first step in building partnerships is to make contact. Using the information you collected about potential stakeholders in Step Five, begin reaching out to various stakeholder groups, requesting meetings and inviting them to trial launch events. Building partnerships and alliances ensures that stakeholders have a vested interest in the research and secures them as important allies. It is essential to establish these partnerships early on — ideally before a trial begins — to ensure community and stakeholder participation throughout all stages of the research process.

**Tips**

Organize “motivator meetings” to inform local and government officials and other stakeholders about the trial’s objectives, potential benefits for trial participants and elements of HIV prevention research. Hold separate meetings for different categories of stakeholders.

Provide opportunities for stakeholders and participants to ask questions, provide testimonies and raise concerns. Document and use these responses to improve strategies for effective stakeholder engagement.

Think about the networks that already exist in your community. Introduce yourself and your trial. By tapping into existing networks, you capitalize on previously mobilized groups of credible operators that can help to disseminate information, establish trust and introduce you to other potential stakeholders. Similarly, establishing relationships with, and gaining the support of, local government and community leaders that others look to for guidance will help to establish your credibility with a wider range of stakeholders and ensure you have the necessary buy-in for your trial.

Be sure to ask stakeholders how and how often they would like to be contacted, and include that information on Tool 6A: Stakeholder contact sheet. You can also use the contact sheet to keep track of how and how often you contact each stakeholder or stakeholder group. Check the sheet often to make sure you keep up regular contact with your stakeholders and track your progress.

2 Establish local stakeholder advisory mechanisms.

**Action:** Establish one or more formal advisory mechanisms for your trial site or research project. For local community representatives to provide a contribution to the research methods and design, you may need to invest in some capacity-building activities. This will be covered in Step Seven: Developing Local Stakeholder Capacity. Include stakeholders in your decisions on how to establish advisory groups. Develop guidelines for the group's purpose, scope and structure.

**Result:** You will have an active and engaged group of local stakeholders who can contribute to your trial and facilitate two-way communications with the surrounding communities.

**Explanation:** Local stakeholder engagement occurs formally and informally. One strategy for formal engagement is to establish one or more advisory mechanisms or groups. In many cases, this has taken the form of a CAB. Although CABs have their merits, a CAB — as it is traditionally conceived — might not be the best strategy for every setting.

Research sites have used a variety of models for advisory mechanisms. Some sites follow the traditional CAB model where a diverse range of stakeholders are recruited or elected to serve on the board. Others have established participant advisory groups made up exclusively of current and former trial participants. Still others have separated stakeholder groups — establishing one group for community leaders, NGOs, community-based organizations (CBOs), service providers and other stakeholders and a separate group for trial participants — or they have chosen to adapt and implement alternative models, like those that rely on
Community advisory boards

Community advisory boards (CABs) — a concept originally advanced by AIDS treatment activists in North America and Europe — are advisory bodies composed primarily of non-scientists whose members advise on research protocols and help to educate communities about the research taking place. In time, however, communities, advocates, and researchers alike began to argue that, although CABs play an important role in research, they suffer from limitations and should not be the only method used to engage and solicit input from stakeholders. As a result, research sites began to implement more diverse and multifaceted approaches to stakeholder engagement in addition to the CABs and other advisory mechanisms.


well-networked peer educators. Some research studies inherit CABs or advisory boards from their host institution — sometimes with a dedicated CAB member to represent their trial. Work with stakeholders and other members of the research team to develop one or more stakeholder advisory structures that meet your needs and circumstances. You may decide that a single comprehensive group is adequate. Or you may decide that a single group cannot sufficiently represent the needs of your multiple stakeholders and will choose to establish two or more advisory groups to serve stakeholders’ different needs.¹

Regardless of the type of local advisory mechanisms you establish, each mechanism should serve similar aims:²

- To serve as community voices, representing local community perspectives
- To act as a bridge between researchers and local communities
- To help make the language of research materials and messages culturally relevant and comprehensible

### Some examples of local stakeholder advisory mechanisms

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Institutional CAB</strong></td>
<td>The Perinatal HIV Research Unit in South Africa is a research organization with established institutional CABs. The unit has three CABs: one that advises prevention trials, one that advises treatment trials and one that supports adolescent research. CAB members are elected, and each of the CABs has developed its own constitution to guide its governance and decision-making.</td>
</tr>
<tr>
<td><strong>Trial-specific CAB</strong></td>
<td>Some studies, when they start, do not have an established institutional CAB at their disposal. In that case, CABs can be established to advise on the specific research project at hand. CAB members are typically recruited or elected to serve, on a voluntary basis, for agreed-upon terms.</td>
</tr>
<tr>
<td><strong>Multiple advisory groups</strong></td>
<td>CAPRISA in South Africa established a number of what they refer to as community research support groups (CRSGs). CRSG members are drawn from NGOs and local health facilities, as well as previous and current trial participants, all of whom can nominate new members to join the group.</td>
</tr>
<tr>
<td></td>
<td>The site for the MDP 301 microbicide trial in Tanzania set up two separate advisory groups — the Stakeholder Advisory Committee (SAC) and the Community Advisory Group (CAG). The CAG is composed exclusively of trial participants. Each elected CAG member represents a geographical area where the members hold monthly meetings with participants who work or live in the area. Quarterly CAG meetings are held to discuss issues in each geographical ward. The SAC includes a wide variety of stakeholders, including medical officers, local nongovernmental organizations (NGOs), community-based organizations (CBOs), faith-based organizations (FBOs), town council members and the media. Four elected CAG members also sit on the SAC.</td>
</tr>
<tr>
<td></td>
<td>The TDF2 trial staff at the CDC HIV Prevention and Research Clinic in Botswana formed a participant advisory group and a community advisory group, and partnered with local youth and HIV/AIDS organizations to solicit stakeholder input.</td>
</tr>
</tbody>
</table>
• To provide input about certain aspects of the trial — notably informed consent and the compensation or benefits that trial participants and the local communities receive
• To serve as a vehicle through which local communities can learn about and provide input to the trial as it moves forward

The type of model you employ is not as important as how it is developed. Regardless of the model, the advisory mechanism(s) should be developed as one part of a broader stakeholder engagement strategy and should not represent the full extent of stakeholder and community engagement for the trial. People become much more invested in processes that they help to create. You should work with local stakeholders to determine the type of advisory group or groups that are needed, how members will be chosen, and the aims and functions of the group(s).

Invite local stakeholders to a workshop to discuss the establishment of advisory mechanisms. Inform the stakeholders about the various models that have been used in other settings and some of the typical roles and responsibilities of advisory groups. Ask participants if they know of other models or have experience serving on advisory groups. Facilitate agreement on some aims of the group or groups and how members should be selected. (See Tool 7F: Facilitating Agreement).

Once the group or groups are established, you will want to have additional discussions about roles, responsibilities and expectations with the advisory group and work together to establish guidelines for the group’s purpose, scope and structure (see Tool 6B: Establishing advisory group guidelines).

In addition to formal advisory groups, consider implementing other advisory and feedback strategies such as these:

• Having meetings or support groups for the trial participants to give them the opportunity to share their experiences, air their concerns and provide feedback about the trial.3
• Providing a comment box in the trial’s clinics to elicit feedback from trial participants and staff.
• If you have a trial website, include a mechanism where people can submit feedback or ask for additional information.

Establishing advisory mechanisms in Mwanza

Charles Shagi, African Medical and Research Foundation, Mwanza, Tanzania

In Mwanza we took a slightly different approach from the traditional CAB model. We thought that in order to get the feedback we needed from participants, we needed to create a forum where they could interact with each other, without other stakeholders present.

First, we conducted a mapping. For our study we were targeting women who worked in recreational facilities (bars, restaurants, hotels, brothels) and women who prepared and sold food and traditional liquor in pombe shops (makeshifts) — the women we refer to as mamalisches. So we mapped where these facilities and women were and organized the area into wards. From there, participants elected a representative — one per ward — to sit on the CAG. Each CAG member would hold a monthly ward meeting to discuss difficulties affecting their participation, problems at the clinics, problems in the community, or any other concerns or suggestions. We held trainings with the CAG members and the ward secretaries (one per ward) to build their counseling and documenting skills so they were better equipped to facilitate the meetings and document what was discussed. Community staff from the site would also be on hand to answer questions or clarify points. The CAG would then meet for a full day every quarter to discuss issues across wards and hear from various members of the research team. It was with the CAG that our team developed our engagement strategy and decided that we needed to reach out to a wider group of stakeholders.

So, in addition to the CAG, we also organized a stakeholder advisory committee (SAC) that included service providers from the hospital and clinics, people from the media and FBOs and community leaders. We put together a kind of job description to explain what was being asked of SAC members and approached different organizations for representatives. We also decided we needed to have CAG representation on the SAC and held elections for four CAG members to also serve on the stakeholder’s group.

We used a number of participatory methods to engage the CAG and to build their capacity, which progressively increased their confidence. The participatory aspect of the methods enabled the solutions to come from the participants and give voice to those most affected by research decisions — the women themselves. It engaged them as partners in the research, peer educators and ambassadors for the trial. Now that the trial has ended, SAC members have helped to place some former CAG members as peer health educators with local NGOs and CBOs around Mwanza.

Charles Shagi is a program officer at the African Medical and Research Foundation and formerly served as community liaison officer with MDP 301.
3 Set expectations

**Action:** Engage local stakeholders early to establish expectations.

**Result:** You will establish clear and agreed-upon expectations between local stakeholders and the research institution.

**Explanation:** Setting expectations early is one of the keys to building sustainable partnerships. It’s not only important to set expectations about what the research will and will not accomplish but also about the level of influence various stakeholders can expect to have. Understanding the potential influence and translating that to a goal for stakeholder participation is a critical component of conducting effective stakeholder engagement and establishing trust.

This is particularly important for local stakeholder advisory groups. It is important to clearly communicate that advisory group members are not members of the research team. The research institution does not employ them nor will they be paid a salary. Instead, their participation is voluntary and their role is advisory. They are not empowered to make decisions about the research, though their advice and recommendations should always carry weight with the research team.

Community perceptions about the advisory group(s) are also important. Even if advisory group members are clear about their role, local communities can wrongly think that members are receiving favors or are being employed by the research site. Sometimes this can be complicated if some advisory group members are able to attend meetings as part of their jobs — for example, if they are community health workers tasked with outreach and engagement.

Engage advisory group members in activities to discuss and set agreed-upon expectations. For other types of stakeholders, be clear in your

---

**Tips**

Stakeholders can have many roles, and it is important that the research team and the stakeholder have a shared understanding of the reasons she or he has been asked to participate in an advisory group.

One stakeholder we know has a good strategy. At meetings where he might have multiple roles, he asks at the beginning which “hat” he is being asked to wear. By doing so, he ensures that everyone understands his role.
Defining stakeholder roles for a community collaboration

Kate MacQueen, FHI 360, Durham, North Carolina

When we wrote the proposal that generated the funding for LinCS 2 Durham, we identified five types of stakeholders as our starting point for outreach and building collaboration: (1) advocacy and policy, (2) community or civil society, (3) the research enterprise, (4) HIV prevention consumers and (5) operations and program development. We met with interested stakeholders to determine the most effective way of working together. These discussions shaped our current “collaborative council.”

Early on we collectively revisited the original stakeholder classification outlined in the research proposal and developed definitions to reflect the diversity of perspectives and roles that the collaborative council sought to include. We use these definitions to track membership in the collaborative council. This strategy helps us identify our strengths in each category so we can ensure that the voices of all stakeholders are represented.

<table>
<thead>
<tr>
<th>Stakeholder classifications</th>
<th>Stakeholder definitions developed by LinCS 2 Durham collaborators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocacy and policy (AP)</td>
<td>AP stakeholders play a remarkable role in generating funding and setting the guidelines and standards for HIV prevention research at the local, state and national levels, based on the needs and perspectives of the other stakeholder groups (GR, RE, PS and TP).</td>
</tr>
<tr>
<td>Grassroots (GR)</td>
<td>GR stakeholders are persons who represent the pulse of the community in terms of identifying strengths and challenges of their community and articulating insight and relevant information about why strengths and challenges exist.</td>
</tr>
<tr>
<td>Research enterprise (CRE or LRES)</td>
<td>The term “enterprise” doesn’t necessarily mean “corporate” or “business” and must include principal investigators (PIs) and those paid by research entities. Community research enterprise (CRE) stakeholders may include people employed by research institutions and persons who self-select as moving research forward. All staff members of LinCS 2 Durham should identify as LRES.</td>
</tr>
<tr>
<td>Programmatic stakeholders (PS)</td>
<td>PS are persons connected to local infrastructures, agencies or programs who serve the population being affected or researched. Programmatic stakeholders may very well connect with persons involved in advocacy and policy, grassroots and the target population to assist in defining their objectives.</td>
</tr>
<tr>
<td>Target Population (TP)</td>
<td>TP would be Black men and women between the ages of 18–30 in the Durham community. This group is disproportionately impacted by HIV/AIDS and depending on environmental context and behaviors may be at a higher risk of becoming infected by HIV than other groups.</td>
</tr>
</tbody>
</table>

Kate MacQueen is a senior social scientist with FHI 360 and serves as principal investigator for the LinCS 2 Durham study.
communication. Explain what you are asking from them and what will happen with the feedback they give you. Discuss expectations about what the research project will accomplish and what it will not. Discuss with them their expectations for involvement and updates.

Also, be sure to communicate the role of your established advisory groups with other stakeholders and the community so that people are clear about the group’s role. The advisory group can be introduced to other stakeholders as a resource and a link between the research team and the wider community.

4 Be visible in local communities.

**Action:** Organize local community events, community dramas and town hall meetings or open forums to educate and engage local communities (see Tool 6C: Organizing an event).

**Result:** Local communities will become informed, knowledgeable, engaged and supportive.

**Explanation:** Connecting with local communities will expand your network and is a good way to gain exposure and support. Being visible in communities fosters a sense of transparency and trust. It signals to community members that you have nothing to hide. Arrange for opportunities to engage in open discussions with participants, their partners and the communities from which they come.

There are several ways to stay visible in local communities. Community events and dramas held in well-attended areas can help to educate members about your trial and HIV prevention research, and help to combat rumors and misperceptions before they start. Open forums and town hall meetings allow for a two-way dialogue — with researchers learning about community perceptions, needs and concerns, and communities hearing from researchers about the need for research and the specifics of the trial being conducted.

Some research sites have also found the following strategies useful:

- Maintain relationships with civil society groups during and after the preparedness phase.
- Hold community education forums and meetings at the trial site or at well-known community sites such as schools or places of worship.

---

• Participate in local events, celebrations, community health forums and events hosted by other NGOs and CBOs. These events are opportunities for you to communicate with the local public, not only about your trial, but also about health issues more generally.
• Work with the trial staff, advisory groups and other partners to draft drama scripts or poetry slams on relevant topics such as myths and rumors, HIV and AIDS, how research works and participant retention. Once completed, seek out spaces to perform the dramas or poems in order to educate participants, their immediate families and the local communities.5

Be sure to document any activities you undertake (see Tool 6D, Field report). When deciding which kinds of events to organize, use Tool 6E: Deciding on a strategy to think through some of the advantages and limitations of each strategy. See additional tools to help you with agenda planning (Tool 6F), brainstorming (Tool 6G) and engaging communities with theatre (Tool 6H).

5 Use local media

Action: Use local media — including radio and local press — to communicate your messages broadly.

Result: You will inform stakeholders and create opportunities to establish transparency about the conduct of your trial.

Explanation: There are many reasons to positively engage with the media. The media can influence public opinion as well as opinions of funders, policymakers, regulatory bodies and potential participants.6 Proactively educating and informing the media about your trial, the need for HIV prevention research and how research is conducted can help to prevent miscommunication and misperceptions about your trial. Some research sites have invited local media to sit on their advisory group(s), involving them as partners in the research endeavor.

6 Robinson ET. Baron D. Heise L. Moffett J. Harlan SV. Communications handbook for clinical trials [Internet]. Research Triangle Park (NC): FHI 360 and Microbicides Media and Communications Initiative (MMCI); 2010 [Cited 2012 April]. Available from: http://communications4clintrials.org/
Using football to engage men in Mtubatuba

Mitzy Gafos

Effective HIV prevention requires the support of both women and men. Studies enrolling women have found that participants’ partners can often present barriers to study participation, retention and product adherence. Engaging men in HIV prevention research — particularly in microbicide trials — has been an ongoing challenge for the field.

As a way to get young men talking about HIV and the need for microbicides, our site decided to host a football tournament — with eight teams playing 14 games in one day. For the prize, we worked with a local sports shop to donate football kits (uniforms) for the winning team with MDP printed on them. Between games, our staff gave talks and facilitated question-and-answer sessions about HIV, the need for microbicides and the MDP study. We also performed songs about microbicides that our staff and participants had written to entertain and educate the audience and teams. At the end of the day a football team called “Disco” won the tournament and the MDP football kit. The members of the winning team subsequently participated in an educational workshop to learn about HIV, microbicides and why we were conducting the MDP study.

Afterward, every time the “MDP” team played football — which was every week — somebody would ask them what MDP was and the team would tell him or her, engaging in a discussion. It was a fabulous way of getting young men to talk about some of these issues. The experience also encouraged them to help educate others and to build community support.

Mitzy Gafos served as a co-principal investigator for the Microbicides Development Programme (MDP) 301, Africa Centre for Health and Population Studies, South Africa.
Using radio in Kisumu

Joel Odondi, Partners PrEP Study, KEMRI, Kisumu, Kenya

Radio can be an excellent tool for engaging stakeholders and potential study participants — particularly those you may not have the opportunity to engage in other ways.

For two years, we held a one-hour radio show every Saturday. We were always careful not to lecture on a topic but to pose questions to the listeners, encouraging them to call in and talk to one another. That way the community works to elevate one another, learning together. We asked questions such as, How can we promote disclosure? Why should people participate in research? And then I would fill in the blank spaces and correct misinformation, helping to build the learning. When participants come to the site to get tested and screened for our studies, we always ask them how they heard about the site. Most of them answer that they heard about us through the radio. Our people listen to the radio. They may go to the farm, but they have a radio next to them.

With limited resources and staff, it can be difficult to find ways to reach large numbers of stakeholders. It can be equally difficult to find creative and entertaining ways of engaging them. Radio provides a way to do both and to help start community conversations about HIV and HIV prevention research.

Joel Odondi is the outreach and retention manager for the Partners PrEP Study.
Beyond avoiding potential misinformation and conflict, local media can be a channel for distributing information. Communicating with people through credible sources they trust is essential to building and sustaining support for the research project. Use local media outlets to advertise community events and forums and to educate stakeholders about your research trial, HIV and AIDS and the need for HIV prevention research. Work with your site’s communications staff or principal investigator to make sure the media has accurate and up-to-date information. Consider holding a radio talk show where listeners can call in to ask questions about the trial.

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

6 Draft and disseminate educational and informational materials

**Action:** Draft educational and information materials.

**Result:** You will create groups of informed, knowledgeable and supportive participants, participant support systems and other stakeholders.

**Explanation:** Informative materials, drafted in easy-to-understand language, are an important component of stakeholder engagement. Materials could include question and answer documents, a backgrounder (such as a summary of the “who, what, when, where, and why” of the trial), a song or video, or a simple brochure that communicates the main points of the research project.

Develop these materials with the help of the research team and your advisory group(s) to ensure that the concepts and the language used are accurate and culturally and contextually appropriate. Research has shown that materials are more acceptable and effective when written in local languages and when pictures and illustrations include relevant objects that are easily recognizable in the local situation.

---


Use the materials widely, giving them to:

- Attendees at community events to encourage further education about HIV, scientific research and your trial.
- Health care and service providers to help educate them about the trial, help solicit their buy-in and encourage them to discuss the trial with their patients.
- Policymakers, advocates and other local research organizations to proactively answer questions they may have about the trial.
- Trial participants and partners to help answer their questions and assist with the disclosure of trial participation.

Detailed information on how to communicate science clearly, craft messages, and develop materials can be found in the *Communications Handbook for Clinical Trials.*
General guidelines for materials production

Before drafting new materials, think about whether or not materials already exist that could be easily adapted for your target audiences. If so, work with other members of the research team and your advisory group(s) to translate them into the local language, ensure that pictures and illustrations are relevant to your setting, and to make any other necessary changes.

Text
1. Choose a type style and size that is easy to read.
2. Use uppercase and lowercase letters and regular type.
3. Test the reading level.
4. Review repeatedly. (Review drafts with the research team first, to ensure technical accuracy, before reviewing them with advisory groups or other stakeholders).

Illustrations
1. Use appropriate colors (colors can have different meanings in different communities or cultures).
2. Use locally familiar images (i.e., activities, clothing, buildings) and symbols (i.e., crosses, arrows, symbols that represent time).
3. Use realistic and simple illustrations.
4. Use a positive approach.

Design and Layout
1. Present one message per picture or illustration.
2. Limit the number of concepts and pages per material.
3. Make the material interactive whenever possible (i.e., include simple question and answer sections).
4. Leave plenty of white space.

**Break it down, don’t dumb it down**

_Natalie T. Eley, FHI 360, Durham, North Carolina_

The LinCS 2 Durham study — Linking Communities and Scientists to Durham HIV Prevention — brings community members and scientists together in an attempt to identify research interventions that might prevent or reduce HIV in the Black community in Durham, North Carolina. A crucial part of the study is the “collaborative council,” which consists of community members and research staff members.

The council provides support to the LinCS 2 Durham research study by influencing the study’s activities. For example, the council offers feedback and actively participates in various study activities. The collaborative council’s involvement in the study helps to ensure the integrity of the study’s community-based participatory research method.

On a number of occasions, the collaborative council has provided comments on our communication materials and presentations at council meetings. A recurring theme stands out in their feedback: Do not oversimplify information with the assumption that target audiences will not be able to understand the words or the concepts.

It is important to respect the intelligence of your audience, while recognizing that they may not be familiar with your ideas or your methods. So we introduce new terms and definitions, but not in an obtrusive way, and we are sensitive to approaches that may be insulting to the audience. Our motto became “break it down, don’t dumb it down.”

We have since applied this motto in all of our meetings, presentations and materials, regardless of the target audience. We have strived to convey the objectives and the activities of our study in a way that is informative, attractive and well received by various audiences.

_Natalie T. Eley is a research associate at FHI 360 and serves as project coordinator for the LinCS 2 Durham study._
Engaging through song

Mitzy Gafos

One creative way we found for engaging the community and communicating about the study was to use songs. The idea for the songs initially came out of a staff training session where somebody’s example of how they would explain microbicides to their family was by using a song. So what we began to do at very regular sessions was to identify a topic or key message that we wanted to communicate. A group of staff and participants would then volunteer to develop a song. They would go away and work on it and then come back in and sing it to the team. The songs were usually to the tune of church songs so they were familiar to people. A dance would often go along with the song. Then, we’d work as a team to refine the song and ensure that the messages were coming across clearly. Once the song was finished, the team would learn it and record it onto CDs so that we could play them in the clinic waiting rooms. Eventually, we developed a CD with a number of songs, a short introduction about the study and a role play of a question-and-answer session that helped to reinforce the messages in the songs.

During the same time, we discovered that there were rumors spreading in the community that study participants were going into town to have sex because they were being seen getting in and out of taxis with their boxes of gel. We began working with the local taxi association to educate the drivers and try to halt the rumors. Toward the end, the drivers agreed to play our CD in their taxis. The CDs were so widely played in the community that it got to the point that our team would walk in to do a talk or a workshop somewhere, begin a song and find that half the audience would join in. The songs helped to get our messages out to the community and also to build a sense of familiarity with the trial and trial staff members.

Mitzy Gafos served as co-principal investigator for MDP 301, Africa Centre, South Africa.
7 Provide regular education and updates.

Action: Use a variety of methods — including local media, town hall meetings, community events, individual stakeholder meetings and targeted educational materials — to communicate with stakeholders. Be proactive in your communication.

- Organize community events.
- Use local media.
- Conduct question-and-answer sessions and open forums.
- Organize participant and partner events.
- Organize stakeholder update meetings.

Result: You will have a group of informed stakeholders and the necessary political buy-in and support for conducting HIV prevention research in the community.

Explanation: Communication is essential to maintain stakeholder engagement; however, effective communication takes time and effort. Communication is a two-way process that involves the exchange, transfer and understanding of information. Clear and proactive communication is critical to ensuring collaboration, partnership, transparency and accountability. Confusing communication can undermine your credibility within the community. Think carefully about what you want to communicate and the best methods to use. Remember to always build feedback loops into your communication processes so you can better judge whether or not you are getting your messages across to your intended audience or if you need to change your strategy. Communicate early and often; don’t wait for a crisis to emerge.

Know your stakeholders, and show interest in their work and circumstances. One time we were going up to the municipality, and we found out that there had been a death of a counselor. So it was very important that we find that sort of thing out before[hand] . . . so we could start our presentation by giving our condolences in an appropriate way.

– Mitzy Gafos, former co-principal investigator, MDP 301, Africa Centre, South Africa
Community events, question-and-answer sessions, open forums and local media provide opportunities to educate and update stakeholders on a large scale. Participant and partner events can be combined with community events or organized separately to celebrate their special contributions. Stakeholder update meetings can be held one-on-one or with groups of stakeholders. Establishing partnerships and sharing your trial’s progress with local and government structures through regular updates will be vital to the ongoing success of your trial. Ask these stakeholders how and how often they would like to receive updates. Do they prefer regularly scheduled in-person meetings, formal presentations to their staff or written updates? Whom do they wish to receive the updates from? What language should be used for the updates? Regardless of the format, be sure you consider the expectations you originally discussed with your stakeholders. Are you updating them as frequently as you promised? Do your original expectations need to be revisited (due to membership or staff changes or other circumstances)? Keep track of how often you are updating stakeholders and any outcomes or agreements from your meetings with them (see Tool 6A: Stakeholder contact sheet).

Also, think about who the best spokesperson will be for your audience. The spokesperson will likely change depending on which group or groups of stakeholders you are engaging. If you’re having a meeting with government officials or high-level community leaders, the principal investigator might be the trial’s best spokesperson. If you are hosting a radio call-in show about a health topic, someone from the clinic staff might be best suited. One study found that for conducting outreach to men employed at a local sugar mill, the study’s Zulu male doctor was best suited because he spoke the language, could speak to health concerns and was respected by the audience.9

The same strategies used for providing regular updates and education can also be excellent capacity-building opportunities. We will discuss this in more detail in the next chapter, Step Seven: Developing Stakeholder Capacity.

8) Monitor and respond to community voices and stakeholder views.

Action: Monitor community perceptions of research and your research project. Respond immediately, and in a transparent manner, to any rumors.

---

9 Gafos M. Personal communication; 2011, April, 7.
Result: You will combat misinformation about your trial and research generally, creating a supportive environment and an informed community.

Explanation: The need to combat myths about HIV prevention trials and overcoming suspicions on the part of potential trial participants and the community is among the most significant challenges faced by researchers. Providing regular communication and building research literacy among stakeholders should help to combat rumors and establish trust. In addition, advisory groups and other stakeholders can alert researchers about rumors in the community. And, when armed with the correct information, these stakeholders can also help to combat rumors. Community events, dramas, educational materials and other initiatives can help to combat myths and rumors before and after they start. Rumors left unattended, however, can have disastrous consequences for trial enrolment and support for research. Consider incorporating all or some of these approaches into your stakeholder engagement plan:

- Invite community leaders, advisory group members and other important stakeholders to tour the trial site to learn firsthand about trial procedures.
- Be visible in the community and transparent and honest in your communication.
- Update stakeholders regularly.
- Use dramas with your advisory groups to explore common myths and rumors and how to address them (see Tool 6H: Engaging communities with theatre).
- Invest in capacity-building activities (see Step Seven: Developing Stakeholder Capacity) to help educate stakeholders about research, research procedures and participant protections.

Maintain clearly written records.

Action: Maintain clearly written records of stakeholder engagement and discussions, agreements and unresolved issues.

Result: You will establish accountability for stakeholders and researchers and create a clear account of your engagement efforts and next steps.

Explanation: To help organize and keep track of your engagement activities, it's important to keep clearly written records. Note which individuals and groups you have organized

---

Combating myths and rumors in Mwanza

Charles Shagi, African Medical and Research Foundation, Mwanza, Tanzania

Myths and misperceptions — if gone unchecked — can wreak havoc on a study, resulting in the loss of stakeholder support and mistrust by the participants. Throughout the study, we were careful to collect information on myths and rumors through in-depth interviews and focus-group discussions and discussed them regularly with community stakeholders. Our CAG members documented any issues that were coming up in the community, and we worked with them and our stakeholders’ advisory committee to incorporate discussions of common myths and rumors into informed consent materials and into community mobilization activities.

But the collection of blood was of particular concern to the community — with many believing that the blood was collected and either sold or stolen for the purposes of witchcraft. In response, we invited a group of community stakeholders to visit the study lab to see how we collected and disposed of blood. For them to come and see firsthand where the blood was being taken and what happened with the blood — how we put it under the microscope and examined it, and how we were protecting confidentiality using only study numbers and not participant names — was crucial. For them, instead of just explaining concepts that might be difficult to grasp, showing them helped them understand it. Once they understood it, then they could speak to it — and they did.

During our study, some trials were closed in West Africa and the media contacted one of our participant CAG members without our consultation. But the CAG member had been to the study and seen our study procedures. Because of that, she was able to speak confidently saying, “We know what we’re doing; there’s no problem here.” Listening to our stakeholders and engaging them in a way that was meaningful to them helped put an end to community misperceptions and resulted in broad understanding and support for our trial.

Charles Shaqi is a program officer at the African Medical and Research Foundation and formerly served as community liaison officer with MDP 301.
meetings with, and follow up on scheduled meetings. Keep track of how and how often you interact with various stakeholders, any agreements you make, any unresolved issues and any concerns or suggestions you discuss. Keeping consistent written records will also give you documentation to refer back to and will help you to stay organized and keep any promises you might have made to the stakeholders.

Use these tools to maintain records of your engagement activities: Tool 6A: Stakeholder contact sheet and Tool 6D: Field log. Also refer back to Step Three: Design a Monitoring and Evaluation System for more suggestions and tools on how to track your progress.

10 Continue to expand your partnerships.

Action: Continue to reach out to new stakeholder groups, and allow currently engaged stakeholders to take on new roles. Understand that some stakeholders may rotate off. Remember to celebrate successes and stakeholder contributions.

Result: You will sustain stakeholder relationships and encourage continued energy and motivation for engaging with the research institution.

Explanation: The best ways to keep individuals and organizations motivated is to involve them, acknowledge their contributions and encourage new people and organizations to become involved. People do not participate if their contributions are not valued and recognized, or if their participation is perceived as not being meaningful. Don’t ask for the involvement and help of community members if you are not willing to give them a role or address their interests and needs.

At the same time, avoid relying on the same small group of individuals and organizations. Involving new individuals and organizations is an important way to maintain motivation. It is equally important to create the opportunity for individuals or organizations to change their roles, allowing them to renew their commitment.

Stakeholder engagement is a balancing act. You want to make sure that stakeholders feel that their participation is valued, while not exhausting their level of commitment. Invite

---
Stakeholders to only those events and meetings that will be most beneficial to them. Prepare for the meetings to ensure the time is used wisely and that stakeholders leave feeling they have contributed to and benefited from the experience.13

11 Learn from others.

Action: Network with staff at other research sites, NGOs, CBOs and other groups engaged in stakeholder engagement.

Result: You will build a continuously expanding inventory of lessons learned, better practices and various strategies for engaging stakeholders.

Explanation: This toolkit and the resources it lists will provide many practical tools and techniques on how to identify, engage, sustain relationships with and build the capacity of a diverse range of stakeholders. However, we encourage you to engage NGOs, CBOs and research staff at other sites — within and outside of your own network — to learn about other techniques and strategies and help to build a community of engagement experts. Networking with colleagues who are also involved in stakeholder engagement can provide some of the best opportunities for learning.

Remember to document the strategies and tools you use for engagement so you can easily share them with others. When written down, these tools can be used as evidence of your growing expertise and can be quickly adapted to use in various contexts. Use the sample template provided (see Tool 71: Template for documenting your own tools) to start documenting your engagement strategies and building your engagement toolbox.

13 Shagi C. Personal communication; 2011 April 5.
Checklist: Step Six

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

- Make contact with various stakeholders from the list you compiled in Step Five. Set up meetings and invite the stakeholders to planned study events.
- Establish one or more advisory mechanisms for your study site or research project.
- Use activities with your advisory group(s) to set expectations and agree on a collective purpose, scope and rules for how you will operate.
- For other stakeholder groups, engage them early on in research activities to establish expectations.
- Organize community events, community dramas, town hall meetings and open forums to educate and engage the wider community.
- Use local media to communicate your messages broadly.
- Draft educational and information materials. Engage the research team, stakeholders and your advisory group(s) to help draft and review these materials.
- Use a variety of methods — including local media, town hall meetings, community events, individual stakeholder meetings and targeted educational materials — to communicate with stakeholders.
- Communicate early and often; don’t wait for a crisis to emerge.
- Monitor community perceptions of research and your specific research project.
- Respond immediately, and in a transparent manner, to any rumors that are circulating.
- Maintain clearly written records of stakeholder engagement, as well as discussions, agreements and unresolved issues.
- Continue to reach out to new stakeholder groups.
- Allow previously engaged stakeholders to take on new roles.
- Celebrate successes and stakeholder contributions.
- Network with staff at other research sites, NGOs, CBOs and other groups engaged in stakeholder engagement.
- Continue to expand your inventory of lessons learned, best practices and various strategies for engaging stakeholders.
- Document the tools you use.
Appendix

Tools: Step Six

Tool 6A: Stakeholder contact sheet
Tool 6B: Establishing advisory group guidelines
  Tool 6C: Organizing an event
  Tool 6D: Field report
  Tool 6E: Deciding on a strategy
  Tool 6F: Agenda planning
  Tool 6G: Brainstorming
  Tool 6H: Engaging communities with theatre
Tool 6A: Stakeholder contact sheet

Use this sheet to keep record of your various stakeholders, how and how often you are updating them, key agreements and expectations and any stakeholder requests. Keep the sheet up-to-date, and check it regularly to track your progress. It is best if this sheet is kept electronically so that you can easily insert additional rows as you need them. Also, remember to periodically check in with your stakeholders about your initial agreements and expectations. Do they need to be revisited (due to membership or staff changes or other circumstances)?

### Tool 6A: Stakeholder contact sheet

<table>
<thead>
<tr>
<th>Stakeholder organization, group or individual</th>
<th>Agreements &amp; expectations</th>
<th>Stakeholder updates/engagement activities</th>
<th>Stakeholder requests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholder</td>
<td>Frequency of updates</td>
<td>Who will do the updates</td>
<td>Special interests/requests</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>---------------------------</td>
<td>------------------------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Stakeholder 1</td>
<td>Frequency 1</td>
<td>Who 1</td>
<td>Special 1</td>
</tr>
<tr>
<td>Stakeholder 2</td>
<td>Frequency 2</td>
<td>Who 2</td>
<td>Special 2</td>
</tr>
<tr>
<td>Stakeholder 3</td>
<td>Frequency 3</td>
<td>Who 3</td>
<td>Special 3</td>
</tr>
</tbody>
</table>
### Example — Completed Tool 6A: Stakeholder contact sheet

<table>
<thead>
<tr>
<th>Stakeholder organization, group or individual</th>
<th>Agreements &amp; expectations</th>
<th>Stakeholder updates/engagement activities</th>
<th>Stakeholder requests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Municipality</td>
<td>Frequency of updates: Every six months</td>
<td>Who will do the updates: PI</td>
<td>Special interests/requests: Concerns about reduction in condom use</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Traditional leadership</td>
<td>Frequency of updates: Every six months</td>
<td>Who will do the updates: PI and Community liaison officer (CLO)</td>
<td>Special interests/requests: General update</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hlabisa provincial hospital</td>
<td>Monthly</td>
<td>Who will do the updates: Medical officer (MO) and CLO</td>
<td>Special interests/requests: HIV and STI prevalence rates</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Tool 6B: Establishing advisory group guidelines

When establishing advisory groups — be it a formal CAB, a more loosely defined stakeholder advisory group or a participant's group, you will need to consider the purpose and scope of the group(s) and how the group will function. What are you asking the group to do? Why does this group need to be formed? How will they communicate and work with one another? This tool provides a series of questions to consider when thinking about the purpose, scope and structure of your advisory groups. Once you have answered some of the basic questions about what the advisory group will do, who will serve and how members will be selected, work with the group to develop working guidelines. For an example of complete guidelines, see the HIV Prevention Trials Network's Community Advisory Boards (CABs) Guidelines, listed in Additional Resources.

Tool 6B: Establishing advisory groups

Purpose and scope

- What are the aims of the group(s)?
- Who is the advisory group representing? Are they involved in choosing their representatives? What contact will advisory group members have with those they represent?
- Will they assist with the development, planning or implementation of stakeholder engagement and community education?
- Will they advise on study procedures?
- Will they advise on reimbursement policies for study participants?
- Will they review and give input on study protocols or on informed consent materials?
- What groups or views need to be represented? Consider government leadership, traditional leadership, study participants, local service providers, advocates, local NGOs, CBOs, FBOs, traditional healers, media representatives and others.
- What power imbalances, if any, exist? Would it be beneficial to separate or combine groups where power imbalances exist?
- Do any groups have opposing viewpoints that need to be considered with regard to establishing separate or combined groups?

Structure and function

How will members be chosen?

- Will you solicit names and invite people within the community to participate as community advisors for the site? If so, who will choose the members?
- Will you identify CAB members through stakeholder meetings and other activities? If so, who will choose the members?
• Will you hold an election for membership? If so, who gets to vote?
• How long will members serve, and what is expected from members?

How will the group(s) function?
• Will they develop their own constitution or terms of reference?
• Will there be group leadership such as a chairperson, secretary or other leaders? If so, how will those positions be appointed or elected? What will the terms be?
• How will the group reach agreement: What decision-making processes will the group use?

How will the group communicate?
• How often will meetings be held? Where will they be held? How long will they last?
• Will the group use other means of communication — short-message service, email, newsletter, etc.?

What will be expected of the group and its members?
• What is the minimum requirement for a member to be considered active?
• What happens if a member is inactive? Will they be given a warning or dismissed from the advisory group? Will their organization be asked to name a replacement?

What can the group expect from the research institution?
• Will members be reimbursed for transport (to and from meetings and trainings)? Will they be reimbursed for their time?
• Which member of the research staff will regularly interact with the group?
• What are the benefits of participation?
• How often will the group receive updates on the study from the research staff?

What capacity exists among the members, and what are the group’s capacity-building needs?
• What trainings does the group require to fulfill its purpose and function? Who will facilitate those trainings?
• What other trainings does the group require or show an interest in?
Tool 6C: Organizing an event

Whether you are organizing a community roadshow, a stakeholder meeting or training, an informational workshop or a participant event, you will need to keep a few things in mind. Use this checklist to help you plan and prepare for each aspect of your event. Adapt the checklist to better fit your setting and circumstances.

Tool 6C: Organizing an event — A checklist

The basics

- Determine the aims and objectives for the event, and decide what type of event you will hold.
- Discuss the event with and obtain any necessary permission from leadership, such as the site's principal investigator, traditional leadership, government officials and so on.
- Identify the target(s) of the event. Whom will you invite? Will the event be tailored to study participants and their partners, the advisory group, policymakers, a diverse range of stakeholders, the community at-large or a mixed group?
- Decide on a date and time for the event (this will likely need to be done in consultation with the study team and possibly other stakeholders).
- Determine the location of the event. Consider the need for special equipment, the cost, whether the location is easily accessible and so on. Will transportation have to be provided?
- Determine limitations: budget, staff time, resources.

Roles, responsibilities and agenda planning

- Assign one person to be ultimately responsible for planning and organizing the event. This includes following up with other staff members and volunteers about specific duties and responsibilities they have been assigned (this person could be you or someone else on your team).
- Ask for volunteers. Include others in the development and organization of the event. Including staff, study participants, advisory group members and other partners will help to build their capacity, ensure the event is appropriate for your audience(s) and generate enthusiasm for the event.
- Hold a brainstorming session or sessions with various stakeholder groups (staff, study participants, advisory groups) to discuss the event's objectives. What are you trying to accomplish? Consider different ways of achieving your aim: What should the event include? Don't come to the group with a set agenda; instead, ask them for their suggestions and discuss the possibilities with them.
- Task volunteers or groups of volunteers with specific assignments and responsibilities — solicit donations from local shops and restaurants to be used as prizes, develop a skit, a song, a talk or a presentation on a particular topic.
- Discuss the next steps, and set due dates for when tasks should be completed. Remember to budget time for reviews (of skits, presentations and materials) and be realistic about your timeline!
- Ensure volunteers are clear about their responsibilities and all due dates and next steps.
- Develop an agenda for the event (see Tool 6F: Agenda Planning), and decide who will lead, facilitate and participate in various discussions, activities and presentations.
- Continue to check in with your volunteers and others who are leading or participating in the event to make sure they are prepared. Ask them about any equipment or materials needed for their portion of the event.

**Budget**
- Establish a budget for the event.
- Be creative: Are there local businesses you can ask for donations (for food, refreshments, or prizes)? Are there venues you can use for free or a reduced cost (from partners or other stakeholders, local churches, outdoor spaces or other facilities)?

**Invitations and advertising**
- Create a list of whom to invite to the event. Will it be a list of individuals or organizations (for a training or workshop), or will it be groups of people you need to target (for a community event, roadshow or similar event)?
- Are there groups or individuals that are important to invite for political reasons — government officials, community or traditional leaders, church leaders, representative from other nearby research sites?
- Decide how to advertise or invite individuals to the event:
  - personalized invitation letters
  - flyers or posters (to be used in the community, in study clinics or other health centers)
  - radio announcements
  - email invitations
  - personal phone calls
  - T-shirts for staff members and volunteers that advertise the event
  - announcements at other events
- Consider whether “too much” advertising could create problems. Can you accommodate everyone who might want to come? If not, how will you deal with this?
- Once the date, time and location have been confirmed, send invitations or create advertising materials. If necessary, you can send a “save-the-date” message to individuals before the time and location have been set to alert them that an event is being planned.
Ask people to respond to your invitations so you can get an accurate estimate of how many people to expect; however, don’t expect the count to be accurate. Consider cultural norms for each stakeholder group when managing responses and planning attendance.

Follow up (by email, telephone or in person, as appropriate) with invitees who have not responded to your invitation.

**Logistics**

- Make a list of any equipment and materials needed — data projector and screen; sound system; information, education and communication (IEC) materials or other print-outs; prizes; materials needed for activities or games and so on.
- Decide if you will serve food or refreshments, and determine how much you will need. Will you need plates, napkins, serving utensils, cups, or will they be provided? Be culturally sensitive regarding food choices, vendors and other choices.
- Determine any transportation needs. Will participants need to be reimbursed for transportation? If you will reimburse the participants, decide in advance how you will handle reimbursements so it does not detract from your event. Let people know if and how this will be done.
- Task someone on staff to be at the event to answer questions, help resolve any problems that arise and handle participant concerns.
- Confirm, confirm, confirm: Confirm all details with the location, any vendors (food, refreshments, equipment, transport), and staff members and volunteer that will be helping with the event.

**Follow up (after the event)**

- Be sure that you or someone on the staff is tasked with sending thank-you notes to invited participants and to follow up with any materials or answers that were promised during the event.
- Evaluate the success of your event. Decide beforehand how you will solicit feedback from participants — focus group discussions after the event, written or interactive evaluations during the event, comment boxes or other means.
Tool 6D: Field report

To track your progress and document any agreements, issues, or concerns among your stakeholders, it is important to maintain clearly written records of your engagement process. This will also help you begin to document the tools and strategies you have put into practice and the success of those strategies (see also Tool 7I: Template for Documenting Your Own Tools). Use this field report template to keep a record of all your engagement activities.

**Tool 6D: Field report**

*Adapted from: Shagi C. A template for field reports. Microbicides Development Programme, Africa Centre.*

**Title:**

**Date:**

**Documented by:**

**Description of activity:**

**Objective(s):**

**Accomplishments/agreements:**

**Staff present:**

**Key lessons learned/issues/concerns:**

**Next steps/recommendations:**

**List of participants:**

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Example — Completed Tool 6D: Field report

**Title:** April 2011 update meeting: Baragwanath hospital

**Date:** 11/04/2011

**Documented by:** Katie West-Slevin

**Description of Activity:** Regularly scheduled update meeting with Baragwanath Hospital leadership and staff. The meeting lasted for approximately one hour and was attended by six hospital personnel. The CLO presented the hospital staff with the monthly update, including current prevalence rates of HIV and STIs, before discussing any concerns or issues the hospital staff might have.

**Location:** Baragwanath Hospital

**Staff Present:** Pauline Mphoto, CLO and Katie West-Slevin, community educator

**Objective(s):** To provide hospital staff with the latest monthly update, including HIV and STI rates, per original stakeholder agreement.

**Accomplishments/Agreements:** Update was successfully given. The hospital director and CLO agreed that the study will provide a joint training for hospital and study counselors and nurses on the study aims, the importance of research and referral procedures between the hospital and the study (date, time, and location to be confirmed).

**Key Lessons Learned/Issues/Concerns:**

It was difficult for everyone to see the prevalence figure and charts. Next time, bring handouts of relevant figures and charts for all participants.

The study is adding to the burden of patient flow at the hospital. Staff at both institutions need to be well trained in the referral procedures that have been set-up.

Not all hospital staff are well informed about the study, and there is some concern among the staff.
Next Steps/Recommendations:
The study will provide a joint training for hospital and study counselors and nurses on the study aims, the importance of research and referral procedures between the hospital and the study (date, time and location to be confirmed).

List of Participants:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gugu Ngakane</td>
<td>Mavis Mohapi</td>
</tr>
<tr>
<td>Pinky Motsepe</td>
<td>Promise Nkasa</td>
</tr>
<tr>
<td>Tebogo Kekana</td>
<td>Gavin Adrian</td>
</tr>
</tbody>
</table>
Tool 6E: Deciding on a strategy

You can plan your stakeholder engagement activities in several ways. Whether planning with your team or engaging stakeholders in action planning, it can be helpful to consider a variety of methods, their potential strengths and their limitations before deciding which will best serve your purposes.

Tool 6E: Deciding on a strategy/activity

<table>
<thead>
<tr>
<th>Goal/ Purpose</th>
<th>Strategy</th>
<th>Strengths</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addressing myths and misperceptions</td>
<td>Role Play</td>
<td>• Good for practicing real-life situations</td>
<td>• Usually used in small groups (more restricted audience)</td>
</tr>
<tr>
<td>about research</td>
<td></td>
<td>• Good for stimulating active audience participation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Radio</td>
<td>• Reaches a wide audience</td>
<td>• Can be expensive</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Appropriate for both literate and low-literate</td>
<td>• Requires preparation (scripts, etc.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Messages can be repeated many times</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community Drama/</td>
<td>• Can be performed anywhere and used multiple times</td>
<td>• Difficult to ensure that the target audience will be present when the</td>
</tr>
<tr>
<td></td>
<td>Theater</td>
<td>• Interactive (can encourage audience participation)</td>
<td>play is performed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• No reliance on technology (low cost)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Ability to improvise allows performers to react to audience responses</td>
<td></td>
</tr>
</tbody>
</table>
Tool 6F: Agenda planning

Facilitation experts recommend that you should spend twice the length of any meeting on planning and preparing for that meeting. That means, for a two-hour meeting, you will typically need to spend four hours preparing to make the meeting as effective as possible. Tool 6F provides a template for planning your meetings and workshop agendas. First, define the purpose of the meeting (why you're having it) and your desired outcomes (what you hope to get out of it). In the far right column, list the topics you wish to cover. Then, from left to right, note the activities and methods you will use to cover the topic (how), who will facilitate that part of the meeting (be sure to also list other roles such as note-taker/recorder), how long it will take (be realistic) and finally, the desired outcome that the agenda item corresponds to. Each activity/topic for the meeting should directly relate to a desired outcome. If it doesn't relate to a desired outcome, it should not be included on the agenda. When preparing an agenda for the meeting’s participants, you can delete the “How” and “Desired Outcome” columns from the template, but leave the columns on the facilitator’s agenda.

Tool 6F: Agenda planning

**Purpose:** [State the purpose of the meeting]

**Desired Outcome:** By the end of this [meeting/workshop/training] we will have:
- [Desired outcome]
- [Desired outcome]

<table>
<thead>
<tr>
<th>Agenda</th>
<th>What</th>
<th>How</th>
<th>Who</th>
<th>Time</th>
<th>Corresponding desired outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Set-up:</td>
<td>Roles</td>
<td>Not applicable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Desired outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Agenda</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ground rules</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Agreement on how decisions will be made</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Activity/Topic]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[Activity/Topic]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Next steps/evaluation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Stakeholder Engagement Toolkit for HIV Prevention Trials
**Example — Completed Tool 6F: Agenda planning**

**Purpose:** To get to know each other, agree on the purpose of and the structure of the group, and establish a sense of ownership among group members.

**Desired outcome:** By the end of this [meeting/workshop/training] we will have:
- A shared understanding of different stakeholder engagement strategies employed by the HIV prevention field
- A shared understanding of values, vision and mission and why they are needed
- Key elements of a vision of success for the group

<table>
<thead>
<tr>
<th>Agenda</th>
<th>What</th>
<th>How</th>
<th>Who</th>
<th>Time</th>
<th>Corresponding desired outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Set-up:</strong></td>
<td>Welcome, Introductions, Ground rules, Desired outcomes, Agenda</td>
<td>Charts / Ice breaker</td>
<td>Katie</td>
<td>9:00–9:30 (30 min)</td>
<td>Not applicable</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Clarity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>How community departments are structured</strong></td>
<td>Each organization was asked to do an exercise before coming to the meeting to share with the group. Groups will then write this out on poster paper and hang on the walls around the room. Participants will do a gallery walk to read all the “reports,” and then we will discuss. Write/visually represent:</td>
<td>Sarah</td>
<td>9:30–10:30 (15 min) Write/draw (15 min)</td>
<td>A shared understanding of different stakeholder engagement strategies employed by the HIV prevention field</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Two sentences describing how your community department is structured (what mechanisms do you use: CAB, etc.). Two things that make your site unique in terms of your community approach. One challenge that you currently face. Create a visual representation of your site/community department/community work</td>
<td></td>
<td></td>
<td>10:30–11:00 (30 min)</td>
<td></td>
</tr>
<tr>
<td><strong>Values, mission, and vision planning</strong></td>
<td>Presentation: What are values, mission and vision, why are they important, how are they different? Q's for Clarification</td>
<td>Emily</td>
<td>10:30–11:00 (30 min)</td>
<td>A shared understanding of values, vision and mission and why they are needed</td>
<td></td>
</tr>
</tbody>
</table>
## Agenda

<table>
<thead>
<tr>
<th>What</th>
<th>How</th>
<th>Who</th>
<th>Time</th>
<th>Corresponding desired outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Vision</strong></td>
<td>Small groups</td>
<td>Stacey to introduce</td>
<td>11:00–12:00</td>
<td>Key elements of a vision of success for the group</td>
</tr>
<tr>
<td></td>
<td>What would success look like?</td>
<td>Michael to facilitate agreement</td>
<td>Small groups</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(5 years from now the Mail &amp; Guardian has written their feature article about our group and our success. What does the headline read? What image is used?)</td>
<td></td>
<td>Report back (~3 min per group)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Report back</td>
<td></td>
<td>Facilitate agreement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Facilitate agreement</td>
<td></td>
<td>Clarity</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Vision</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Lunch</strong></td>
<td><strong>Lunch</strong></td>
<td></td>
<td>12:00–1:00</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Logistics:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>How the group will function and work</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
<td>Jill</td>
<td>1:00–2:15</td>
<td>A draft plan for how the group will operate</td>
</tr>
<tr>
<td></td>
<td>(So we’ve talked about what our purpose is. How should we then organize ourselves to achieve our purpose? How will we communicate with each other: calls, email forum, meetings? How often should we meet? Do we need to have particular roles to accomplish our mission (who, what)?)</td>
<td></td>
<td>Small groups</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Small groups</td>
<td></td>
<td>Report back</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Report back</td>
<td></td>
<td>Facilitating agreement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Facilitate agreement</td>
<td></td>
<td>Clarity</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Closing</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Plus/delta</td>
<td>Katie</td>
<td>2:15–2:30</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(On a flip chart write two columns: one with a plus (+) and one with a delta (∆) to signify change. Ask participants, “What did you like; what can we improve?” List responses on the sheet. Use this sheet to improve the next meeting or, if a multiday meeting, to review the agenda and improve for day 2.)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Tool 6G: Brainstorming


**Objective:** Quickly gain ideas from a group.

**Materials Needed:** Flip charts, markers

**Approximate Time:** 10 to 20 minutes

**How to Use It:**
1. Ask participants to think of as many ideas as they can about the topic in question.
2. Ask participants to share their ideas (this can be done by participants raising their hands or by having the facilitator call on each participant).
3. Write participants’ ideas down on a flip chart so everyone can see them.

**Facilitator Tips:** When making long lists on flip charts, use two different colored markers, alternating colors in the list (e.g., blue, red, blue, red, and so on). This makes it easier to distinguish ideas from one another and makes the list easier to read.
Tool 6H: Engaging communities with theatre


**Objective:** Using community drama or theatre is a creative way to explore sensitive issues and to get your messages across in a nontargeting and engaging way. Dramas can be developed and performed by trial staff members to engage and educate communities about your trial, prevention research, HIV and AIDS or other health topics. Dramas can also be used as capacity-building tools during stakeholder workshops and trainings.

**Materials Needed:** Written scenarios, stopwatch (to keep time)

**Approximate Time:** 2 to 2.5 hours (depending on group size)
For dramas developed and performed by staff members, the preparation and practice time may be longer and the performance time may be shorter (approximately 10 to 30 minutes).

**How to Use It:**
1. Divide actors (or participants) into three or four groups, depending on the number of participants.
2. Describe three or four different scenarios or characters (see example below for “Exploring Common Research Myths and Rumors”). Give each group a description of one of the scenarios, and ask them to develop a short drama (five to 10 minutes). For the “Exploring Common Research Myths and Rumors” example, ask participants to act out the myth or rumor and then ask them how they might respond to it. Each group will have 45 minutes to one hour to develop their drama.
3. Ask each group to perform their drama (five to 10 minutes). Use a stopwatch to keep track of time.
4. Once all groups have performed their dramas, encourage the participants to discuss what the dramas revealed. What were the challenges? Are there any key messages that the dramas did not touch on?

**Facilitator Tips:** There are many ways to use community drama as a tool — be creative!
### Community Drama Example: Exploring Common Research Myths and Rumors

*Reprinted from Prevention Research Literacy Training Curriculum, Global Campaign for Microbicides. (Used with permission from the Global Campaign for Microbicides.)*

<table>
<thead>
<tr>
<th>Myth/Rumor</th>
<th>Facilitator Notes:</th>
</tr>
</thead>
</table>
| **Myth 1: on trial product:** “The trial products contain HIV and will infect the participants.” | • HIV prevention products under research are made to reduce sexual transmission of HIV and in some cases other sexually transmitted infections (STIs).  
  • The trial products [pills/gels] do not contain HIV. They are being tested in clinical trials to see if they can help protect men and women from HIV infection.  
  • Participants in HIV prevention clinical trials receive risk reduction counseling and are provided with high quality condoms and educated on their use. They are also treated for STIs. However, despite these risk reduction measures by the clinical trial staff, some participants will become exposed to HIV. Not because of the trial but simply because, as we know, not everyone is able to use a condom at every sex act. |
| **Myth 2: on determining the efficacy of a product:** “For researchers to find out if the gel works, they are deliberately exposing participants to HIV.” | • To establish whether a product works, researchers randomly divide the participants into two groups at the beginning of the trial. One group gets the product with the active drug, while the other group gets a placebo or comparator (a similar product but without the active drug). HIV infections are monitored throughout the trial process. And at the end of the trial, the researchers compare the number of infections in the active drug group and the placebo group to determine if the product works or not.  
  • Participants in the active group and the placebo group get condoms, are instructed on how to use them and get risk reduction counseling. Because of the intensive counseling and use of condoms, rates of HIV among trial participants are lower than they are in the surrounding community. Yet despite these measures, and because trials have to take place in areas where high rates of HIV occur, some participants in both groups will become HIV positive during the trial. Not because of the trial but simply because, as we know, not everyone is able to use a condom at every sex act. |
### Community Drama Example: Exploring Common Research Myths and Rumors

*Reprinted from Prevention Research Literacy Training Curriculum, Global Campaign for Microbicides. (Used with permission from the Global Campaign for Microbicides.)*

<table>
<thead>
<tr>
<th>Myth/Rumor</th>
<th>Facilitator Notes:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Myth 3: on funding by big drug companies:</strong></td>
<td>• HIV prevention products such as microbicides and PrEP are what are referred to as “classic public health goods” because they would most benefit communities highly affected by HIV. As such, governmental institutions and private philanthropic foundations, not pharmaceutical companies, mostly fund HIV prevention research.</td>
</tr>
<tr>
<td>“Big pharmaceutical companies are conducting research among poor uninformed African communities exposing them to huge health risks and exploiting them.”</td>
<td>• A series of ethical principles guide how HIV prevention research is conducted. Under these principles, there have to be benefits to the participants for volunteering to take part in a clinical trial. Participants typically receive a range of services that can include the provision of contraceptives, contraceptive counseling, risk reduction counseling, provision of condoms, screening and treatment for a range of STIs, and in some cases cervical screening and Pap smears. Because of these prevention and care services, HIV rates among trial participants tend to be lower than those of the surrounding communities.</td>
</tr>
</tbody>
</table>

| **Myth 4: on the promotion of promiscuity:**                             | • Researchers promote risk-reduction measures to trial participants through comprehensive risk-reduction counseling, partner reduction, safer sex and provision of high-quality condoms as well as treatment of STIs.  |
| “Researchers are encouraging (or paying) women to have more frequent sex with different partners.” | • While trials sometimes use the term “sexually active women,” this means that the women have sex and are not celibate. It does not mean that women have multiple partners or increase frequency of sex.  |
|                                                                           | • Despite risk-reduction measures, not everyone can or chooses to use a condom at every sex act. This is why a wider range of prevention options is needed in the first place. |

| **Myth 5: on satanic rituals and witchcraft:**                           | • Blood samples are used to test for HIV and sometimes other STIs. Because it is important to monitor the HIV status of each participant regularly, blood samples are taken at regular visits so that each participant can be monitored and, at the end of the trial, the researchers can be able to see how many people got infected. Beyond the trial results, it is also important to monitor participants’ HIV status so that if they do become HIV+, researchers can help them to access care, treatment and support services as soon as possible and so that a woman, if she chooses, can inform her partner so that he can also get tested. |
| “Blood drawn from participants is used for Satanic rituals or sold for witchcraft purposes.” |                                                                                                              |