Chapter 8

Communicating Science Clearly

Misunderstandings about scientific research can happen for many reasons.

For example:

- Scientists often use technical jargon.
- Some words—such as significance and trial—have different meanings in a scientific context than they do in everyday usage.
- Fundamental concepts—randomization, double-blind trial, efficacy—are not commonly understood.
- Some terms—like hazard ratio—cannot be easily translated into other languages.

Fortunately, whether you a researcher, community liaison officer, or advocate, there are ways to make sure you are communicating scientific concepts clearly.

Research teams can reduce the chance of a misunderstanding by paying attention to how communities talk about these issues and by following some simple guidelines to communicate more clearly. This chapter provides guidance on how to talk to different audiences about clinical research.

In this chapter

I Why research is necessary

As someone involved in clinical trials, you may take it for granted that medical research is important. But many people do not have a clear understanding of why clinical and behavioral studies are needed. Explaining the need for research is crucial for the clear communication of scientific information.

Anita Khemka

A health worker in Tamil Nadu, India, speaks to men at a train station about HIV testing.

Geoff Oliver Bugbee/IPM

Consider these guidelines when you convey scientific ideas:

Guideline 1. Emphasize the health impact of your research. How will your study potentially benefit the health of the general public? Clearly stating the potential health impact of the research is one way to show how studies provide necessary evidence for health interventions. For example:

- This study is exploring how to develop an easy way for women to protect themselves against HIV.
- Currently, there is no malaria vaccine on the market. This study could help create a vaccine that could save millions of lives each year.
- Our research is trying to find out how well a new drug can reduce respiratory problems in children with chronic asthma. If we find out it works, this could help thousands of young people participate more fully in daily activities.

Guideline 2. Show how your study fits into the bigger picture of public health needs and research. Explaining the connection between your work and the big picture of public health can help others to see your team as part of the global community of scientists. People will come to appreciate that their involvement in the study has value.

For example, if you are about to start an HIV prevention trial, you will need to talk about HIV/AIDS in the community—perhaps by providing a simple explanation of prevalence and incidence.

- Begin by asking, "How have people in your community (or town, district, country) been affected by the virus?"
- Respond to their stories with information about the numbers of people locally, nationally, and globally who were infected with the virus in the past year, are living with HIV, or have died of AIDS.
- Explain how research has helped to find better ways to care for people who are infected with HIV by, for example, ensuring the safety of drugs that are used for treatment.
- Discuss how your study might address the epidemic in the community and worldwide.

Guideline 3. Explain that all research asks a question. Whenever you talk about a research study, point out that the research team does not know what the results will be. All research tests a hypothesis, and no matter what the result, the study will add to our knowledge about how to prevent or treat the disease. When communities understand that no one has the answer, researchers and community members can appreciate their shared purpose and feel solidarity with one another.

For example:

- We do not know if this medicine works, so we are doing this study because we want to find out whether it can help protect children from diarrhea.
- We know this vaccine protects mice against influenza. Our study is trying to find out whether the vaccine can also protect humans.

Anita Khemka

To see if your messages are clear and easy to understand, try them with people who fit the profile of your intended audience. Pictured here is a peer educator conducting a group discussion on HIV in New Delhi, India.

Guideline 4. Explain why the study is being conducted in a particular community. Provide an honest explanation of why the community was chosen. It is important to explain that the scientists are trying to solve a problem in the community. Communities that are provided with a specific explanation are less likely to feel that they are being exploited by the study.

In the case of HIV prevention trials, for example, one might say:

- Large-scale HIV prevention studies must take place in settings where the HIV incidence is high and where prevention is most needed.
- We must ensure that products work in this community and are acceptable to residents.
- Studies must be conducted in areas where there are scientific institutions and trained research personnel.
- Communities and countries hosting studies are contributing to worldwide progress in preventing HIV infections.

Guideline 5. Provide some background information about your field. Whether you are drafting a press release or preparing a talk for a Ministry of Health, you should be able to explain quickly the purpose and context of your research, including the studies that came before. For example:

> "Scientists have been studying microbicides for the past 20 years. We have been getting better at determining what might work, and we recently discovered problems with certain approaches. This study is the latest step in this process."

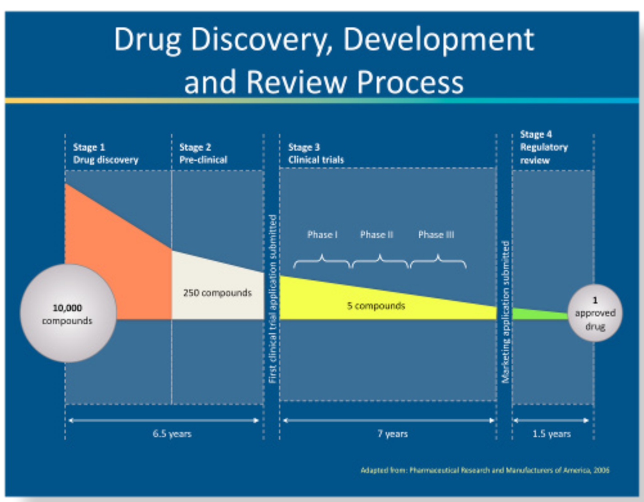
Guideline 6. Outline the process of clinical research. Few people understand how much effort, cost, and preliminary research is required before investigators launch a large-scale clinical study. Although it is not necessary to explain the details about the phases of research, it can be helpful to mention that extensive lab work, animal testing, and studies involving small groups of people are conducted for safety and side effects long before a product or intervention is tested on a large group of people.

Most people intuitively understand that a treatment must be shown to be safe before it can be shown to be effective. Pointing out that this principle is integral to the structure of all clinical studies helps people to understand that scientists strive not to harm anyone who volunteers for a study. The research process itself is designed to minimize risk to participants and maximize the chance of success.

As you explain clinical research, consider the scientific literacy of your audience. The same information can be presented in many different ways. The graphic examples below (Figures 8.1 to 8.5), which explain the phases of drug development and clinical research, assume different levels of reader sophistication.

A sophisticated audience can apprehend a great deal of information in a single image. For example, Figures 8.1 and 8.2 explain the process of drug development, including the phases of a clinical trial, the success rates of products as they advance through each phase, and the development timeline.

Figure 8.1. Explaining the process of drug discovery to a scientifically literate audience

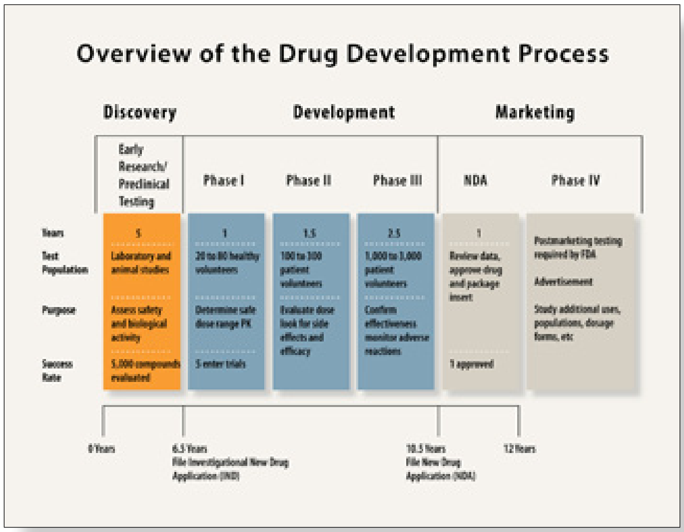


Reprinted with permission from the International Partnership for Microbicides, Silver Spring, MD, 2010.

The International Partnership for Microbicides adapted the chart above to explain the process of drug discovery to their donors, a relatively sophisticated audience. It highlights the number of candidate microbicides that are tested at each phase, illustrating that only the most promising products move forward and only one safe and effective product may emerge.

Figure 8.2 explains the stages of research more fully:

Figure 8.2

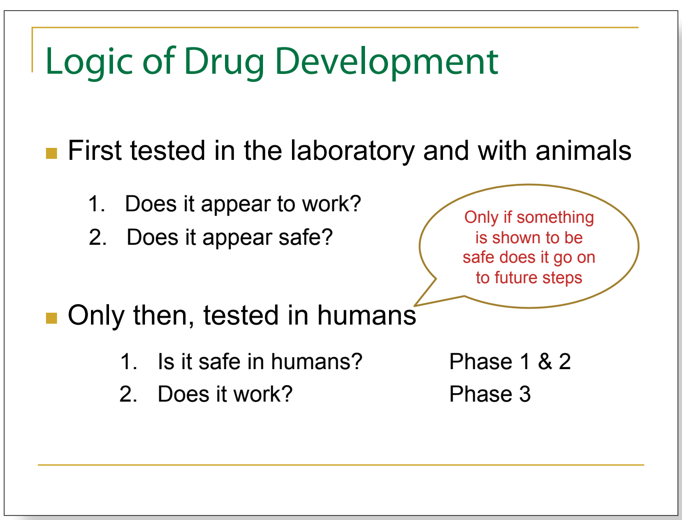


These figures might be too complicated for many audiences. But similar information can be presented in a much simpler way.

The Global Campaign for Microbicides (GCM) uses a series of "mix-and-match" slides to simplify these concepts for nonscientific audiences. The GCM slides demonstrate simple ways to reinforce key concepts, such as the duration of drug development, and illustrate some options for providing more or less information depending on the audience's scientific literacy.

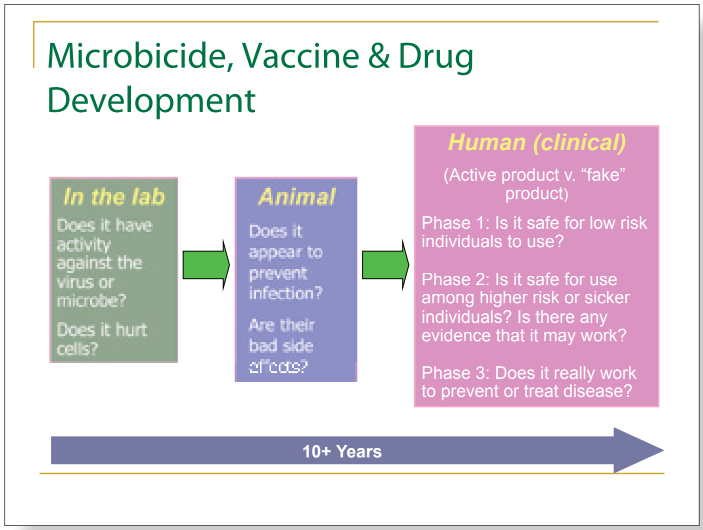
GCM's first slide (Figure 8.3) emphasizes that all experimental products are tested in the laboratory and in animals before they are considered for testing in human beings.

Figure 8.3.



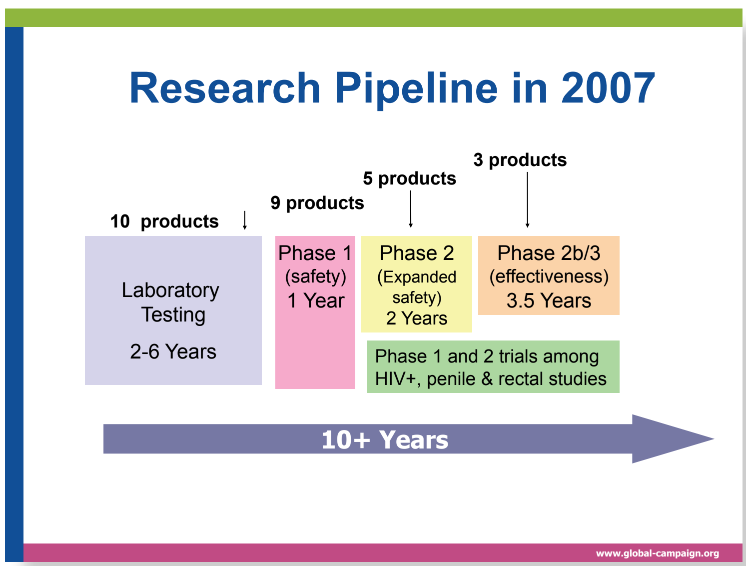
The second slide (Figure 8.4) reinforces this notion and provides a little more information about the different phases of a clinical trial:

Figure 8.4.



An alternative slide (Figure 8.5) provides additional information on the duration of each phase and the reduction of viable products with each successive phase:

Figure 8.5.



Guideline 7. Frame research as serving the common good. Whenever you talk about your study, emphasize the positive outcomes of medical research. For example, flu shots, medications to treat HIV, contraceptive pills, tetanus shots, and the eradication of smallpox are all public health successes of medical research. Emphasize that your study also hopes to find answers to health problems.

Remind listeners that public health research has always been a global effort. Highlight that the same product may be tested in numerous safety studies in the United States and Europe and then tested in Asia, South America, and Africa in later-stage trials before it is approved for use and implemented at a country level.

II Translating the language of clinical studies

The key to writing easy-to-read materials is to get outside of your own head and stop thinking about what you know and what you think is important, and try to think of it through somebody else's eyes and what they will think is important to know—and then write your materials with this audience in mind.

—Anna Forbes, former Deputy Director, Global Campaign for Microbicides

Researchers sometimes fear that simple explanations dilute important scientific concepts. However, it is essential to communicate clearly and credibly with nonscientific audiences so that potential participants, trial communities, politicians, and others will understand why their support is needed.

Listen to the language used by your audience. Pay attention to the patterns of speech used by people who live and work where your study is being conducted. How do local staff members and journalists discuss the health issues you plan to study? What words or analogies do they use? Journalists care about readability, and they are careful to use language to suit their audience.

In Kenya, for example, journalists often refer to "the cut" when they write about male circumcision because that is what Kenyans call it. Scientists who are conducting research on male circumcision can take this into account when they explain their work to community members.

Jim Daniels

A clinician at a clinic in Cambodia handles blood specimens. Drawing and storing blood has raised issues in some communities. Communicating clearly about how blood is handled in a clinical trial can be an important way to allay community concerns.

Box 8.1. Replacing jargon with everyday words

Jargon	Everyday language
vaginal intercourse	sex
coitally dependent	when you have sex
disinhibition	take more risks
transmission	infect
acquisition	become infected with
concentration level	strength
systemic toxicity	side effects
seroconvert	become HIV positive
accrual	participants joining the study
retention	participants staying in the study
terminate	end

Translate scientific terms into everyday language. You can keep it simple without sacrificing the meaning of a concept. Some people follow the two-syllable rule (Forbes 2009): questioning the use of all words that have more than two syllables. Try to replace complicated words with shorter terms or with language that is more familiar. (See Box 8.1 for an example of how to replace jargon with everyday words.)

You should also be alert to double meanings. Even the most commonly used terms in clinical studies can be misinterpreted. Sometimes a seemingly neutral scientific word or phrase can have negative connotations to others or different meanings in a local language. This can create stumbling blocks that interfere with the implementation of a study. (Box 8.2 demonstrates three such instances that may require a further explanation from you.)

Consider the use of images to tell your story. An illustration can do much to explain a concept. Graphics can help you transcend language differences and cultural barriers and can make complicated ideas easier to grasp. Of course, the same visual tool may not be effective for every audience. (See Box 8.3 and Figure 8.6 for examples of visual aids that are appropriate for lay audiences.)

Anita Khemka

Performing plays is an excellent way to illustrate scientific concepts. In this photo, young women in New Delhi, India, act out "The Immune System Dance," an activity to help understand how HIV is transmitted.

Box 8.2. Everyday words that can mislead

Come join our trial!

You hold a *trial* to decide if someone is innocent or guilty of a crime. Am I in trouble?

This is a Phase I safety trial of a new HIV product.

Oh good, the trial will help keep me *safe* from HIV!

We have censored 30 participants.

Why were some participants *censored* and not allowed to speak?

Box 8.3. Baobab trees used to explain serodiscordance

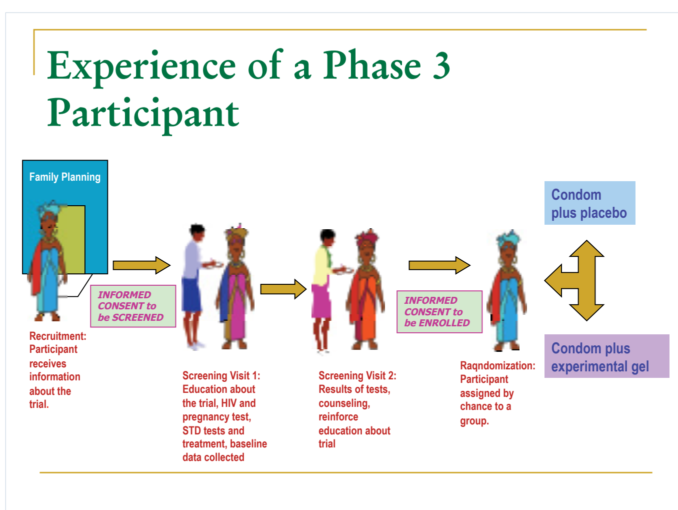
The Partners in Prevention (PIP) HIV/HSV Study enrolled people who were in serodiscordant relationships (where one partner in the couple was HIV positive and the other was HIV negative). The PIP team needed to explain the concept of serodiscordance in a way that could be understood by the study's participants in eastern and southern Africa. The team used an image of two baobab trees (left), one of which is infested with termites that can destroy one or both trees. Partners in Prevention used the illustration to show that HIV can infect one or both partners, but that it cannot be diagnosed without testing.

You should also consider the use of software, such as PowerPoint, which allows you to use compelling photographs, drawings, and simple, colorful charts. A good slide has a minimal amount of text. If you use a graph or a chart, make sure that the axes and the data are clearly labeled. Do not read aloud from a slide; use it as an outline, not a script.

The slide from GCM shown in Figure 8.6 provides a visual introduction to civil society stakeholders of a randomized controlled trial from the perspective of a trial participant.

Use props when you present scientific information. Props can help you explain concepts in an engaging way. Props make a presentation more interesting and memorable (see Box 8.4).

Figure 8.6.



Katie West Slevin/GCM

Tabita Mahlangeni, community educator with the Aurum Institute of South Africa, participates in an interactive exercise, "Understanding the HIV Life Cycle," with a group of trial site staff, CAB members, and advocates during a prevention research literacy training conducted by the Global Campaign for Microbicides in Johannesburg, South Africa.

Pay attention to local context and culture. The tools you use to explain your study must be relevant to the community. Multisite studies may need to adapt materials to the needs of each site (see Box 8.5).

Box 8.4. Using props to explain clinical trial concepts

Concept	Prop	Exercise	Lesson
Placebo	Two glasses of water, salt	Bring out two glasses of water. Stir salt into only one glass. The glasses will look the same, but one now has an "active ingredient"—the salt.	A placebo is a word that refers to something that looks like medicine but isn't, and has no effect on the person who takes it.
Double-blinded	Two glasses of water, sugar	Bring out two glasses of water. Ask someone from the audience to pour the sugar in without anyone else seeing them do it. Ask the audience to guess which glass has sugar in it.	Neither the participants nor the researchers know which participants are receiving the test drug and which are receiving the placebo.
Randomization	Paint a cardboard box to look like a die, each side with a different number of dots from 1 to 6.	Ask each person to roll the die and remember the number that appears on top of the box. Divide the group according to these numbers: 1 to 3 on one side of the room; 4 to 6 on the other.	When people are randomly assigned to either the intervention group or the placebo group of a study, the only determining factor is chance.

Box 8.5. The importance of field-testing materials: lessons learned from Orange Farm

When staff members of the Bophelo Pele Male Circumcision Project at Orange Farm, South Africa, began a research study to determine whether adult medical male circumcision would help to reduce the risk of HIV transmission, they were surprised to find that many men did not know whether they were circumcised or not. The staff quickly printed brochures with photographs of a fully circumcised penis and an uncircumcised penis, so that men could see the difference.

Some community members were disturbed seeing photographs of penises in materials. "We asked for suggestions of other ways to explain the differences, and community members suggested that we use drawings, which were less offensive to them," said Dirk Taljaard, project manager of the Bophelo Pele Male Circumcision Project. The team immediately revised the materials, and now uses drawings to show the anatomical differences.

Use stories and analogies to explain scientific concepts. Years after people forget facts and statistics, they will remember a good story, especially if it sparked a moment of understanding. Make sure that the analogies you provide are culturally and politically appropriate. Here are some examples of narratives that explain certain scientific concepts:

> *Hypothesis testing.* Farmer Batayan has grown maize for five years, and he now wants to begin growing millet instead. He is not sure if the fertilizer that helped to grow his maize will increase his millet crops. The fertilizer might harm the millet or have no effect on the millet. To find out for sure, Farmer Batayan must test the fertilizer on his fields. Farmer Batayan decides to plant two separate plots of land with millet seed. He adds the fertilizer to the first plot and nothing to the second plot. He can now compare the plots directly and determine if the fertilizer helps the millet grow. If it does, he will apply the knowledge he has learned and add fertilizer to both plots next season.
>
> *Monitoring by a data safety and monitoring board (DSMB).* A mother asks her daughter to make a meal. As the daughter cooks the meal, the mother opens the pot to check if all is going well. When the food is ready, the mother tastes the food before serving the family. Although the daughter (the research team) is cooking the meal (running the study), the mother (the DSMB) is there to make sure the food is cooked properly.
>
> *Different strengths of the same product.* When one part of a trial that was testing a higher strength of the PRO 2000 microbicide gel was stopped, many people could not understand why a lower dose might work, when a higher dose was ineffective. Investigators began using the analogy of brewing a good pot of tea—a popular beverage in most of Africa. They explained that four tea bags will make the tea taste bitter, whereas tea made with one bag tastes better.
>
> *Protocol.* A study protocol is like a recipe. Just as a recipe provides a list of ingredients and the instructions for preparing a dish, research protocols provide all the elements (product, population) and the plan (study design) for carrying out a study.

Translate scientific concepts into local languages. Even high-level stakeholders who speak English will appreciate hearing news in their own language. When briefing national government officials, consider providing background materials not only in the official national language, but in the main local language. When translating technical terminology into local languages, allow enough time for the translation and back-translation of important materials.

III Demystifying statistics

The use of numbers can be challenging when you want to communicate scientific information. Statistics are often misreported or misinterpreted by journalists and the general public. Follow these rules to help them understand your study:

- Simplify numbers. Instead of saying "51.2 percent," say "about half."
- Be careful with fractions and proportions. For example, if you say, "A vaccine reduced risk by one-third," many people jump to the conclusion, "That must mean that two-thirds of people in the study got infected!"
- Use numbers and numerical comparisons that people can relate to their own lives. For example: "Three out of four women of childbearing age in Province Z told us that they currently do not want to get pregnant but they have no way to control their fertility."
- Know how to explain common statistical terms.

Consider these examples:

Statistical significance
Short description: If a result is reported as "not statistically significant," it means that the finding could be due to chance rather than a real difference between groups.

Longer explanation: When researchers say that the difference between two groups is not statistically significant, they mean that, given the number of people in the study, they cannot be confident that any difference observed reflects a true difference between the two groups.

This does not mean that there was no difference. It means only that any difference observed in the sample might be the result of chance. Scientists tend to say that a difference is not statistically significant if the possibility that the difference is merely due to chance is greater than 5 percent.

Confidence interval
Short description: the range of values within which the true value is likely to be; the margin of error for a result.

Longer explanation: Because a trial must limit participation to a subset of a much larger populace, it can only provide a result that is an estimate of what the true effect would be in the broader population. To assess the accuracy of this estimate, one must look at the confidence interval, which provides the range within which the true effect is likely to lie. The narrower this range, the more certain researchers are that the estimate is close to being accurate and that the same result would be seen again if the trial were repeated. As such, confidence intervals are important for fully understanding the strength and reliability of the result, even one that is statistically significant.

Trials typically use a 95 percent confidence level (95% CI), meaning that there is a 95 percent chance that the true result lies within the interval. For example, if a trial demonstrates that a product reduces HIV infections by 40 percent, and the 95% CI is 22 percent to 68 percent, there is a 95 percent chance that the true effectiveness of the product is somewhere within that range.

Elizabeth T. Robinson/FHI

Explaining statistical concepts in a clear way is one of the greatest challenges of communicating about science to lay audiences.

Incidence and prevalence

The difference between these terms can be confusing.

Incidence refers to the number of **new cases** of a disease or condition in a specified time period—for example, the number of people who acquired an illness in a certain region within the past year. Incidence is often expressed as a percentage. The term is usually used for comparisons, to describe whether the new cases of a disease are increasing or decreasing.

A researcher might say that the incidence of malaria in community X has risen because over the past 12 months there were 500 new cases of malaria in the community, whereas there were only 400 new cases in the previous year. If community X has 10,000 people, the incidence of malaria would be 5 percent (500/10,000).

Prevalence refers to the total number or proportion of **old and new** cases in a specified time period—for example, the total number of people in a region who have an illness at the moment. For a chronic infectious disease, it would include people who are newly infected and people who have been infected for several years.

Prevalence is often expressed as the number of cases per 100,000 people. A researcher might say that the prevalence of HIV in a city of 1 million people is 5,000 per 100,000 (or 5 percent) because their estimates suggest that 50,000 people in the city are currently carrying the virus.

It should also be noted that the incidence and prevalence in a community can be very different. For example, a community may have a high prevalence (i.e., many people living with HIV) but a low incidence (i.e., very few new infections are occurring, perhaps because of successful prevention and treatment programs).

Box 8.6. Present scientific results in simple, clear terms

By Dr. Kawango Agot, Director, Impact Research and Development Organization, and Principal Investigator of the Bondo, Kenya, site of the FEM-PrEP trial

It is so important to convey research results clearly and simply. Concepts like partial efficacy can be particularly confusing. This is something I have witnessed many times. People are very creative in the way they apply math! For example, if a given treatment is found to be 50 percent effective, some people might interpret this to mean that all they need to do is take double the recommended dose and they would be fully protected.

In 2007, I was part of a research team that published a scientific paper showing that medically performed male circumcision is safe and can reduce men's risk of HIV infection during vaginal sex by about 60 percent (Bailey and others 2007). Our study was one of three that found similar results. The findings were exciting, but explaining them has been a challenge. Everyone talks about male circumcision providing 60 percent protection, but not everyone understands what it means. Our attempts at explaining this statistic have revealed gross misunderstandings. One interpretation we often hear is that if you have unprotected sex with an infected partner ten times, six of these times you will not get HIV. Another interpretation is that once a man is circumcised, it is okay to have sex with infected women as long as he stops or uses a condom after the sixth one.

Michael Stalker/FHI

After three randomized clinical trials showed that male circumcision provides men partial protection against HIV infection, the Government of Kenya decided to expand male circumcision services.

After we announced the study results, our research team held numerous dissemination meetings with the media. We found in one media training workshop that the slides we were using were difficult for journalists to understand. One journalist dismissed the results as invalid because the percentage of protection was not exactly the same in all of the studies—reducing the risk by 51 percent in one, 59 percent in the second, and 60 percent in the third. To correct this misunderstanding, we took great care to emphasize that even though the results appeared slightly different in each of the three countries where the research was conducted, the difference was negligible and could be explained by differences in populations targeted by the studies, not differences in the effect of circumcision on HIV infection.

How we train our community educators to explain partial protection can also be useful when explaining it to journalists: Everyone who engages in unprotected sex has a chance of getting HIV whether they are circumcised or not, but men who are circumcised have a lower chance of getting HIV than do men who are not circumcised. We explain that in the research studies, circumcision prevented 60 percent of the infections that would have occurred if the men remained uncircumcised. In other words, 60 percent of all the infections that occur in men who are not circumcised would be prevented if those men were circumcised. For me, this experience with drastically inaccurate interpretations of scientific research has emphasized how important it is for researchers to take the time to make sure they are communicating their results simply and clearly.

IV Five ways to avoid misunderstandings

No one can guarantee that all audiences will understand your trial. However, here are five things you can do to limit misunderstandings or misinterpretations of your study:

1. Limit the use of acronyms.
Most people will not be familiar with the acronyms you use in your work. If you must use an acronym, be sure to spell out the complete term on first use.

2. Use respectful language.
Research protocols often use terms that carry scientific value but may seem dehumanizing to nonscientists. For example, scientists sometimes refer to people who participate in a clinical trial as subjects. Use the words participants or volunteers to describe people who enroll in trials. These terms honor their willingness and effort to be involved in the trial.

3. Use neutral, straightforward language.
Terms such as target group and control arm can be confusing or trigger negative responses. Other terms—such as seroconversion—are too technical for lay audiences. See Box 8.7 for alternatives.

Box. 8.7. Speak in ways that emphasize the human face of trial participants

Our study targets sex workers.	▶	Our study enrolls sex workers.
Fewer infections were found in the experimental arm.	▶	Fewer infections were found among community members who received the experimental drug.
Many subjects were noncompliant and deviated from the study protocol.	▶	Not all participants used the study product as directed.
Ten percent of subjects seroconverted during the trial.	▶	Ten percent of the participants became HIV positive during the study.
We censored women who became pregnant during the trial.	▶	The analysis of HIV infections did not include participants who became pregnant during the trial.

4. Use consistent language.
Many study products and interventions have multiple names, which can cause confusion. For example, the drug Viread is also known as tenofovir, and some people refer to pre-exposure prophylaxis (PrEP) as an oral microbicide.

When introducing a new product or concept, it is important to refer to it consistently with the same name to avoid confusing people. It may also be helpful to point out the other terms that may be used to describe the same thing (such as Viread and tenofovir).

5. Avoid promising more than you can deliver.
Research has no guarantees, so you should present realistic timelines and expectations.

Use the conditional tense—with words such as could and might—when you communicate timelines and possible scenarios. Temper your description of the study's goals with the realities of scientific research. Be positive about your research without overstating its potential.

For example:

- We hope to release our results next December.
- If this product works, it might help save millions of lives.
- If the government approves this intervention, we will be ready to launch a new program.

Similarly, be conscious of the many interpretations of the terms you use. In everyday language, we tend to use many terms interchangeably—and words can mean different things to different people. For example, when talking about prevention, it is important to make a clear distinction between absolute protection—a product that prevents infection 100 percent of the time in 100 percent of the people—and partial protection—a product that reduces the risk of infection in some people.

Key points to remember

- The first step to communicating clear information about your scientific research is to take a step back and explain the big picture. Remember to outline the public health benefits and process of clinical research, contextualize the need for your study, explain its purpose, and address why this research is taking place in your particular community and country.
- Consider the scientific literacy, learning styles, and cultural context of your audiences when explaining clinical research. Incorporate creative techniques to connect with your audiences. Images, graphs, props, theater, analogies, stories, PowerPoint slides, role-plays, and songs are powerful communications tools that can help you explain and simplify complex scientific concepts.
- To limit misunderstandings, translate scientific terms into everyday language, avoid jargon, simplify numbers, and do not promise more than you can deliver.