



Prove It: Documenting Rights Abuses





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About *Know It, Prove It, Change It:* *A Rights Curriculum for Grassroots Groups*

The *Know It, Prove It, Change It! A Rights Curriculum for Grassroots Groups* series is created specifically to help grassroots organizations in communities affected by HIV/AIDS to understand their basic rights, document rights abuses, and design and implement advocacy campaigns. The series has three parts:

- *Know It: The Rights Framework* discusses international human rights law and how it applies to people living with HIV/AIDS and other marginalized communities.
- *Prove It: Basics of Rights Documentation* explains how to plan and conduct rights research.
- *Change It: Ending Rights Abuses* shows how to plan and conduct local, national, and international advocacy based on the research.

Each book includes a manual, which describes the steps to take; and a trainer's supplement, which has the same information in the form of lesson plans, sample exercises, and templates to use in a training or workshop.

The *Know It, Prove It, Change It* series is created by three organizations with extensive experience in rights training. Thai AIDS Treatment Action Group (TTAG) from Bangkok, Thailand, works to achieve equal access to AIDS treatment for all and advocates on behalf of highly marginalized groups including people who use drugs and people in prison in Thailand. The mission of the Korekata AIDS Law Center in Beijing, China, is to defend the rights of people living with HIV/AIDS and to advance the development of Chinese law to protect the rights of people with AIDS. Asia Catalyst is a nongovernmental organization (NGO) based in New York, United States. It is a resource for grassroots NGOs in Asia, and offers long-term coaching and short-term technical assistance to new NGOs. All three organizations regularly offer training on rights documentation and advocacy, and conduct local and global advocacy.

In order to create a series of handbooks that would be useful in different contexts, we asked several experts from the Asia-Pacific region to read drafts and give comments. We held two focus group meetings (one in Thailand and one in China) with representatives from grassroots AIDS and harm reduction groups from





both countries. After our final draft was complete, we held pilot workshops at the International AIDS Conference in Vienna, and with members of Chinese and Thai NGOs in Bangkok, to test the curriculum and get additional input.

Our goal was to use this diversity and real-life experience to make the manuals better. As you use them, we hope you will contact us with your own thoughts and suggestions. You can email us with your suggestions or questions at info@asiacatalyst.org.

What is the relationship between HIV/AIDS and human rights?

Human rights and HIV/AIDS have a close connection. First, violations of human rights increase the risk of contracting HIV/AIDS. If drug users or sex workers know that they are likely to be imprisoned and beaten by police, they are less likely to take part in government AIDS education and prevention programs, for fear of being caught.

At the same time, having HIV/AIDS often leads to the violation of human rights. People living with HIV/AIDS often face discrimination by hospitals, employers, landlords, schools, and others. They may face barriers to ARV treatment, or violations of the right to privacy as well.

International experience has found that it is necessary to address the connection between HIV/AIDS and human rights and to protect basic rights as part of national and local responses to the epidemic. The appendix explains a few of the basic rights each person has under international law. For a more detailed discussion, please see our first book, *Know It: The Rights Framework* (forthcoming 2011).

Is a Rights-Based Approach Appropriate for Every Country?

One question we are often asked is: Each country has its own unique context. Are rights-based approaches always culturally appropriate?

While we agree that each country has its own traditions, styles of communication, and ways of managing politics (something that is especially important to keep in mind when planning advocacy), our three organizations—one Thai, one Chinese, and one American—find that our colleagues in marginalized communities all share similar experiences when it comes to their rights. Whether they are sex workers in Beijing, drug users in New York, or transgender people in Chiang Mai, the people we work with face discrimination, lack of privacy rights, lack of access to information, and police abuse—as well as other rights abuses that increase their vulnerability to HIV/AIDS.

HIV/AIDS does not respect cultural differences or national boundaries. It affects everyone, especially people in each country who are marginalized from





mainstream society. Globally, we've made great leaps and bounds in scientific research and improved access to treatment, but these things on their own have not been enough to end the AIDS crisis. Rights protections are an important part of the fight against HIV/AIDS, and rights documentation skills are a way to empower people most at risk of HIV to reclaim their human dignity and ensure that governments actually implement their policies. Working together on rights advocacy, both locally and across borders, can reduce everyone's vulnerability to HIV/AIDS.





INTRODUCTION

The Power of Testimony

One time, before I got tested, I felt sick, and I went for a checkup at a small hospital. They started to examine me, and they did a blood test. Did they test for HIV? I don't know...the doctor came to me late at night and found an excuse: he said they did not dare to treat me because their treatment was not good enough. He said I should go to another hospital....[Since then] I call up the hospitals first and tell them straight out that I'm HIV-positive. They won't treat me.

*A PLWHA in Kunming, China*¹

At K., age 33, an HIV-positive peer educator in Chiang Mai, explained that [as a result of the Thai war on drugs], HIV-positive drug users like him "would not go to the hospital unless we are dragged there." "The war on drugs has had an impact on me personally," At K. said, "The policy continues. HIV-positive injection drug users won't see the doctor because this policy has been there for too long and it's starting again now. My friends won't dare go to the hospital.... My friends say it's a state unit, it's a government office." ²

These two quotes are examples of rights testimony: a statement of the truth as experienced by someone who is a survivor of a rights abuse. Because they have the ability to move the people who hear them and read them to action, testimonies are the jewels of rights research. This manual, *Prove It: Documenting Rights Abuses*, explains step-by-step how to conduct research at a high international standard and obtain powerful testimony.

Part of the power of testimony comes from the fact that the survivors use their own words to describe the pain they experienced. These voices move us and compel our attention in a way that statistics and rhetoric often fail to do.

The power of testimony also comes from the fact that the survivors' experiences are not unique to them as individuals. Many people affected by HIV/AIDS are victims of discrimination and rights abuses every day. Some people in marginalized communities find rights abuses are so much a part of everyday life that they begin to believe that they deserve the abuse. But rights abuses are a

¹ Human Rights Watch, *Locked Doors: The Human Rights of People Living with HIV/AIDS in China* (New York: Human Rights Watch), September 2, 2003. Available at: <http://www.hrw.org/en/node/12273/section/10>.

² Human Rights Watch, *Deadly Denial: Barriers to HIV/AIDS Treatment for People Who Use Drugs in Thailand* (New York: Human Rights Watch) (November 2007), p.28. Available at: <http://www.hrw.org/reports/2007/thailand1107/>





violation of basic human dignity and of our fundamental equality. The fear of rights abuses, and the stigma and shame that surrounds HIV/AIDS, makes people in marginalized communities much less likely to come forward to be tested or to seek out treatment.

How do we end rights abuses? The first step is to prove that they have happened at all. One of the worst things that rights abusers do is to deny that abuses take place, and deny the truth and the experience of the survivors. As researchers, our task is to uncover the truth that has been hidden by others. This truth, spoken in the survivor's own words, is one of the most powerful tools we have in the global fight for rights.

Because grassroots organizations already have the trust of marginalized communities, these organizations are in the best possible position to gather rights testimony. Many of the people you work with every day may be abuse survivors. When you learn to do rights research, you can help to make their voices heard by others.

Rights research is slightly different from other research approaches used in the HIV/AIDS response, and that difference has to do with rights researchers' focus on the words and experiences of the abuse survivors.

Putting the Survivor at the Center

There are basically two kinds of social science research: quantitative research, in which researchers aim to get information about a large number of people, and qualitative research, in which interviewers gather more detailed information about a smaller number of people. One approach is not better or worse than the other—they are each useful for different purposes.

Many groups that work in the HIV/AIDS field are familiar with quantitative research, because that is the approach often used by medical scientists, governments, and large international donors. In quantitative research, the researcher produces a carefully-written questionnaire, trains assistants to use the questionnaires to interview others, and gathers information from a large number of people. In this approach, the researchers decide on the questions. The people they interview are the objects of the research, and they cannot rewrite the questions. If the questions don't exactly fit the circumstances, those differences may be left out, because the priority is to ask the same questions each time.

The head researcher in a quantitative research project may not ever meet the people whose information he gathers, or go to all the places where the research is conducted. She analyzes the research using computer programs and draws her conclusions based on the numbers.





Quantitative research is very useful for getting a big picture of a problem that affects large numbers of people. For instance, it is an excellent tool for studying economics and the spread of epidemics across populations. But it's not a great tool for understanding the differences in conditions on the ground, and why something happened to an individual. Quantitative research puts the questionnaire at the center of the research, not the individual's experience.

Rights research is qualitative research, a slightly different approach. In rights research, the researcher puts the individual abuse survivor at the center of the work. Instead of having the survivor fill out a questionnaire, the researcher leads her in a discussion in which she shares her experiences. The people you interview may raise questions you didn't even think to ask, or give you information that leads you in a different direction than you planned. The rights researcher carefully notes down every word the individual said, because her goal is to faithfully record the words and obtain a detailed testimony from the abuse survivor. The rights researcher also pays attention to the context and gathers information from observations and other interviews to help her to understand what the testimony means.

In both qualitative and quantitative research, informed consent is essential. In rights research, we have an added responsibility to consider the risks to interviewees of participating in a politically sensitive project, to make sure the interviewees understand those risks and are willing to face them. We also spend time thinking and preparing for the possibility that our interviewees may suffer from Post-Traumatic Stress Disorder (PTSD), and help them to cope with it.

This may sound like more work than quantitative research. But while quantitative research can really only be done and analyzed by someone with an advanced education and special computer skills, qualitative research can be done by anyone who is able to read, think, take notes, and keep their notes organized.

Being Systematic

The point about keeping notes organized is important, and is discussed in more detail in Chapter 3: Writing the Report. One key to successfully doing any kind of research is to be systematic about it: develop a plan, organize the information as it comes in, and do the research in a careful, professional, and thoughtful way. This makes it possible to evaluate and analyze the information you gather, find information later, and organize everything you learn into a report. Being systematic about the research also helps to lay the foundation for the advocacy you will do with the research later.





Our Case Studies

To illustrate the process of creating a rights report in real life, we draw on two reports that authors of this manual wrote.

CASE STUDY | CHINA HIV/AIDS DISCRIMINATION REPORT

Locked Doors: The Human Rights of People Living with HIV/AIDS in China, was released by Human Rights Watch in 2003. The report documented discrimination against people with HIV/AIDS who were turned away from hospitals because they were HIV-positive. Human Rights Watch researchers interviewed survivors and experts in China and released the finished report to the media. Human Rights Watch worked with other NGOs to visit government officials, UN officials, international donors, and other experts and give them copies of the report and the news stories. Along with the efforts of many Chinese organizations and AIDS activists, as well as progressive government officials who pushed for change from within, the report helped to bring about policy changes. Today, China has a national policy prohibiting discrimination by hospitals against people living with HIV/AIDS, but it isn't always enforced. (Laws and their limitations are discussed in more detail in Know It: The Rights Framework).

CASE STUDY | THAI DRUG USERS REPORT

Deadly Denial: Barriers to HIV/AIDS Treatment for People who Use Drugs in Thailand was a unique collaboration between a grassroots HIV group, Thai AIDS Treatment Action Group (TTAG), and Human Rights Watch (HRW). The report documents barriers injecting drug users (IDU) face in accessing AIDS treatment in the context of Thailand's brutal "war on drugs." Before the report was finalized, the two groups held a report-back meeting for the IDU community from whom data was collected, as well as related NGOs, government agencies, the UN and others was held in Bangkok. Together, they developed policy recommendations. The two organizations held a press conference for international and Thai media. The Thai government was confronted with the reality that their "universal (HIV treatment) coverage" policy was failing, and began to integrate appropriate IDU responses into their national AIDS plan.





Each of these reports took many months to research and write: the China report took one year to research, write, edit and publish, and the Thai report took five months. In the process of creating the reports, the researchers encountered all kinds of challenges and had to work with our communities to come up with creative solutions to them. Documenting rights abuses has to be done carefully, in order to protect the victims from further abuse and psychological harm. It has to be done systematically, to gather evidence that is totally reliable. In our experience, small organizations have to work harder than a large, established organization to prove their credibility. Any mistakes or errors can easily be used by people in power to dismiss a small group.

By reading this manual and running through the exercises, you will develop the skills you need to collect reliable evidence and become a professional rights researcher.

The Steps to Documenting Rights Abuses

Here are the steps to take to systematically conduct rights research and produce a report:

- Prepare a detailed research plan, including how to manage risks for yourself and others
- Obtain informed consent from each person you interview
- Conduct interviews and take detailed notes
- Create a system to organize information as you collect it
- Analyze the information and create an outline for the report
- Write the report...and rewrite it...and rewrite it again...
- Understand the international and local laws that apply to your case

Each of these steps is explained in detail in the following chapters. First, we begin with a basic overview of HIV/AIDS and human rights.





CHAPTER 1

Planning Your Project

Comprehensive planning should happen before you start your research. To keep your project on track, there are four preliminary steps you need to take. This chapter will help you to work through each one.

REMEMBER: A report is not the end of the project—it’s only the beginning.

In doing rights research and writing a report, you are creating a **tool** that you can use to leverage the power of others to create positive social change. By doing the planning described in this chapter, you are making sure you create a tool that will be useful in your advocacy. Always remember to keep the focus of your work on **ending the abuses**, and plan to create a tool that can you help to do that.

THE FOUR STEPS | PLANNING YOUR PROJECT

1. “Map” the project: Figure out who the players are in your subject area, and the “added value” your organization brings to the issue.
2. Define the target: Identify the person or people you want to influence in order to end the rights abuses, and the kind of information you need to influence those people.
3. Assess and manage risks: Figure out the level of risk involved for every person and how to avoid or respond to a “worst-case” scenario.
4. Plan the research: Set out a plan for how to proceed with gathering information.





STEP 1: MAP THE PROJECT

This section will cover the following aspect of project mapping:

- ▶ Three reasons why mapping is important
- ▶ How to map a project
- ▶ Working with other groups

CASE STUDY | CHINA HIV/AIDS DISCRIMINATION REPORT

When we began to work on the report on the rights of people with HIV/AIDS in China, there seemed to be a lot of potential issues to study, and we didn't know exactly what rights issue we should focus on. We started by meeting with every organization we knew of working in this area. This included other human rights organizations, Save the Children, Doctors Without Borders, university professors, foundations that support HIV/AIDS programs in China, and Chinese AIDS NGOs. With each organization, we learned about their programs and approaches, and also about their experiences working with people with HIV/AIDS. We learned that a number of NGOs were providing training and frontline services to people with HIV/AIDS, and that some UN agencies were working with Chinese lawmakers on a law to prohibit discrimination against people with HIV/AIDS. We also learned that former President William Clinton was beginning to talk to Chinese officials about China's HIV/AIDS programs.

During these meetings, we heard of many cases of discrimination by hospitals, who were testing people for HIV without their knowledge and then finding excuses to refuse treatment. It seemed clear that this was a situation where a report could be used by many organizations and officials to press for policy changes, and so we decided to focus on discrimination. Because we had met with so many organizations before we began the report, once the report was completed, we had a long list of names and email addresses of people who could use it—including staff in President Clinton's office, in government agencies and in international NGOs.





THREE REASONS WHY MAPPING IS IMPORTANT

You should always focus on your community's needs—but there are three important reasons to spend the time to create your map.

1. **It is pointless to duplicate work** that is already being done by others. If you just repeat research that other groups are doing already, you will have to compete with them for funding and attention.

2. **Stake your claim.** The first question donors and the people you take the report to will ask is, “Have you spoken with [X group]? I hear they are working on the same issue.” If you have to tell them that you haven’t spoken with X group, you will look inexperienced and uninformed about the field.

By speaking to other groups, you are also letting them know that your organization plans to join the field.

3. **Assess the resources at your disposal.** Through mapping your project, you will be able to see how many people and what kind of resources other groups have needed, and what resources you may need. This information will also help you decide whether or not you need to or want to partner with another group.

HOW TO MAP A PROJECT

Before you decide on the nature of your project, it’s important to “map” the project: identify what other groups are working on this issue, who the players are, and what “added value” your organization can bring to the field. This stage of planning your project may seem time-consuming, but it can make all the difference in how successful your project is in the end.

Keep in mind that the following tasks can be divided up among your research team, so that it doesn’t become a burden on just one person.

→ *Please see the supplement for an example (Lesson 2.2: Project Map Worksheet and Template)*

1. **First, read everything** you can about the issue you plan to research: news articles, NGO reports, blog posts. The Internet offers easy access to a lot of information, but keep in mind that information found online (e.g., blogs, personal websites) can be incomplete or inaccurate. Even government or UN information may have inaccuracies. It is better to not rely on one source only, but try to find other sources to verify the information.





2. **Then, draw up a list of groups that are working on the issue you plan to research.** This is something that everyone in your group may be able to help with. To keep track of your information, it can be helpful to develop a list of contacts on a computer or on paper.

3. **Next, go and meet with as many of these groups or individuals as you can.** Tell them that you are interested in doing a research project and what issues you are interested in studying. Ask what they are doing in this field and what gaps they see in the area—areas that are important and that no one else is researching yet.

IMPORTANT: At the end of each meeting, always ask if there is anyone else working on this issue that you should meet with. Then, follow up and meet with that person or group. You can build your network this way.

4. **Finally, discuss what you have learned with your own team.** Based on what you read and learn from the meetings, and the strengths of your own organization, create your project map. You can use this to narrow your own topic.

It is best to **define your research project as narrowly as you can:** for instance, focusing on a specific issue or city. You may find that by successfully tackling a smaller issue first, you lay the groundwork to work on the next larger issue.

What if the other groups see us as rivals and won't tell us anything? Some groups are so used to competing for funding that they won't even share basic information with peer NGOs. If that is the attitude you get from a certain group, don't worry—have the meeting anyway! At least you will be able to tell donors and other experts later that you tried to meet with the group. In the long run, this will make you look more professional and trustworthy. It will build goodwill with your donors.

CASE STUDY | THAI DRUG USER REPORT

In the case of *Deadly Denial: Barriers to HIV/AIDS Treatment for People Who Use Drugs in Thailand*, a community-based organization in Bangkok, the Thai AIDS Treatment Action Group (TTAG), partnered with an internationally-renowned organization, Human Rights Watch (HRW), to maximize attention and impact. We found that we were able to draw on the advantages of both groups. In TTAG's case, we had community contacts and in-depth understanding of the issues on the ground. In HRW's case, they had expertise in the international legal frameworks and experience in rights reporting. Working together, we were able to produce a stronger report.





WORKING WITH OTHER GROUPS

Should we join up with another group to work on the research? In your meetings with other groups, someone may suggest that two or more groups join together to do the research and/or advocacy. Many groups face the same problems. Joining together makes your movement larger and possibly stronger.

With several groups working together on the same project, you can get more interviews. A higher number of interviews helps to **strengthen your evidence**: for example, if you are able to prove that hundreds of people in different locations share the same problem, it cannot easily be dismissed as a “local problem” by media and officials. A larger survey sample can also help you to see patterns in the way that the abuse happens.

However, partnerships also means more work in maintaining relationships and communicating with each other. Here is a **checklist of questions** to answer **before** you start to work together:

- Are both organizations equal partners or is one organization going to take the lead on managing funds and making decisions?
- Will you split up certain tasks, or do you want to form committees for each task with members of either organization?
- How will you communicate—through regular meetings, or through emails, or by cell phone? A regularly-scheduled meeting is a good way to prevent people from forgetting to keep in touch.
- Do you have a plan if disagreements arise?
- Do you trust this group? In past experience, have they behaved in a way that is fair to others?
- Do your organizations’ strengths and weaknesses complement one another? For instance, if two groups that are very creative work together, but neither group is good at organizing and managing tasks, then the organizations may have a lot of fun thinking up cool ideas, but they will have a hard time getting anything done.
- Do both groups agree on the approach you will take to government, media, the UN?
- Does everyone agree on the budget? Does everyone agree how much each individual will be paid out of any funds that get raised?
- Do you agree on ownership of data and how it may be used by each partner?
- Do you have a clear timeline for each organization’s roles and responsibilities?





To avoid misunderstandings and fighting between cooperating groups, it is essential to make sure at the beginning that **all partners know and agree on the terms of cooperation**. A written contract that addresses these questions and that all participating organization sign can help you avoid problems later. Fighting between organizations that represent the same communities or work on similar issues does not help your cause. It only strengthens the position of your opponents, who can use your problems to challenge the objectivity of your research results.

Who should do this work? Should rights research be done by people in the community or outside groups? There are various advantages and disadvantages.

Outside researchers and international organizations may have specialized expertise or contacts, and may be more objective about some problems because they do not know the people involved. An international organization may be able to get attention to the problem at a higher level than a local group, and may be able to get higher-level advocacy meetings than some local groups. For these reasons, local groups may want to consider partnering with international organizations on research projects.

On the other hand, international organizations may have different goals than local groups, and may care about different issues. It can take an international organization many months to finish writing and publishing a report, whereas a small group can produce one more quickly. A local group may not want the kind of international attention that a foreign group can bring. People from the community are more involved in the issues, and thus have a better understanding of the local context and cultural constraints. They obviously also speak the language and do not need a translator.

We wrote this manual and curriculum because we wanted to make it possible for more local groups to do their own research. If a local group can find an international group to give their expertise and advice, especially when it comes time to do the advocacy, then that may help a local group to produce better work. Just be sure you have a frank conversation about how you will work together before you start.





CASE STUDY | INDONESIAN REPORT ON POLICE ABUSE OF DRUG USERS

To stop the rapid increase in drug use, the Indonesian government has launched a “war on drugs” that includes extensive arrests and high sentences for possession of drugs. From late 2007 until early 2008, Jangkar, an injection drug user (IDU) network with 75 member organizations, ran a large project using both quantitative and qualitative research methods to document police abuse against drug users.

Jangkar held training workshops in thirteen cities for staff and volunteers from member organizations. The trainers talked about the standards for documenting human rights abuses and provided the staff and volunteers with two sets of standardized questionnaires. The first questionnaire asked about the interviewee’s age, gender, occupation, educational level and marital status, and if the person had experienced police abuse.

In order to keep the participant’s identity private, interviewers did not record the person’s name and instead used codes on all documents. If the person had experienced abuse or discrimination, interviewers then asked the victim to sit down and do a more in-depth interview. They then used the second questionnaire to take the victim’s complete testimony.

By using a network of groups, Jangkar was able to interview over 1,000 injection drug users in thirteen cities around Indonesia. Their final report was influential and received attention at senior levels of the police, as well as from international donors and the UN.

Today, Jangkar is working with police to provide training to officers in how to interact with drug users.





STEP 2: DEFINE THE TARGET

This section will focus on defining the target:

- Identify the target audience for your report
- Decide what kind of information you need to influence that audience

IDENTIFY THE TARGET AUDIENCE FOR YOUR REPORT

Once you have mapped the field and know what issue you should work on, the next step in project planning is to think about who you want to read the report. Once you know the answer to that question, you will know what kind of information you need to gather.

Ideally, you may want many audiences: experts, government and UN officials, as well as donors, but there should be a defined group that you focus on. Ask yourselves:

1. Who has the **power to end** the rights abuse?
 - o The answer to this question could be: national lawmakers, the Ministry of Health, the police, the local school
2. Who or what has the **power to influence those people**?
 - o The answer to this question could be: domestic media, voters, international health experts, more senior police officers, parents in our community
3. What kind of information would influence all the people we have identified?
 - o The answer to this question could be: a written report, news stories, an article in a medical journal, a video for local parents

This is called **target analysis**: the process of identifying the advocacy target and figuring out how to influence that person or group.

Once you have identified the targets of your project, you will be able to decide how to best communicate your message. You have many different options of formats that can bring your message across. You can use press releases and articles to raise awareness. You can also use audio or video material, your organization's website, and news media in general, or more formal written reports and presentations. If you mount a campaign for several months or more, you could use a combination of different formats.





In any case, knowing your target will enable you to design your research project to address them in a way that will affect them.

EXERCISE: TARGET ANALYSIS

EXAMPLE: DENIAL OF ANTI-RETROVIRAL THERAPY (ART) TO PEOPLE WHO USE DRUGS

Problem: Doctors refuse to provide antiretroviral therapy to people who use drugs, requiring them to quit (even methadone, in some cases) before prescribing.

Who has the power to end this rights abuse (advocacy target)? Doctors, hospital administrations, Ministry of Public Health

Who can influence the advocacy target? Professional medical associations, high-level government health officials, WHO, UNAIDS, well-respected HIV advocacy NGOs

What kind of information will impress those people? A report documenting the scope of the problem, showing clear contradiction between the government's policy of "universal access for all" and the doctors' discriminatory, discretionary behavior in "real life."

YOUR ISSUE:

Problem:

Who has the power to end this rights abuse (advocacy target)? _____

Who can influence the advocacy target? _____

What kind of information will affect those people? _____





STEP 3: ASSESS AND MANAGE RISK

Rights research is different from other kinds of AIDS research in that people who participate in the project sometimes face the risk of retaliation. Thinking about potential risk and planning for the “worst-case” scenario is also part of planning a rights project. These steps include:

- Researchers’ ethical responsibilities
- Assess risks for researchers and interviewees
- Plan to avoid risks
- Prepare for a “worst-case” scenario

RESEARCHERS’ ETHICAL RESPONSIBILITY

Rights activists often demand that those in power be held accountable when they abuse others. Because political power and economic interests may be at stake, you, your family and friends, your organization, and the victims of rights abuses who dare to stand up and talk about the abuses they have survived may sometimes face the risk of threats or retaliation.

Rights advocates have an ethical responsibility to survivors of rights abuses to “do no harm.” You must take every step you reasonably can to empower and protect your staff, volunteers, and community. Although you may not mind sacrificing your own safety for a cause, not everyone around you is willing to do so. You must carefully assess and manage the risks for everyone involved in your project and avoid hurting others by making rash decisions.

ASSESS RISK FOR RESEARCHERS AND INTERVIEWEES

Before starting on the project, the researchers must think seriously and discuss the following questions. There are no right or wrong answers to these questions. Everyone is willing to face a different level of risk, and everyone’s feelings about danger are equally valid and worthy of respect.

You and your family and friends. What is the level of risk to you personally if you undertake your project? What has happened to other people who do the same kind of work? Will you be threatened, evicted from your home, fired from your





job, beaten up, arrested, or kidnapped? Which of these dangers are you willing to face? Is your family willing to stand by you and suffer alongside you if you choose to do this work? Families of rights advocates are often victimized simply because of their proximity to rights work.

Your colleagues and your organization. Are your colleagues in any danger if you pursue this project? Have you discussed the possible dangers with them? While taking a risk is a personal decision, it can also affect your organization, its reputation, and the safety of its staff. Even if you personally would not mind taking a specific risk, the organization as a whole may decide against it in order to protect itself from negative consequences.

The victims you will interview. What will happen if rights abusers find out that abuse victims have told their stories? Will individual victims be fired from their jobs, evicted from their homes, threatened or beaten or detained because they participated in their project? If there is any risk to victims, you must frankly and fully discuss the possible risks of the project before you interview them.

You should clearly communicate to your interviewees what your advocacy goals are and how you are planning to achieve them. When people know why and how you are planning to use the information they share, they can make an informed decision about whether or not they feel comfortable about participating. This is called informed consent, and all people have the right to informed consent when participating in any research project.

→ Please see Chapter 3 for a more detailed description of informed consent

It is possible that once they are informed about the risks, people may choose to not be part of your research. While this may make it harder to find interviewees, you cannot skip this step. It is their right to choose. If we advocate for protection of rights, we should embrace these rights in our own actions and respect the decisions that others make.

PLAN TO AVOID RISKS

There are some ways to minimize or avoid unnecessary risks. Once you have assessed the risk to yourself, your organization, and the victims, you can choose the strategies that fit your specific situation. Here are a few, but you may think of others.





CASE STUDY | THAI DRUG USERS REPORT

In *Deadly Denial*, TTAG and HRW decided to use initials rather than names or even nicknames for interviewees who were people using drugs. In this way, we aimed to maximize their anonymity while retaining some aspect of their true selves. Hospital staff who shared sensitive information with TTAG and HRW about denial of care or police collaboration were given the choice to simply refer to the region of Thailand where their hospital was, rather than naming the hospital, city or even province. In this way, we aimed ensure anonymity and protect staff from potential backlash.

Anonymity. You can change the names and identifying information of victims you interview, such as their age, hometown, and/or gender. Sometimes, witnesses or other informants may also want to protect their anonymity if they provide you with sensitive information. If you plan to use the information in a court of law, however, you will have to prove that the incident occurred as you described it, supported by real identifying information. In addition, taking a case to court may also require you to gather other specific kinds of information.

Partner with a larger, more established or less sensitive group. Larger groups can afford more protection because of their visibility and connections. Together with a larger group you could also agree to frame the issue differently or choose a language or tone that is less confrontational.

Choose a strategic media approach. Many people become very angry when they are criticized in the media. It might be safer to present the report to authorities in private, or even at an academic conference instead of publishing it to the press and on the Internet.

Meet with advocacy targets in advance. If you are planning to release a public report, you could meet with the targets before it is release to prepare them for what is coming. While you may feel that this will lessen the blow you were aiming for with your report, it may at the same time decrease the risk.

In Thailand, TTAG and HRW budgeted for a meeting to report back to interviewees and relevant organizations and intergovernmental agencies about the results of the report before releasing a final version to the press. We used the meeting to solicit feedback, make necessary changes, and ensure the recommendations were as strong, comprehensive, and community-driven as possible.

Be aware, however, that conditions can change over a period of time. What may





have worked fine last time may be more risky this time because there could be more official attention to what you are doing or the political climate may have changed.

PREPARE FOR A “WORST-CASE” SCENARIO

If there is risk to people involved in your project, you should think about the “worst-case” scenario. If someone faces retaliation, what will your organization do? Who can help you? Who will take what kinds of responsibilities?

Discuss the worst-case scenario in detail, in advance. No one likes to talk about the possibility that something bad may happen, but it is important to be prepared. This helps to reduce errors and panic. Discuss what you would do if someone disappears and cannot be found. How long will you wait before taking action? What actions will you take?

Who are some trusted allies who can help in an emergency? Prepare a list of people you can trust to help you, as well as a press release or public statement to send out. Discuss how long will you wait to send it out and what level of detail it will include. In some cases, it is better not to go public. Discuss this with everyone who may be affected. Make sure someone trusted knows where you are in the field at any given time.

Collect basic information in advance. Make sure that everyone doing the research has each others’ cell phone numbers, ID or passport numbers, and emergency contact information. Make sure your family and friends also know how to reach other staff in your group. Keep this list safe.

Set up a system of regular check-in calls. If a colleague is at risk, she should call you in the morning to tell you where she is going, and then call you in the evening to report that she is home safe. You should agree in advance exactly what actions you will take if you cannot find her.

Provide victims with a cover story. To protect the victims you will be interviewing, it can be helpful to have another explanation they can give to anyone who asks for why they spent so long talking to you. Perhaps they can say that you were helping them with treatment access, giving them legal advice, or helping them with a language lesson.

Follow up with victims at risk of retaliation. Check in regularly with people you have interviewed to make sure that they are okay and have not been harassed, detained or disappeared. This follow-up is your ethical responsibility. This helps to establish and maintain trust with those whom you interview.





IN CASE OF A DISAPPEARANCE

CASE STUDY | DISAPPEARANCE

An Asian rights organization was working with a local AIDS activist who suddenly disappeared after attending a dinner with other activists. He didn't go home or answer his cell phone.

First, the organization staff's gathered all the information. They spoke with other activists who had been at the dinner, and learned that one of them thought he had recognized plainclothes police on the street outside the restaurant. The organization checked to make sure that everyone else at the dinner had gotten home safely, and noted the location and time that our colleague was last seen.

Then the organization met with the activist's wife and family to ask what they wanted to do. They asked the organization to wait for a few days to see if the activist would be released, and not talk to the press about his detention until then. They were afraid that if the media reported on his detention, he would never be released. The organization was not sure about that, but agreed to respect the family's wishes.

The next thing that the organization did was to gather all the staff and volunteers together, tell them what was happening, urge them to stay in contact, and ask them not to talk to the media. The staff spoke with other activists who had been at the dinner and asked them to keep it quiet also. Staff also contacted some advisors to the organization who had good relationships with the police, and asked them to call the police to politely ask about the activist. Finally, the organization decided that when the family agreed to let them speak to the media, only one person would do so, and they decided what that person would say.

After that, the organization tried to get on with their normal work, but it was certainly hard to concentrate that day. Fortunately, their colleague was released that night.





Here are the steps to take if someone from your group, or a person you have interviewed, is missing:

It sounds obvious, but...stay calm. Breathe deeply. Remember that others around you will be looking to you for guidance. This is a good time to be as mature and calm as you can, even if you are scared. It is not a good time to be dramatic or to act emotional. If you panic, everyone else will panic too.

Rule out all other logical explanations. Is it possible the missing person had a car accident and is in the hospital, got drunk and overslept, or just forgot to recharge her/his cell phone? Call around and make sure before you assume the worst.

Get the details straight. Talk to people who saw him or her last and find out the exact sequence of events and what was seen. Write it down somewhere. Are there witnesses who can describe what happened? Were other people affected?

Contact the disappeared person's family. Make sure that you and they have the same information, and that you have their permission to go public if necessary.

Get everyone in your group in line. Gather your staff and volunteers together and explain what has happened and what you are doing. Instruct them not to publish this information online or talk to media until the organization is ready. If necessary, contact other NGOs and ask them not to publicize anything until you are ready. Some rights advocates are illegally kidnapped by thugs who do not work for the state, and it may be important to report their cases to the police and to get the media and other NGOs to respond as quickly as possible. Other people may be detained for a few days by the police and then released; in those cases, going public too soon can pressure the police to issue a formal arrest.

Talk to allies. Do you have any friends or advisors at large NGOs, at the police, or in the government who can help to find your colleague, and help you to negotiate with whoever has him?

Consider legal aid. Find out what the legal rules are in your country on detaining people. How long are the police allowed to hold a person detained? When do they need to provide what official forms? Do you know any legal aid organizations that you can raise the case with and that can possibly help you?





Tips for handling the press. Responsible journalists will be sympathetic to your stressful situation. Be sure to be clear when you are talking “on the record” (things the journalist may print) and when you are talking “off the record” (things you tell the journalist to help her understand the situation, but which she is not allowed to print).

What to say “on the record.” Ideally, you will control when and how the information about the incident is released to the press and to the public. We recommend a very simple statement expressing concern for your colleague and hoping she or he is back safe very soon. In press interviews, it is important for everyone to stick to the same message of concern and not add any political commentary that may worsen the situation.

If you are not ready to talk “on the record,” you can take down the reporter’s contact information and say that you will get back to him/her when you have a comment. If the journalist is not sympathetic, you do not need to talk to him or her at all.





EXERCISE: ANALYZING RISK MANAGEMENT

CASE STUDY | THE PETITION PROBLEM

A drug user advocacy group decides to organize a sign-on petition by victims of police abuse to draw attention to the recent deaths in detention of several drug users. The group uses their local community network to collect signatures from victims of police abuse in support of their petition. Victims sign the petition using their real names and their real hometowns. However, the petition organizers do not discuss the potential risk with petition-signers. They also do not discuss what will be done with the petition.

In order to increase the pressure on the authorities, the group mails the petition with the signatures and names to local government departments, and also publishes the petition on the Internet. Soon after, petition-signers start receiving threatening phone calls. Because their identity as drug users is revealed to many people in the local community and to their families, petition signers also begin to experience personal repercussions: their children are discriminated against in school, and some families announce they will sever their ties with the people who signed.

In order to protect themselves and their families' reputations, petition-signers start to disassociate themselves with the campaign. They tell local police they never signed onto the letter. They also go to another NGO to ask for help, sparking a public feud between two NGOs. Some victims even sue the group that organized the petition, demanding financial compensation for their suffering.

- What went wrong with the petition campaign?
- What are some steps the group could have taken to minimize the risk to abuse survivors of participating in the petition?

The group did not get informed consent from the petition-signers. Participants did not know what would be done with the report, nor did they understand what sort of risks could be involved. That caused problems for the signers, and ultimately for the organization.





STEP 4: PLAN THE RESEARCH

Once you have mapped the field, analyzed your target, and planned for any risk, you are ready to plan the research:

- ▶ Choose your interviewees and interviewer
- ▶ Consider your relationship to the interviewees
- ▶ Choose the type of information you will collect
- ▶ Create a timeline

Based on your advocacy target, the scope of the issue, and the number of groups involved, you should come up with a research plan.

CHOOSE YOUR INTERVIEWEES AND INTERVIEWER

Who do you want to interview? For example, do you want to talk to people living with HIV/AIDS, youth living with HIV/AIDS, young drug users living with HIV/AIDS, or young female drug users/sex workers living with HIV/AIDS (to name a few specific categories of individuals)? Roughly how many people do you aim to interview? Also, think about who else can provide you with supportive information and whom you may therefore want to interview. This will depend on the issue you are working on. If you are working on access to medication or medical discrimination, you may want to talk to hospital staff and doctors. If your issue is linked to the government, you may want to talk to staff of government agencies, UN officials, or experts.

How many interviews should you do? The answer to this question really depends on your goal. If you want to show a problem is “systemic” (meaning it exists throughout the system, and not just in one or two places) then you will need many interviews from a variety of places. If your goal is just to highlight problems at a specific hospital or prison, then you only need enough interviews to prove that the problem is not just with one doctor or one guard, but the whole institution.

Before you start, you should have at least a handful of contacts lined up for interview; the more the better, since inevitably there may be cancellations. You can ask those people to introduce you to other individuals who are willing to be interviewed.





Remember that it is not only important to get a specific number of interviews, but also important to get good interviews—a small number of powerful testimonies can communicate a strong message to the target audience.

Where will you find people? It is easy to interview people that you know already, because you know where to find them and how to contact them. However, think about whether they will be a fair sample that accurately represents the group of people you are trying to understand? Will it result in a biased sample that only includes people who we know will say what we want to hear?

You can also try to identify places where you may be able to meet your target population in order to create a more balanced sample. However, in some cases you may need permission to access those places, as in the case of a methadone clinic where people who use drugs are easily found. TTAG requested permission from the Thai government agency running a methadone clinic before approaching their clients.

Who will do the interviewing? Remember that the interviewer will influence the kind of responses you get. If the people you want to interview are young women, you might want to train young women to do the interviews. Or maybe young women will feel more comfortable being interviewed by older women. If the issue you are documenting has anything to do with sex, young women will probably not feel comfortable talking to men.

In some cases, you may want to have two people conduct the interviews: one to ask questions, and one to take notes.

CONSIDER YOUR RELATIONSHIP WITH INTERVIEWEES

Will we pay people to be interviewed? In some cases, people who are interviewed expect to be paid for their time, particularly if they are being interviewed away from their home or place of work. But bear in mind that this has a downside. If people know you are paying for interviews, a few may make things up and lie in order to get paid. Your advocacy targets may also use this to criticize you, saying that you bribed people to tell lies about abuses that never happened.

Some organizations get around this by just giving people money for travel costs, or by buying a meal for the person who is interviewed instead of paying for them. Whatever your group's policy is, you should make it clear at the beginning to everyone, and apply it equally to everyone without exception.





CASE STUDY | CHINA AIDS DISCRIMINATION REPORT

When HRW produced the report on discrimination against people with HIV/AIDS in China, they had a very strict policy about not paying interviewees. They felt that this would undermine public trust in the results of their research. However, the researcher did purchase some crafts and artwork that had been created by people she interviewed.

CASE STUDY | THAI DRUG USERS REPORT

During the data collection process of Deadly Denial, TTAG and HRW agreed that TTAG would cover travel costs for all interviewees who travelled to be interviewed, and in other cases provided snacks, water/soda and cigarettes when culturally appropriate. No one chose to be interviewed in their home, perhaps due to the sensitive nature of openly discussing HIV, drug use, and other private issues.

What kind of help can we give to victims? Aside from money, the interviewees may have other urgent needs: they may need medical care, jobs, or schooling for their children. Before beginning the research, some organizations prepare a flyer with a list of organizations and government services to refer people to for help. This can include local clinics that you know are reliable, organizations that help people get PMTCT or methadone, groups that help people with housing, or other local resources that exist in your community. Your organization has limits and you cannot do everything for everyone, but you can direct interviewees to other sources of assistance. You can also give your own contact information or business card, in case the interviewee wants to follow up on the information they gave, the status of the report and when it's finished, and if he wishes to be part of any subsequent activities related to advocacy on the issue at hand.

CHOOSING THE TYPES OF RESEARCH MATERIAL

Last but not least, you should decide what kinds of information you will use for your report. These include testimony, questionnaires, field visits, and other materials. Here is some information about each to help you decide which you want to use:

Testimony

Individual testimonies from victims are at the core of rights research, because of their power to move and to mobilize. When human rights abuses happen, the





voice of the individual survivor is our most effective tool. A strong testimony can capture the attention of media and inspire people around the world to take a stand against rights abuses.

A testimony is a true narrative account of an incident from a person who experienced or witnessed it. In rights research, testimony describes exactly what happened in detail. The person tells their true recollection and how it affected and harmed them. If you gather good and useable testimonies, you do not need a lot of interviews to create a strong report.

→ See Chapter 4 for more detailed information on how to gather testimony.

Questionnaires

As discussed in the introduction, questionnaires are most often used in survey research that aims to show how a problem affected a large number of people.

Questionnaires aren't the best tool for gathering testimony because they are impersonal, and gathering testimony requires an in-depth, face-to-face interview, in which an interviewer and a victim develop some trust. When using questionnaires, you should state clearly: "Please respond only to the questions you are comfortable answering. You do not have to answer all the questions."

Here are some examples of possible questions:

- **Who:** Who was the victim? Who was the person or persons that committed the abuse? Did you know the person? What was his name? How many victims were there?
- **What:** What happened? What was the rights abuse? Can you remember what the perpetrator said?
- **Where:** Where did the incident happen? Do you know the exact location/place name? What kind of place was it—a school, a park, on a street, or in a prison? If it was in a prison, can you describe where it was, and what the conditions were like?
- **When:** What time did the abuse start? What time did it end? How many times did it happen?
- **Why:** Why did the abuse happen?
- **How:** How did the abuse happen? Can you describe exactly what happened—were you beaten, tortured, harassed, or threatened? How many people were there?

→ See Chapter 3 for more details on the major questions to ask (**THE SIX QUESTIONS: WHO, WHAT, WHERE, WHEN, WHY AND HOW**).





Field visits

Field visits are a good way to gather objective information about conditions in a specific place. For instance, it is best to see for yourself what the conditions are like in a brothel, or to understand how prisoners are treated in detention. Thus, it is best to visit the site, if you can do so safely.

For prison visits, refer to the United Nations Standard Minimum Rules for the Treatment of Prisoners, for a guideline on adequate conditions. Keep an eye out for the following:

- **REGISTRATION:** All prisoners should be registered by the detaining facility, with their names, the reason for their detention, and the time/date of their admission and release.
- **SEPARATION OF CATEGORIES:** Men and women should be detained in separate facilities or at least separate parts of the same facility. People awaiting trial should be detained separately from convicted prisoners. Youth should be kept separately from adults.
- **ACCOMMODATIONS AND HYGIENE:** Is it overcrowded? Are there sufficient sleeping accommodations for all prisoners? Are there adequate bathroom and shower installations?
- **CLOTHING AND BEDDING:** Is the clothing and bedding provided suitable to the climate and clean? The clothing provided should not be degrading or humiliating.
- **FOOD:** Is the food adequate for health and strength? Does the prisoner have access to drinking water?
- **EXERCISE:** The prisoner should get at least one hour of exercise outside a day (if weather permits).
- **MEDICAL SERVICES:** Does the prison provide medical services and access to hospitals, and have at least one medical officer with training in psychiatry? Are there provisions for women who are pregnant, including pre-natal and post-natal care?
- **DISCIPLINE AND PUNISHMENT:** Are all disciplinary measures determined by laws and regulations? Corporal punishment and all cruel, inhuman or degrading punishment must be prohibited. Are chains, irons, or straitjackets used as restraints?
- **COMPLAINTS:** Do prisoners have a way to make complaints about their treatment, or about other aspects of the institution?
- **CONTACT WITH OUTSIDE WORLD:** Are prisoners allowed to talk to their families and friends periodically (by writing and through visits)? Do foreign





nationals have access to their diplomatic and consular representatives? Are prisoners allowed to read newspapers, magazines, or other publications?

- **BOOKS:** Prisoners should be allowed to read books. Does the prison have a library?
- **RELIGION:** Are prisoners allowed to practice their religion as conditions permit?
- **PROPERTY:** Prisoners' property must be held for safekeeping, and an inventory kept. When the prisoner is released, all his items should be returned.
- **NOTIFICATION:** The spouse or nearest relative must be informed if the prisoner dies or suffers serious illness or injury. They must also be informed if the prisoner is moved to a different facility or to a hospital.
- **INSTITUTIONAL PERSONNEL:** Do the personnel have adequate education and intelligence to manage the institution? Are there social workers, teachers, psychiatrists, and trade instructors on staff? Women prisoners should be attended to and supervised by women officers.
- **INSPECTION:** Is the facility inspected regularly by the appropriate authority? Is it in compliance with existing laws and regulations?

Video documentation

As digital media becomes more and more popular, video documentation is used more and more by activists all over the world. WITNESS, a leading video advocacy NGO, provides workshops and information online on how to effectively use video in advocacy. They suggest that it is most effective when used alongside other advocacy tools such as litigation, monitoring, and research. Images can often bring stories to life better than a straightforward text, and encourage more concern and action. As with the other methods listed here, video documentation has both strengths and its weaknesses, which you should consider thoroughly before deciding to make use of it for your project.

Other materials

Sometimes you may not be able to conduct an interview in person, or you may be studying a population with whom you cannot easily communicate. Here are some materials that you might use in research and the written material you will develop, if the people who created them give you permission. These can also be useful to give added dimension or richness to your report. Which material you choose will again depend on the issue you are working on. Here are some





examples:

1. Children's drawings
2. Diaries or journals
3. Letters
4. Photographs
5. News articles

PLOTTING A TIMELINE

When you are planning your research, it pays to think ahead to when you want to be finished. It can help the success of your campaign if you link your outputs to important advocacy dates. So, when planning, think ahead to when you might best release the findings—there are many different opportunities such as at a National/World AIDS Conference; on a national holiday like Constitution Day; or an internationally recognized date such as International Human Rights Day. Think about the many different steps that you will have to complete before your research will be completed and plan ample time for each.

CONCLUSION

Good research starts with thinking about and answering a lot of questions when you are still in the preparation period.

In this chapter, we learned to:

1. Map the project
2. Define the target
3. Assess and manage risks
4. Plan the research

Working through all of these steps creates a solid foundation for your research and advocacy. These steps also help you to build unity within your group and trust within your community. Some of these steps, such as assessing and managing risks, are our ethical responsibility as rights advocates.

In the next chapter, we get down to the skills involved in conducting an actual rights interview.



CHAPTER 2

The Rights Interview

Rights researchers and advocates aim to shine a light on truths that people in power either ignore, or sometimes actively attempt to cover up. Because these are serious allegations against others about violations of basic legal rights, some people in positions of power may say that the allegations are untrue or that the organization that produced it is unreliable.

Professional rights researchers prepare for this by taking a number of steps to protect the truth that they uncover through their research. This chapter explains how to gather detailed information that can meet the highest standards of reliability.

THE SIX ELEMENTS OF A RIGHTS INTERVIEW:

1. Obtain informed consent
2. Prepare a list of questions
3. Create the right setting
4. Record the interview
5. Build rapport and get the information you need
6. Deal with Post-Traumatic Stress Disorder

STEP 1: OBTAIN INFORMED CONSENT

This section explains how to obtain informed consent:

- The four elements of informed consent
- How to discuss the project with an interviewee
- Verbal consent versus written consent





THE FOUR ELEMENTS OF INFORMED CONSENT

Before you begin your interview, you need to formally introduce yourself, explain your project, and obtain informed consent. You need to do this yourself, even if other people have already explained to the interviewee what you are doing, and even if you have briefly mentioned it yourself. The reason why researchers do this is that while a researcher may think the other person knows what you are doing, the interviewee may not have paid careful attention or given the project much thought. For you, the research project is very important. But for the interviewee, it's just one of many different things they have to do during the day. Another reason to do this is that it gives the interview a formal beginning, middle and end, so that you have the researcher's complete attention and involvement throughout the process.

So at the beginning of the interview, explain in detail what you are doing, and make sure the interviewee cannot come back to you later and complain, "I didn't understand that you were interviewing me."

An important part of this discussion is getting informed consent. The four elements of informed consent are:

1. **Disclosure.** Discuss the purpose of the project and any risks with the interviewee in detail. You want to make sure the interviewee understands how you will use the information and that she understands the purpose of your documentation and advocacy.

This should also include clarification of whether or not you will use the person's real name, part of her real name, her/his initials, a fake name, or a number or code.

2. **Voluntariness.** When the person agrees to be interviewed, s/he must be able to make a free decision without feeling pressured – either at the moment of the decision or at any time before or after it. The decision to participate should be completely voluntary.

3. **Comprehension.** The person you interview must understand all the risks or implications of the interview. You may need to spell out some of the risks very clearly – for instance, "We are doing a research project on police abuse against drug users, and some police could become angry if they learn about the project."

In addition, you need to make sure that you explain clearly how you are planning to publish the final report. For example, if you plan to publish the report on the Internet, make sure that the people you interview understand





that once the information is published online, there is no way of regulating or even knowing who will see it.

4. **Competence.** This is the ability and mental capacity to understand the project and the possible risks, and to make a responsible choice. Some people who may not be competent include children, people with mental disabilities, or those who have suffered severe trauma. If in the course of your discussion with an interviewee, you discover that she or he is not competent to give informed consent, you must end the interview.

You must also advise the interviewee that s/he can always choose not to answer a question or to stop the interview at any time. Tell the interviewee that if he says something that he does not want you to include in the report or in your notes, he can tell you to remove it from your notes or delete it from your camera or audio recorder. He can also ask you to show him that it is deleted.

EXAMPLE | HOW TO DISCUSS THE PROJECT WITH AN INTERVIEWEE

Here is a sample introduction. See if you can underline the four elements of informed consent.

PAISAN: Hi, I'm Paisan Suwannawong and this is Karyn Kaplan. Thank you so much for meeting with us today. We will need about 90 minutes of your time. Is this a good time to talk?

INTERVIEWEE: Sure.

PAISAN: Okay, great. As Mas may have already told you, we are collecting information on human rights violations against people who use drugs in Thailand. We're going to four regions of the country to talk with people who use drugs about problems with the police, health care, justice system, etc. We would like to take the time to get your consent to being interviewed by telling you about the project and your rights as a participant. Would you like us to continue?

INTERVIEWEE: Yeah, go ahead.

PAISAN: Great. By the way, here is my business card, you can call me any





time. My name is Paisan and I am the director of the Thai AIDS Treatment Action Group (TTAG). I am also living with HIV, which I got while injecting drugs at Chiang Mai prison. Karyn co-founded the organization with me, and today she'll be taking notes while I ask you questions. We'd also like to request your permission to audiotape our conversation. We will destroy the tape after we transcribe it. At no time will your name be recorded; feel free to give us your nickname or a pseudonym. We want to reduce any chance of your being identified in the report we are writing. We want to write a report to show the government evidence of abuses against people who use drugs, so that they cannot deny this wrong behavior by state agents any longer.

In fact, we'd love you to be a part of this process and longer-term movement. We're trying to build a movement of people who use drugs to stand up for themselves and have their rights recognized like anyone else. If you are interested, we can talk after the interview.

During the interview itself, you can stop at any time to take a break, smoke a cigarette, or whatever. You don't have to answer any question you don't like or feel uncomfortable with, just let me know. If you change your mind about being interviewed, we will totally understand.

Your story is incredibly important; there are many people like you who experience these things, me included, and we hope that by collecting these stories we can ultimately end the abuses, but of course we can't guarantee it. More importantly, we'd love you to be involved. We can talk later about how to stay involved through Mas's center locally or with our national drug user network. We can also provide a list of other services you might be interested in at the end of the interview. Do you have any questions for us?

INTERVIEWEE: No, I don't think so.

PAISAN: Okay, so let's get started then. We are not taking your signature, so once we start the tape, please say your nickname and that you are ready to begin. We will consider that your consent to be interviewed. Thank you for your participation!





Can you identify the four elements of informed consent?

1. **Disclosure.** “We are collecting information on human rights violations against people who use drugs in Thailand. We’re going to four regions of the country to talk with people who use drugs about problems with the police, health care, justice system, etc... My name is Paisan and I am the director of the Thai AIDS Treatment Action Group (TTAG).”

This researcher has explained what the organization and the report are about. He also explained what steps he will take to protect the confidentiality of the interviewee.

2. **Voluntariness.** “During the interview itself, you can stop at any time to take a break, smoke a cigarette, or whatever. You don’t have to answer any question you don’t like or feel uncomfortable with, just let me know. If you change your mind about being interviewed, we will totally understand.”

The researcher is making it very clear that the interviewee has total control over the interview process. Paisan makes sure the interviewee is not under any pressure to continue if s/he does not feel comfortable, and that s/he can stop the process at any time.

3. **Comprehension.** “Is this a good time to talk?...Would you like me to continue...?”

Throughout this exchange, the researcher gives the interviewee a number of opportunities to ask questions, express concerns, or refuse permission to continue. At the end, he gives the interviewee a way to make his consent official, by saying his name on the tape.

4. **Competence.** “Do you have any questions for us?”

Some people with limited education or mental disabilities do not have the capacity to understand a project like this, and cannot make a responsible decision about the risk they are taking. You should try to detect this in your first conversation with the potential interviewee. Giving the interviewee a chance to ask questions is also a way for you to assess his competence.

Another fact worth noting in the example above is that Paisan identifies himself as a person who formerly used drugs and who is living with HIV/AIDS. You don’t have to reveal anything about yourself, but it is one way to establish a basis for trust between the interviewee and interviewer.

Remember, if the interviewee does not give consent, or does not seem competent, you must stop the interview. You will earn the trust of the interviewee if you do not pressure him, and s/he will be more likely to agree later or refer other friends to be interviewees if s/he trusts you.





VERBAL CONSENT VERSUS WRITTEN CONSENT

Depending on the circumstances, you may choose to obtain informed consent verbally or in written form. Each one has advantages and disadvantages. Whichever one you choose, the process of obtaining consent should be a discussion you have with the interviewee, in which the interviewee can ask questions and make changes.

Situations where you may choose verbal consent

Whether you use verbal consent or a written form, you should tell your interviewee the same information. A written consent can make the process more formal, but it can also make the interviewee feel intimidated, especially when the case is a sensitive one and he is afraid of signing a document using his real name. In this case, a relaxed, face-to-face conversation (with no details recorded on paper) may help the interviewee to feel more at ease.

Situations where you may choose written consent

In contrast to verbal consent, written consent is a good way to provide standard information in a more permanent form. Written consent forms are widely used in many settings. For example, in hospitals, they are used to document that the patient has received sufficient information from the hospital about her illness, the treatment process, any possible side effects, and/or the cost. It can be used as evidence in medical dispute and as such, has a legal function. A written form can be preserved, and included in a file or archives. Some organizations use written consent forms to protect themselves from being sued.

Please refer to the supplement for a sample informed consent form. If the interviewee understands the project and is willing to participate, she should sign on the form, and keep a copy of the document.

Note: Using an informed consent form does not mean that you just present the form to the interviewee and ask her or him to sign. A written consent form is not a substitute for the discussion about informed consent that you should have with every interviewee, especially for interviewees who may have low literacy levels. You can read the form together with the interviewee, and ask whether they understand or have any questions. The interviewee has the right to make changes to the form if s/he wishes. You must tell the interviewee what you will do with the form, and ensure confidentiality.



STEP 2: PREPARE A LIST OF QUESTIONS

Obtaining consent is only one part of the interview process. This section will prepare you to draft a list of questions for your field research by following these steps:

- ▶ Prepare before you go
- ▶ The six basic questions: who, what, where, when, why, and how
- ▶ How to get the information you need
- ▶ Interview skills

PREPARE BEFORE YOU GO

Before you meet with the interviewee, you should prepare a list of questions to ask. Without a list, even an experienced researcher may forget that there are specific things necessary in order to make the testimony useful for research purposes.

THE SIX QUESTIONS: WHO, WHAT, WHERE, WHEN, WHY AND HOW

The core pieces of information you need to have strong, credible testimony are the same questions journalists have to answer when they write a news story: who, what, where, when, why and how. Even if you don't write a list of questions, we recommend writing these six words on the top of your notebook so that you do not forget them.

Who

Who was the victim? Who was the person or persons that committed the abuse? (Does the victim remember his/her name, badge number, rank, title, uniform, or any details of what he or she looked like?) Did the victim know the abuser before the abuse happened? Who, if anyone, witnessed the abuse when it took place? Was someone ordered by someone more powerful to do something abusive? Does the victim have any reason to believe that senior-level people knew about the abuse—and if so, why does the victim believe that?

It is important to get as many details as possible in order to identify the abuser in case you and the victim later decide to initiate court proceedings, or try to get the





abuser(s) held accountable by others for what she, he or they did.

For instance, if the victim says:

“I was beaten by police.”

Some questions you can ask:

“How did you know they were police? Did they identify themselves as police? Did you recognize a uniform or a badge? Are these police you have seen or met before? How many police were there? How many were men or women? What did they look like? How old did they appear to be?”

What

What exactly happened? What was the sequence of events? Can the victim remember exactly what the abuser said and did?

Again, if the victim says,

“I was beaten by police.”

You can ask:

“Exactly what happened? Did the police stop you and beat you on the street? What did they say on the street? Did the police arrest you or formally charge you? Did the police ask you to sign a confession? Did the police ask you to pay a bribe? How many times did the police ask before they beat you?”

Where

Where did the abuse happen? If it was on a street, then which street? If it was in a building, which part of the building? Did the victim move to different parts of the building (for instance, different wards in a hospital or prison)? Were other people present? Are you aware of any witnesses and is there a way to talk to them?

If the victim was detained somewhere, then where exactly was the person detained? What were the conditions like? Were the lights on day and night? Was the prison clean? Was there food and drink available and was it adequate? How many people were detained in the same cell? Were they allowed to exercise regularly? Did they have access to toilets? Were there beds? All of these details are extremely important in order to prove without doubt that conditions are abusive and in order to prove who the abusers were.





When

On what date and day of the week did the abuse take place? (Bear in mind that if you are interviewing rural people, they may have difficulty answering this question, but may be able to tell you what the date was on a lunar calendar, or may know whether it was market day in their town.) At what time of day did the abuse take place? How long did the abuse continue for? All of this is important to make it possible to verify the victim's account, and to establish who was on the scene of the crime.

Why

Sometimes, victims may not wish to volunteer information that would put him or her in a bad light, but it could be crucial for you to know the context of the abuse and the relationship, if any, between the victim and the abuser.

For instance, it is a violation if someone is beaten by the police, but if the person began by threatening the police with a loaded gun, obviously that's a bit different. Similarly, it is a problem if police demand that a victim pay a bribe, but if the victim sold drugs and regularly paid bribes to the police for many years and then suddenly decided to stop, then that is a more complicated relationship.

It does not justify the abuse, because police are still required to follow the law and to respect human rights. But it is important for you to know as much as possible about the context of the abuse before you start making allegations, because your own credibility is at stake as well.

How

This can be the hardest question to ask, but it is important that you know as much as possible about how the abuse happened.

For instance, if the victim says,

"I was beaten by police."

You can ask:

"How many times were you beaten? What were you beaten with? On what part of your body were you beaten? Were you touched sexually? On what part of your body were you touched? Were you beaten more than once?"

The end result of these questions should be a **detailed testimony**.

Now that you know the six basic questions, let's practice ways in which you can use them to get the information you need.





EXERCISE | HOW TO GET THE INFORMATION YOU NEED

Here are two examples of testimony from reports about police abuse in Indonesia. Please read them and discuss the questions after each example.

EXAMPLE 1:

"I have been beaten by the police many times. They always beat us because we are drug users. Sometimes they ask us for money."

What questions do you think the interviewer asked?

What other questions could the interviewer have asked?

Is this useful and powerful testimony? Why or why not?

This is a general statement. From this statement, it is hard to tell if the interviewee is talking about a recent experience or one that happened years ago. Because it is so vague, it is not very useful as testimony. To find out more details, the interviewer could ask probing questions using the five questions:

- **What** exactly happened? Then what happened? What happened after that? What did the police officer say when he asked you for money? Did he threaten you with some specific consequence if you did not pay him?
- **When** was the last time this happened to you?
- **Where** did it happen to you?
- **How** did the abuse happen? When the officer beat you, how many times did he hit you? Did he hit you with his hand, or with something else? Where on your body were you hit?
- **Who** was the police officer who hit you? Do you know what his rank was? What did he look like?

EXAMPLE 2:

Around 11 p.m., two policemen arrested me. They accused me of selling putau [low-grade heroin]. They searched my friend and me. They found nothing. After thirty minutes, three more policemen came. One of them was the head of the unit. I was taken to a car. In the car, I was beaten up and my toenails were pulled out so that I would admit that I sold putau. It lasted four hours.





What questions do you think the interviewer asked?

What other questions could the interviewer have asked?

What are the differences between these two testimonies?

This is stronger testimony than the testimony in Example 1. It includes answers to most of the five questions. The interviewer could ask a few more specific questions:

- ▶ Where were you when you were arrested?
- ▶ How did you know the officer was a Unit Head?
- ▶ Was the car a marked police car, or unmarked?
- ▶ How many police officers beat you? Where on your body did they hit you? Did the Unit Head beat you, and was he there during the beating and torture?
- ▶ At any point, did the police officers offer you medical care? Did you ask to see a doctor, and if so, what did they say?

INTERVIEW SKILLS

You may have additional questions you need to get answered for your specific project. Because your interview is oriented towards getting powerful testimony and not filling out a questionnaire, we recommend starting with **open questions**.

An open question is one which lets the interviewee reply in many different ways, and which encourages the interviewee to tell the story in his or her own words. Examples of open questions are: "What happened next?" and "Can you tell me what happened when you went to the hospital?" To follow up on the open questions, you may want to use **closed questions**, or yes-or-no questions. Examples of closed questions include, "So after you were arrested, they refused to let you call your lawyer, right?" and "Were you abused after you were taken into police custody?"

Also, consider **how to ask about a person's HIV status**. Remember that you may not violate your interviewee's right to privacy. If it is necessary for your research to know about the HIV status of an interviewee, you can start by asking questions indirectly, such as, "Have you gotten a HIV test?," "Did you go back for your result?," or "Do you know your status?" The interviewee may volunteer to share her or his status. But NEVER ask "Are you HIV-positive?," without FIRST discussing the interviewee's right to refuse answering.

You may ask if the person is okay with telling you their status before you





actually ask the question. It is possible that you already know ahead of time that somebody is HIV-positive, because you have reached her through an organization that works with positive people. But if you want to confirm, find a sensitive way that respects the person's right to confidentiality.

Once you have a list or outline of the main questions you want to ask, practice the flow of your questions with a colleague and think about possible follow-up questions. If you memorize your questions or have a list ready, you are less likely to get confused during the interview. You will be able to make your interview more like a conversation and less like an interrogation.

STEP 3: CREATE THE RIGHT SETTING

An important element of a rights interview is the researcher's ability to establish rapport with the interviewee. "Rapport" means ease, comfort and trust between the interviewer and interviewee. One of the keys to doing this is to find a good setting for the interview.

- ▶ A stress-free environment
- ▶ How to choose the right setting

A STRESS-FREE ENVIRONMENT

Sometimes you are not able to choose the ideal location for an interview. But you can take a moment to look around for the best available option, keeping in mind the following factors:

Try to make the situation as stress-free as possible. A room with comfortable temperature and sufficient light are important. You may also want to provide some water or snacks, and some people may want to be able to smoke. In some cases, the interviewee will be recalling violent or otherwise painful experiences and may become emotional.

Protect privacy. Since it is possible that the interviewee may have chosen not to tell their family, friends or colleagues about the rights abuse, you do not want to put the interviewee in an awkward or compromising position. In a public setting, other people may eavesdrop—neighbors, passersby, volunteers you do not know





well—and this could affect the security of the interviewee, as well as your own security.

Other people present could also interrupt or influence what the victim says. As a rule, there are only two situations where you should allow others to be present during an interview:

- ▶ Individuals who are going to talk about traumatic experiences may prefer to have a close friend or family member close by
- ▶ Children should always have a parent or guardian present during an interview.

In more sensitive cases where there are security concerns, you and the interviewee decide on a cover story that explains your meeting. This could include a language lesson, helping someone to look for a job, or giving someone advice on their medical situation. You may also want to have a friend or colleague stationed outside to warn if there is danger or to observe if you or your interviewee are detained.

The interview should not be too short or too long. This is part of making the interviewee feel comfortable. You should allow her enough time to tell her story, and to give her the attention she deserves. On the other hand, the interview should not drag on for hours. On average, an interview should not last more than one and a half hours without a break. You can always continue the interview later in the day, or the next day, if necessary.

EXERCISE | HOW TO CHOOSE THE RIGHT SETTING

What are advantages and disadvantages of each of these settings for a rights interview?

1. On the street

- | | |
|-----------------------|---|
| Advantages: | Easy to access, easy to end the interview quickly if you get unwanted attention |
| Disadvantages: | Noisy, lots of distractions, no privacy so other people may overhear, not a safe space for interviewee who may become emotional or upset while describing the abuse |





2. In a hotel room

Advantages: Private, quiet

Disadvantages: Might be uncomfortable for female interviewees if they are being interviewed by men; expensive to rent

3. In a restaurant, café, or bar

Advantages: More private than on the street, convenient place to sit for a long period

Disadvantages: Other people may overhear, not a safe space if interviewee becomes emotional or upset

4. In a bathroom

Advantages: _____

Disadvantages: _____

5. In an office

Advantages: _____

Disadvantages: _____

STEP 4: RECORD THE INTERVIEW

In this section you will learn about how to record an interview:

- Prepare your equipment
- Tips for recording the interview
- Do you want a field diary?





PREPARE YOUR EQUIPMENT

In order to get powerful testimony, it is important to note down the exact words that the victim uses to tell her or his story about the abuse. Every single word should be written down accurately; you'll find out when you start to write later just how valuable the quotes of interviewees really are. At the time that you do the research, you don't necessarily know which words will turn out to be the most important ones. Sometimes, weeks or months or even years later, a passing detail will jump out and turn out to be vitally important to your advocacy. So you definitely want to get the original testimony in as much detail as you can.

If you are making a recording, make sure to check the equipment when you are in your office and be sure that it works. Whether you make an audio recording, a video recording, type notes into a computer, or take hand-written notes, we strongly recommend that you have a second, back-up method—another recorder or just a pen and paper. For instance, something could go wrong with an audio recording device—the batteries could fail, there could be too much background noise to hear clearly, or the interviewee could change her mind and decide she doesn't like being recorded. We often take notes even if we're recording also, in case it turns out later that the recording was not audible.

You need to get the victim's permission to record anything. If the interviewee does not agree to be recorded, please don't do it, not even secretly. Remember that the first principle of research is to protect the abuse survivor and respect her rights.

Avoid writing the interviewee's full name in your notes, in case someone else sees them. We recommend using a code to name each interviewee, and keeping a list of codes and real names somewhere separate from your interview notes.

If demographic information is important to your research, remember to mark down gender, age and anything else you need at the beginning.

When you are done, make sure to read through your notes to make sure it is legible and fill in anything you did not have time to write down.

TIPS FOR RECORDING THE INTERVIEW

FOR ALL EQUIPMENT:

- Always check that the equipment works before you leave for the interview.
- Do you have a charger and/or extra batteries?
- Make sure you have sufficient tape or enough space on your disk for the full interview.
- Is there background noise that will make it difficult to hear the interviewee?





- Record a few seconds with the interviewee talking and then play it back to make sure that the audio recording is clear and audible.
- Take a break from time to time to verify that the device is still recording.
- Turn off your cell phone or mute it.
- Bring a notebook and pencils or pens so that you can take notes.
- If a sound drowns out part of a testimony, stop, and start again from the beginning.
- As soon as possible after the interview, review all notes and recordings to make sure they are complete.
- As soon as possible after the interview, write down any impressions you had from the interview, follow-up questions for other interviews that you thought of, or any other thoughts or observations you had about the interview or interviewee that may be of use later.

AUDIO RECORDINGS:

- Watch out for keys in your pocket, cups on the table, anything that could make distracting noises. Notice if you are in an area with loud animals, motorcycles or other traffic around.
- Keep the microphone still. Moving it around will change the volume level.

VIDEO RECORDING:

- Do not record the face of a rights abuse victim. This could place the interviewee at risk of retaliation for having participated in the research.
- Film a few seconds and play it back to check that the interviewee is visible and that the light is good.
- While recording, prop up the camera on something so that it does not move. Very tiny movements appear huge on a video camera, and even when you are standing still, your breathing will make the camera go up and down.
- Bring a clip microphone to get better sound quality.
- If possible, bring a camera tripod.
- If the interviewee said something that you think should be useful in a video clip, you can ask her to re-state the comment more concisely to get a more useable clip.





TAKING PHOTOGRAPHS:

- Do not photograph the face of a rights abuse victim. This could place the interviewee at risk of retaliation for having participated in the research.
- It is invaluable to have photographs to illustrate your report, post online, publish in other materials, or use to create an exhibit about the issue.
- Examples of photographs that do not endanger the identity of the interviewee include: photographs of their hands, backs, feet; photographs of the locations where abuses took place.

TAKING HAND-WRITTEN NOTES:

- Practice writing while maintaining eye contact.
- It is fine to ask the interviewee to pause so you can complete writing something down, but it is obviously better to minimize interruptions while they are talking.
- Keep the notebook on your lap or under a table so that it does not attract attention.
- Make up shorthand or abbreviations in advance that you can use in your notes.
- Review your notes and fill in shorthand notes immediately following the interview, before the next interview begins, to ensure all the data has been recorded.
- It is common for interviewees to continue giving important information after the interview has been formally ended or the audiotape machine turned off. You may want to ask them politely to record this information as well, or else quickly write it down afterwards.

DO YOU WANT A FIELD DIARY?

In addition to interviews, some researchers keep a field diary in which they take notes about other information helps to put findings into a context. Keeping a field diary on top of just writing down the answers can help you trace your thoughts, feelings, or any other personal impressions you have had during the day or throughout an interview. When you look back at it later, it can help you to reflect on an interview and your performance as an interviewer, evaluate your first impressions, or remind you of something you have forgotten.

Here are some questions you may want to answer in your field diary:





- What did I see or hear around the interview setting?
- Were there any interruptions?
- What feelings did I have during the interview?
- How was the interviewee acting?
- Was there anything that surprised me?

If you note down these things, as well as basic information on setting, time of day, and who was with you at the time, it can help you refresh your memory of each interview situation. Apart from anything unusual or surprising, include details that seem obvious at the time, as they may turn out to be important later. It also helps others using the field diary to visualize your experiences.

STEP 5: BUILD RAPPORT

As mentioned above, building rapport is part of making the interviewee feel comfortable enough to tell you the story in her or his own words. Here we discuss:

- The importance of building rapport
- How to build rapport
- How your reactions may affect others
- What if the interviewee lies?

THE IMPORTANCE OF BUILDING RAPPORT

You and the interviewee have different and sometimes different goals. Your goals as the person conducting the interview will include gathering material for your advocacy campaign, maybe even finding a case you can bring before court.

The interviewee, on the other hand, probably has more personal goals. This may include finding other people who care about what happened to them. Sharing





a story of a traumatic experience can be a powerful personal experience, which requires someone to be vulnerable and to trust the listener.

Because it takes time to build rapport with an interviewee, it is a good idea to not just dive into the abuse testimony, but rather to build up to the most sensitive and emotional part of the interview in gradual steps, giving the interviewee a chance to become more comfortable with talking to you.

HOW TO BUILD RAPPORT

Introductory questions. Start the interview with introductory questions that are simple facts, questions you might ask anyone you are getting to know. Good examples of introductory questions are:

“How old are you?”

“What is your educational level?”

“What is your occupation? How long have you had that job? How did you get into doing it?”

“Do you live alone, or with others?”

The interviewee is going to probably going to be talking with you about a painful experience. It is sometimes helpful if you can find something in common—a shared interest or experience to show that you have something to share. Continue the conversation for a minute or two until the interviewee appears to be comfortable and relaxed enough to broach a more sensitive topic.

Body language. Body language is the way you express yourself physically. Do you sit up straight, fidget with your hands, cross your legs? Mirroring the posture and body language of the person you are interviewing is a subconscious way to make them feel understood. You should sit on the same level as the interviewee, not over them. In some situations, it is appropriate to smile or make jokes to make someone feel more comfortable; in other places, it isn't. Be aware of the practices where you are doing your research, and within those constraints, do what feels natural in order to put the other person at his or her ease.

Find things in common. In the informed consent discussion above, Paisan shared that he was living with HIV, something he may have in common with his interviewee. You may not have anything so clear in common with your interviewee, but try to find some common ground. Perhaps it is that you and the interviewee come from the same town, that you are both parents of small children, or that you both like to smoke. Whether it is something major or something simple, finding some common ground can help the interviewee to relax.





HOW YOUR ATTITUDE MAY AFFECT OTHERS

Remain nonjudgmental. In the course of doing rights research, you will probably hear things that are disturbing or even shocking. You have to try not to act shocked or show a strong emotional reaction. In terms of your attitude, you want to be sensitive and caring towards the person telling their story, but at the same time, remain professional. If you feel upset, try to wait and deal with your own emotional needs later; during the interview, you should remain calm, and your focus should remain on the interviewee and on taking good notes.

→ Please see Step 6 for more details on dealing with your own trauma

Both male and female survivors of sexual abuse often blame themselves, and feel shame and embarrassment about what happened to them. If you suspect that your interviewee has survived a sexual assault and is having a hard time talking about it because she is afraid of saying something shameful or shocking, you can say:

“You can say anything you want, because I have met people who have suffered all kinds of abuses and I have heard everything you can imagine. I have known people who have survived molestation, rape, sodomy, and incest, so nothing can shock me.”

It's important here that you name specific sexual acts that people are usually too embarrassed to say out loud. Do not do it in a callous or unfeeling way—the point is not to show off how tough you are. By naming things that people usually feel ashamed to say, you show that you will not pass judgment on the interviewee. This is a way to make it safe for your interviewee to relax and talk about what happened to her, even if she has never spoken about it before to others.

Even if you think the person may have shown poor judgment and made a mistake that resulted in the abuse, never reveal those thoughts, either verbally or in your facial expressions. It is not your job to pass judgment during an interview—it is your job to accurately record the truth in the words and experience of the survivor. You will have time for analysis and verification of these allegations later.

Try not to interrupt. You want the interviewee to do most of the talking. If you interrupt your interviewee too much they may get insecure or forget what they wanted to say. However, if your interviewee gets totally off track and you are not getting any of the information you need, it is okay to interrupt them and ask a more specific follow-up question, such as, “I don't really understand [xxx] yet, can you talk more about that?”

Don't push too hard. Remember that sharing an abuse experience can be very painful for interviewees. It is okay to probe for more information if you need it, but if you see that the interviewee is getting too upset, offer to take a short break to let him or her go to the bathroom, drink some water, or get fresh air. Remember also that in the beginning, you gave your interviewee the choice not



to answer a too uncomfortable question. Respect his right to make that choice. The first principle of rights research is not to harm the abuse survivor.

Don't put your words into their mouths. The goal is to get the testimony in the interviewee's words, not your own. Try to formulate your questions as open questions that cannot be answered with only a "yes" or a "no." Ask questions that are short, and don't provide too many options.

Here are different ways to ask the same question. The interviewee was refused ARV treatment at a hospital.

WRONG: "So the doctor denied you antiretroviral treatment, right?"

This is a leading question—you are telling the person what to say.

RIGHT: "Tell me what happened when you went to the hospital."

This is an open question—the person will have to use her own words to explain what happened.

Try to get the interviewee to walk you through the sequence of events one step at a time. And remember in every step to get who, what, where, when, how and why very clear in your head and in your notes.

If the interviewee skips a crucial fact, you can stop her and ask her to go back and explain in more detail about exactly what happened. If you are unsure you understood, go back and repeat what is in your notes to the interviewee and ask her if you have it correct. Doing this also gives the interviewee a chance to reflect on what happened and perhaps to add some more details.

If you feel that you are at the end of the interview ask:

"Is there anything else?"

WHAT IF THE INTERVIEWEE LIES?

Unfortunately, not everyone in the world is honest. Keep your mind open to the possibility that the interviewee may, for her own reasons, make up the testimony. For example, she may not want to say anything that would make her look bad. Be aware of conflicting details, a sequence of events that does not make sense, or an interviewee who constantly adapts what he says in order to please you.

You can also try to verify what you learn in an interview through talking with others, but **remember to protect the confidentiality of everyone you interview.**



You should never directly attribute what you have heard to any one person.

Instead of saying,

WRONG: “Mei told me that the People’s Hospital never treats people with AIDS.”

You can say,

RIGHT: “I have heard people say that the People’s Hospital never treats people with AIDS—do you know anything about that?”

CASE STUDY | POLICE ABUSE AGAINST SEX WORKERS IN HONG KONG

One of the authors of this manual once conducted a project to document police abuse of sex workers in Hong Kong. During an interview, a sex worker became very emotional and excited as she described a police raid on the brothel, where she was taking a nap. She said, “They woke me up and told me to come to the station, so I pulled on my shirt and pants.” Later she described how she was forced to strip at the station. She said, “The police officer forced me to take off my shirt and they pulled off my skirt.”

So which was it—pants or a skirt?

There were two possibilities here. One is that the sex worker was lying about the incident. The other possibility is that she was suffering from Post-Traumatic Stress Disorder (discussed below), and that she became upset and confused about the details of the event. The researcher didn’t know which it was, so she chose not to challenge the sex worker in the interview or accuse her of lying. Instead, the researcher wrote a question mark in her notes (“pants or skirt?”) and tried to verify some of the details of the raid with other sources.

STEP 6: DEAL WITH POST-TRAUMATIC STRESS DISORDER

Physical abuse leaves scars that are visible, but it also leaves invisible emotional scars that may remain long after the physical scars have healed. The same is true of sexual abuse. Since a rights researcher’s first job is always to protect and uphold the rights of the abuse survivor, it’s important to have a basic understanding of Post-Traumatic Stress Disorder (PTSD).



This section will cover the basics of dealing with PTSD:

- What is Post-Traumatic Stress Disorder?
- Coping with PTSD during the interview
- Finishing the interview
- Secondary traumatization—the risk to you

WHAT IS POST-TRAUMATIC STRESS DISORDER?

Post-Traumatic Stress Disorder is related to the body's natural response to fear. All of us have a “fight-or-flight” reflex that is automatically triggered in our bodies by an immediate threat to our lives. People with PTSD experience this physical reaction even after the immediate threat has passed.

PTSD was first identified by psychologists working with soldiers returning from war zones. Eventually, psychologists realized that many other people are also affected by PTSD, including survivors of sexual abuse, survivors of childhood abuse, and even people who witness traumas, such as witnesses of natural disasters.

The symptoms of PTSD vary, but they can include lack of sleep, nightmares, being emotional often or also a total lack of emotion, and being short-tempered. Many are “hyper-vigilant,” meaning that they are always on the alert for a possible attack. Depression, anxiety, rage, self-blame and thoughts of suicide are other symptoms. Many people who suffer from PTSD turn to drugs or alcohol; some begin to abuse others. It is very common for trauma survivors to minimize their experiences, and to say that what happened to them was not so terrible, but what others have experienced is much worse. Very commonly, people with PTSD are in denial about their emotional condition. Some may experience it for just a few weeks after the trauma, while others may experience it for many years. Some people, especially children, suppress the traumatic memories, and only experience PTSD when the memories resurface, years after the incident.

One facet of PTSD is that people suffering from it often go through long periods where they feel fine, until they encounter a “trigger”—a sound, sight or smell that reminds them of the trauma. When they encounter that trigger, the trauma survivor can experience very intense symptoms. A classic example is the soldier who returns from a war zone and panics whenever he hears an airplane fly overhead, because it reminds him of bombing. For survivors of sexual abuse, a trigger could be something that reminds them of the place where the abuse happened, or physical contact that triggers panic or fear. For many abuse survivors, the anniversary of the date of the abuse is a powerful trigger.

Psychologists who have been through special training can assess a trauma victim





and identify whether or not the person is suffering from PTSD. For the rest of us, it is not possible to tell who has PTSD and who does not. Some interviewees may become very emotional during an interview, while others may “dissociate,” talking about their experience coldly as if it happened to someone else. In both cases, the person may have PTSD and may simply be handling it differently. Since a rights researcher does not necessarily know who does and does not have PTSD, we should try to treat everyone as if they might have PTSD so as to avoid causing any further harm to them.

COPING WITH PTSD DURING THE INTERVIEW

It is possible for PTSD to be treated and even cured over time. Psychologists have successfully used medications for depression, group therapy, and individual therapy sessions to cure PTSD. You can't cure your interviewees of PTSD without a lot more training, but you can do things to prevent their being “re-traumatized,” or getting hurt and traumatized a second time during the interview.

1. ***Give the interviewee control.*** One of the worst things about suffering through a rights abuse is the feeling it gives to survivors that they have no ability to control their basic safety. You can find small ways to give the interviewee power in the interview. Some examples include allowing her to choose a fake name for herself, choose the interview setting, or make any other choice that gives her a feeling of control.
2. ***Your attitude matters.*** Again, your nonjudgmental and supportive behavior is essential to avoid “re-victimizing” an abuse survivor by making him feel that he really was at fault. Take every opportunity available to show empathy and consideration, and to reinforce to him that the blame for the abuse lies with the abuser, not with the victim.
3. ***Talking can heal.*** For the abuse survivor, talking about what happened to her is a very powerful experience. The stigma of abuse forces many people to be silent, and telling her story is a way for the abuse survivor to assert that her experience was real and that it was wrong. It can help her to begin to heal from the abuse experience.
4. ***Talking can hurt.*** At the same time, telling the story is a “trigger,” and it will activate all the traumatic feelings that the victim has lived with since the abuse. Make sure that the environment where she is telling her story is supportive. If possible, prepare some resources for her in advance explaining PTSD. It might also be helpful to set up a support group in your community where people who have suffered the same kind of abuse can talk about and share their experiences as they heal.





5. **The symptoms are normal.** People with PTSD often feel shame about their symptoms, and feel that they should just “get over it and move on.” You can help the person by letting them know that these symptoms are completely normal and are very common.

6. **Do not reinforce the shame.** For sexual abuse survivors in particular, there can be deep feelings of shame about the abuse. Unfortunately, this may be reinforced by friends, family and loved ones around the survivor who are reluctant to talk or listen about the abuse and who find the details upsetting to think about. You can help the survivor by letting her know that you are not shocked by anything she may have to tell you, and that you have “heard it all before.” It may help if you can start off by listing things that you have heard about and are not shocked by: “I’ve heard people talk to me about rape, sodomy, molestation, you name it, I’ve heard it.” The fact that you have named the acts yourself may make the victim feel safer in talking about it, if one of those things has happened to her.

FINISHING UP THE INTERVIEW

With your discussion of informed consent, you created a formal beginning to the interview. How you end the interview is an important part of helping the person with PTSD to transition back to his everyday life.

1. Try to shift the topic from the past (the abuse) towards the future. Ask about the person’s hopes and dreams, or about their children if they have children. For many people, talking about the future gives them hope and a sense of power over their lives.
2. Let the person know that as a result of the interview, it’s possible that some emotions may come up over the next few days. She may have nightmares, feelings of fear, or feelings of shakiness. Let her know that this is normal and that many people experience it. Find out if she has people to talk to who can offer support when those feelings come up. If not, make sure that she or he has your contact information.
3. Make sure that the interviewee has a safe way to get home after the interview. You definitely do not want the person to get on a motorcycle or into a car and drive away, full of rage and fear. Check that the interviewee has someone around to talk to them or take care of them after the interview.

Outside the interview setting, many people who work in the rights field are surrounded by friends and family who are living with PTSD. You can help those people to recover by being available to talk and listen, by taking them out for walks or to places where they can rest, by doing creative things together (cooking, gardening, or other constructive things such as repairing bikes or making crafts).





People coping with trauma often find it helpful to play with pets or to be around small children. Also, be aware of possible triggers in the life of your friend or loved one. Think about doing something positive together when the anniversary of the abuse comes up, and avoid taking him to a movie where there might be a scene that is similar to the abuse your friend survived. With time and emotional support, most people do recover from PTSD.

SECONDARY TRAUMATIZATION—THE RISK TO YOU

While the interviewee may feel better after talking to you about his abuse, you may find, after a few weeks of interviewing abuse survivors, that you feel a great deal worse.

It is very common for rights researcher to also experience PTSD as a result of hearing so many traumatic experiences. You may begin to have strong feelings of being upset, anxious or fearful, or begin to have nightmares, or find yourself unable to sleep at night.

Your feelings are real and they matter. While your focus during the interview must be on the needs and the testimony of the interviewee, when the interview is over, you must find ways to attend to your own emotional needs. Some rights researchers respond to their own PTSD by driving themselves to work very long hours or by drinking too much; but this only delays the symptoms, it does not cure them.

Take breaks from your research project to do something that you enjoy and that makes you feel good, such as walking in the park, having some physical exercise, or having a night off with friends or family. Make sure also that you have regular contact with other rights researchers who know what you are going through, so that you can provide support to one another or just relax together.

When your research is done and you are able to share the voices and the stories of the people you have heard, the emotional hardships you experience as a researcher will eventually make you a more powerful advocate. You will begin to treasure the words of the interviewees, because you now have a personal connection to the individuals who shared them, and you understand the price they paid.

CONCLUSION

Learning to be a good interviewer is a sophisticated skill and it involves some trial and error. All researchers make mistakes along the way, but if you try to be aware of them, think about them yourself and share your experiences with your team, you can become an expert rights researcher.



To review, the key steps in the interview are:

1. Create a list of questions using the six basic questions: who, what, where, when, why and how
2. Evaluate different potential settings for an interview
3. Prepare to record the interview using audio, video, photography, and/or by taking notes
4. Obtain informed consent using the elements of disclosure, voluntariness, comprehension and competence
5. Build rapport with an interviewee by using body language and open-ended questions
6. Work with an interviewee who may suffer from PTSD

In the next chapter, we will discuss how to organize and analyze all the information that you have gathered.



CHAPTER 3

Writing the Report

By the end of the research project, the researcher will have collected many kinds of research material: interview recordings, transcripts, notes, photographs, videos, and field diaries. In the final stage of your project, you need to make sense of what you have gathered, analyze your results, and identify any areas where you need additional information to prove that rights abuses are taking place. A great deal of confusion and wasted time can be avoided at this stage if you have created and used a system to organize your materials.

The five steps in writing the report:

- Organize the information
- Analyze the information
- Conduct follow-up interviews
- Create an outline
- Write and edit the report

STEP 1: ORGANIZE THE INFORMATION

A key part of being a professional rights researcher is using a systematic approach: that is, creating a system of regular actions and steps that you do the same way each time. By being systematic, you are able to obtain powerful testimony, and show that the rights abuse you document is systemic—that it doesn't just affect one or two people, but that it is a widespread problem, a pattern of abuse that can only be addressed by legal or policy changes. In order to do that, though, you will need a system that you use to organize your information as you bring it in. Without a system, you'll never be able to find the data you need to write the report.



This section outlines the following key steps to organizing your information:

- Creating a filing system with case folders
- What goes in the case folder?
- Protecting the security of your information

CREATING A FILING SYSTEM WITH CASE FOLDERS

Set aside a filing cabinet or drawer for the research project, and create a folder for each case. Your case folders could be grouped together by topic (“discrimination by nurses,” “discrimination by doctors,” “discrimination by hospital administrators”). Alternatively, they could be grouped together by locations (“police abuse in Chiang Mai,” “police abuse in Mae Sot,” “police abuse in Bangkok”). Decide what makes the most sense for your project.

Each folder should be labeled with the name or number you use to identify the individual who was interviewed. All materials relating to that individual should go in the same folder. Each transcript, recording, photograph or brochure in that folder should be labeled with the name or number you have used to identify that individual. If you have computer folders on your research project, make sure that the folders on the computer are labeled in exactly the same way as your paper folders.

If you pull anything out of the folder for another purpose, make sure to put it back after you are finished with it. Tell everyone who has access to the folders that they if they remove anything from the folder, they must put it back in the same place.

Important security tip: If you have used pseudonyms or numbers to protect the confidentiality of your interviewees, keep a separate list of these names or numbers on a sheet of paper or a computer file. Keep this list in a different location (or on a different computer) from your case files, in order to make it harder for someone else to break in and identify who you interviewed. If possible, you can encrypt this list for added security.

WHAT GOES IN THE CASE FOLDER?

The case folder should contain everything you collect that relates to that individual case, such as:

- Transcripts
- recording logs
- photographs
- brochures from the individual’s organization, and





- even slips of paper on which you have written notes or questions to yourself.

It should also include a **case cover sheet** with the following information: the code/reference number that you will use to identify the individual, the age and contact information for the individual; contents of the file, which can include notes or transcripts from the interview, photographs documenting injuries or the location of the abuse, and your notes. The cover sheet can also include a few lines describing the person's history, and space where you can write updates about services your organization provided to that person over the years.

Please see the supplement for a cover sheet template (Lesson 4.1: Processing the Information)
→

Transcripts – These are written versions of everything that has been said in an interview. Although it would be ideal to have comprehensive transcripts of all audio and video interviews, it is very time-consuming to transcribe recordings. If you don't have the time or enough volunteers to do a full transcription of each recording, you could create a transcript outline instead.

A transcript outline includes the time on the tape and the corresponding topic (e.g., 0:01—introduction; 3:47—encounter with police; 16:23—the raid on the brothel; and 26:25—beaten by police). This way, when you write the report, you will know how far to fast-forward to reach the section that you need. Then, you can just transcribe certain portions of the tape that you will be using, based on the outline.

Recording logs – If you have taken photographs or made audio or video recordings as part of your research, you should create a log, or a list of all the photographs or recordings. The list should use the same numbering system as your case files, and should include a few words to identify what is on the photograph or recording, as well as the date it was made.

Watch out for photographs – Many small rights groups rely on photographs of violence or abuse in order to shock other people and raise concerns about a specific abuse. But this often has the reverse effect: experts who see the photographs are not so easily shocked, and they may become more skeptical of your objectivity and suspect that you are trying to manipulate them. In this digital age, it is easy for some people to create fake photographs or to alter videos.

We recommend including photographs as back-up documentation in your final report, but only when you have a lot of interviews to corroborate the photographs. In our experience, powerful testimony can have a far greater effect than photographs.





PROTECTING THE SECURITY OF YOUR INFORMATION

Just like you protect the security of your interviewees before and during the interview, you need to protect them afterwards.

Did your interviewees request anonymity? Stick to the fake name or identifying number throughout all your materials and in your final written product.

Find a secure place for your files. It is important that you separate the transcript of an interview from any personal information or hints that could lead to discovering who the person is. The reference list, which links the interviews with the real identities of your interviewees, should be kept in a secure place, like a safe, or encrypted electronically. Make sure only authorized staff has access to the files.

Similarly, make sure you keep the personal contact information of interviewees in a safe place. You will have a list of peoples' real names with their code names somewhere; this list should never be in the same place as the testimonies.

Be cautious of computer and online security. On the Internet, you never know who is watching you. Computer antivirus programs are only effective some of the time, and everyday, hackers are developing new viruses. Is your computer used by several people in the office? Consider setting up different user accounts, so that each person can have their own desktop and files, which are accessible with passwords. If this isn't possible, you can consider keeping all important files on a USB drive or another external hard drive that you can keep with you at all times. Also, consider learning about encryption and using this tool in your communications of highly sensitive information.

If you don't have your own computer, never store your files on public computers. Even if you delete it, it is still in the computer's trash. If you delete it from there, there are still programs to reconstruct deleted files. One way to provide additional protection is to encrypt your information; there are several programs available online for free. Lastly, if you do not know the person sending you an email, do not open any attachments (such as PDF, DOC, or JPG files)!

On your own computer, change passwords periodically—say, every two months. Make them stronger by combining random letters and number rather than using whole words that have significance to you, such as your pet's name or your address. This way, it will be more difficult for other people to guess your password. Never use the same password twice, and never save passwords in your computer or browser.

If you are handling very sensitive information, it may be best to not use a computer. If you write by hand, the files will have no electronic trace. Keep copies of all your files in a separate place. Some rights activists have even buried files underground to protect them from raids.

You should **keep important data as long as possible**, especially if you think that it





will be useful for future use in truth commissions, prosecutions, or for personal histories.

We have outlined one approach to organizing your information. There are other ways to do it that might work better for your organization. Whatever system you use, it's important to keep these things in mind:

- ▶ **Be consistent** – Whatever system you use, use it for all the information you organize, and don't get lazy about it or postpone labeling and filing until later.
- ▶ **Be universal** – Make sure that everyone involved in using the system knows how the system works and strictly follows the same rules to keep information organized.
- ▶ **Be thorough** – Make sure that you are taking steps to protect the security of your interviewees, even if you are not sure you need to do so. It's better to be overly cautious than to have regrets.

STEP 2: ANALYZE THE INFORMATION

This section explains how to analyze the information you gather from your interviews:

- ▶ Take notes on your notes
- ▶ Use visual maps to find patterns and organize issues
- ▶ Corroborate your data

TAKE NOTES ON YOUR NOTES

It sounds silly, but yes, you really do need to take notes on your notes.

Once you have completed your interviews, it's time to analyze your data and figure out what you can prove objectively. Remember, one rights incident is not a systematic pattern of abuse that requires policy change – it's just one unlucky person.

First, spend some time reading carefully through all your interviews, as if you





have never read them before. As you read, write notes on a separate sheet of paper—for instance, listing some of the common issues or problems in several interviews. Make notes of any really remarkable quotes or powerful testimony. You can use a highlighter or a different colored pen to mark these, so that you can find them later.

Next, group testimony according to type of violation. For example, if your report is on hospital discrimination, you can use yellow to highlight quotes from interviews that relate to discrimination by hospitals against pregnant women, and pink for discrimination by hospitals against children. In this way, it's easy to see how much evidence you have of each problem.

Another way to do this is to copy key quotes or specific issues onto index cards, and group them together by topic. When you write a new card, always be sure to also put the interview ID number (or whichever coding system you used) on the card, so that you can find the original interview again later. Some people like to use these cards because they can rearrange information into different groups more easily.

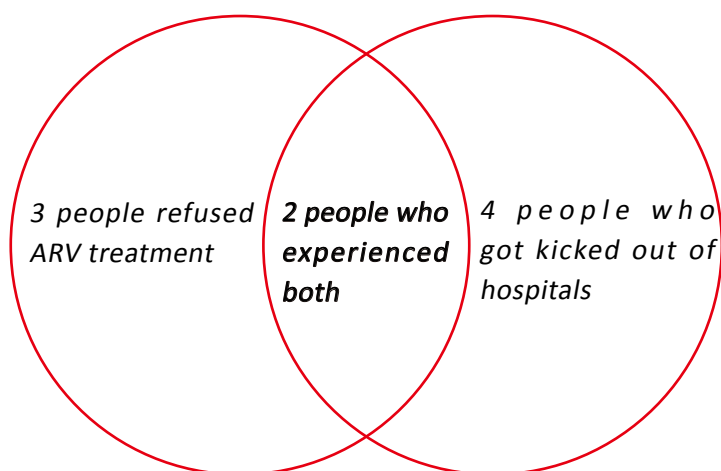
USE VISUAL MAPS

Some people prefer to think about things visually, so they create maps to illustrate problems. Here are a few ways to organize information using different kinds of visual maps: Venn diagrams, mind maps, and matrix scoring charts.

Venn diagrams

A Venn diagram is useful if you have several kinds of information and need to see where they overlap. For instance, on the topic of discrimination against people living with HIV/AIDS in China, we could draw the following Venn diagram to organize interviews with people who experienced being refused ARV treatment, people who were kicked out of hospitals because they were HIV-positive, and people who experienced both kinds of abuse:



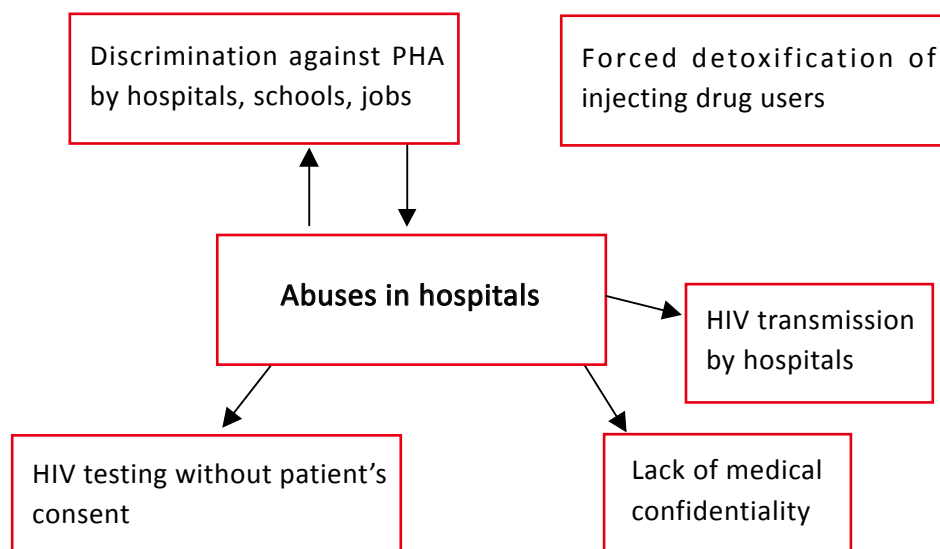


1. Venn diagram

This is a simple version of a Venn diagram, but a Venn diagram can have more circles, and more places where they overlap.

Mind maps

Mind maps are useful if you have a bunch of different kinds of information, and need to see how they relate. To create a mind map, using a large piece of paper, draw circles to represent the different issues, and then connect related issues with arrows. Some larger issues in larger circles can be surrounded by smaller issues in smaller circles. Here is a mind map for a report on HIV/AIDS in China:



2. Mind Map





As you draw the mind map, you may begin to realize that some issues are smaller issues relating to a larger issue, and that other issues are totally unconnected to anything. In that case, you may want to ask yourself: is the unconnected issue really part of this report? Or does it need to be part of a separate report, or a later project that we do just on that issue? In the example above, it seems that some issues are closely related to the hospital setting (such as HIV transmission in hospitals and lack of medical confidentiality), and other big issues are sort of related to hospitals (discrimination by hospitals, schools and employers against people living with HIV/AIDS). But one issue, the forced detoxification of injection drug users, is not really directly related to either discrimination against PHA or to issues in hospitals. It's more or less a separate topic.

In the case of the report on HIV/AIDS in China, the organization debated for a long time about whether or not to include the forced detoxification issue in the report. It seemed like an important issue, but it didn't really fit into the other rights issues in the report. Finally, we included a short section about it, just because we felt at the time that it was an important issue that was being neglected by other organizations. Because we included it, more organizations expressed interest in the topic, and later on, more detailed reports appeared on the issue.

Drawing a mind map is a good team exercise, both for brainstorming or analyzing. You can then use the mind map to draft your outline and report.

Matrix scoring charts

A third tool you may want to use in analyzing your information is a matrix scoring chart. This can be useful if you have a lot of different interviews and you are having a hard time figuring out the advantages and disadvantages of each one. This can be a good way to figure out whether you have enough information to show that a rights problem is widespread and part of a pattern, or whether it's just something that affects a few unlucky people.

Here is an example of a matrix scoring chart on a report on HIV/AIDS in China. The researchers planned that the report would document four rights abuses: discrimination by hospitals, discrimination by employers, violations of medical confidentiality, and testing for HIV without the person's consent. In this chart, we are rating our interviews on a scale of 1 to 5, with 5 being really strong and useful testimony, and 1 being not so useful. A zero means that the person didn't talk about that topic at all. The interviewees are not referred to by their names, but by the city where they live and a number.





Interviewee	Hospital discrimination	Employer discrimination	Lack of confidentiality	Tested without consent
Zhejiang-1	5	2	5	5
Zhejiang-2	0	1	5	5
Zhengzhou-1	0	1	5	4

3. Matrix scoring chart

After filling in this chart, the researchers may realize that they don't have much testimony on the issue of either hospital discrimination or employer discrimination, but they have a lot of good testimony on lack of medical confidentiality and on testing without consent. Right now, they don't really have enough testimony to show that hospital discrimination is widespread and part of a pattern. From the evidence, it appears to have affected only one person.

Once they see this, the researchers have two choices:

- They can do more follow-up interviews and try to get more testimony and corroboration on the issue of discrimination (more on this below).
- Or, they could just write a report on lack of confidentiality and testing without consent, and come back to the issue of discrimination in their next report. Testing and confidentiality are still important issues and a report on these issues can be quite useful. It's better to do a report that covers one issue well than one that covers a lot of issues poorly.

What the researchers have figured out they definitely *cannot* do is to publish a report which makes big claims about discrimination as a widespread problem, when they only have one interviewee who has experienced it. Even if the researchers know in their hearts that discrimination is a widespread problem, right now, they just don't have the evidence to support that claim.





STEP 3: CONDUCT FOLLOW-UP INTERVIEWS

Once you have done the initial analysis of your information, you need to do the hard work of figuring out what claims you can make and getting the last pieces of information to finish the report. This process includes the following steps:

- Show that there is a pattern of abuse
- Interview officials

SHOW THAT THERE IS A PATTERN OF ABUSE

This is the moment when you decide whether or not you have enough evidence to prove that a rights abuse is widespread and is part of a pattern.

How much evidence is enough? There are several different approaches to this question.

For instance, some researchers will only accept that a specific incident took place if there is a minimum of **three eyewitness accounts to one abuse**. For an abuse that takes place in public, such as a public beating or killing, it may be possible to find three witnesses. But with research into problems faced by people with HIV/AIDS, that may be an impossible standard to meet, because there may be no witnesses at all to a case where a person was refused treatment by a hospital due to his HIV status.

If you can't get three eyewitnesses to a specific incident, you could try instead to find a **larger number of similar cases that affect a group of people**. If you can prove that twenty or forty people have all had similar experiences of a particular problem, then this suggests that there is a pattern, and it suggests that the individual cases are probably true.

If you can't get a large number of similar cases, another solution is to **interview experts**: NGO staff who are familiar with a large number of cases, professors who have researched the issue, lawyers who have handled a lot of cases, or others who can verify that the small number of cases you have are representative of many more cases.

In addition to interviews, you can also **use other reports**: news reports, NGO reports, books, and magazine articles that describe similar cases. Adding these reports of similar cases to the testimony you have collected can help to show that the problem you describe is widespread and part of a pattern. When you





use these other reports, though, be sure to state clearly which information you gathered in your interviews, and which information you got from other sources.

In some cases, you may realize that you forgot to ask an important question in an interview. Or, you may have confusing information in your notes and not be sure that you have the correct understanding of what happened. This is also the moment when you should take another look at any case where you suspect that a person you interviewed may have been dishonest. In any of these cases, you may want to schedule a **follow-up interview**—a short interview with someone you have already interviewed once where you just ask a few specific questions.

INTERVIEW OFFICIALS

If you are making claims about a failure of official policy, then it's only fair to give the officials a chance to tell their side of the story.

If you can do so securely, you should **interview the relevant government officials** about the abuses you are uncovering and give them a chance to explain their policies, or to describe what they are planning to do to address the problem. Most important, if you can get a government official to acknowledge that this kind of abuse does happen and that the government knows about it, you will have obtained something very valuable: a government admission.

If you can't find anyone who is willing to be interviewed, you could write a formal letter asking for information on specific questions, saying that you would like to include the government's views in your report, and requesting a reply by a specific date (at least a few weeks ahead, so they have time to reply to your letter). Even if the government never replies, you can include the letter you wrote as an appendix in the report, in order to show that you made a good-faith effort to be fair.

If you meet with the government, though, we do not recommend that you tell them all the details of your report or when the report will be released to the media (if you are planning to publish it). They may take steps to divert media coverage to something favorable to the government.

If your report makes references to international laws and policies, you should also **request interviews with the relevant UN agencies** (UNAIDS, WHO, UNODC, UNFPA, etc). It is their job to clarify international law and to make statements supporting the rights of vulnerable groups.

Finally, if you haven't already, it's a good idea to **interview some experts**, academics, or staff from larger NGOs or international NGOs about the issue you are documenting. Even if these people are not willing to have their names quoted in your report, having a few quotes from "a doctor with 20 years of experience of treating HIV/AIDS," or "a program officer working at an international harm





reduction organization,” can give your report added reliability.

Whether you are interviewing an academic, someone from another NGO, or a government official, remember **that the principles of informed consent still apply**. Anyone you plan to quote in your report must be informed of your project and have the option to not be interviewed if she or he does not wish to be interviewed.

Once you have completed all these interviews, you are ready to sit down and write the report. Before you begin writing, it’s a good idea to create an outline.





STEP 4: CREATE AN OUTLINE

Writing an outline can help you to organize your ideas, create a logical argument, and helps you to figure out the relationships between ideas in your report. The outline is not included in the report -- it guides your writing in the draft stages.

- ▶ Sample outline
- ▶ Elements of a report

SAMPLE OUTLINE

An outline uses numbers for the major topics and letters or small numbers for the smaller topics that will be included in major topics. It is not necessary to write full sentences for each topic—just a few words to help you remember the idea. Here is a sample outline:

Executive Summary

1. Introduction
 - a. Background to the issue
 - b. Methods for this report
2. Official policies and laws on the issue
 - a. International law
 - b. National and local laws
3. First rights abuse
 - a. Background: Explain what happened
 - b. Quote testimonies of victims
 - c. What experts say about the problem
4. Second rights abuse
 - a. Background: Explain what happened
 - b. Quote testimonies of victims
 - c. What experts say about the problem





5. Third rights abuse

- a. Background: Explain what happened
- b. Quote testimonies of victims
- c. What experts say about the problem

6. Conclusion: Summarize all patterns, causes, context for the rights abuse

7. Recommendations: What should be done to put an end to the problem? Who should do it?

ELEMENTS OF A REPORT

This outline includes a few elements that should go in any written report, whether it's 5 pages or 50 pages long:

An executive summary – Unfortunately, people are busy, and few of them will read the whole report. But many people will read your executive summary: a one-page overview of the issues, summarizing what you found in your research.

A methods section – This section explains how the research was done, when it was done, how many people were interviewed, and that the researchers obtained informed consent. This is useful for readers who can judge for themselves whether you were thorough.

Official policies and laws – Every rights report should explain what the policies are on the abuses you are documenting. If you do not know the relevant laws, you should ask a larger NGO or an expert to help you find out what they are. Perhaps there is a legal rights group that can even help you to write this section.

Testimony – We probably don't have to say this again, but we will—the words of your interviewees are the most valuable part of your report. Many people who read it will remember the words the interviewees said, long after they have forgotten the rest of your report. Use the testimony you have gathered to help create a vivid picture of each abuse. In your outline, make a note of which interviews you will use.

Conclusion – This can be the hardest part to write, but it helps the reader to summarize all the key issues in the report.

Recommendations – It's not enough to document the problem: exactly what do you want the government to do about it? Make your recommendations specific and achievable. Just writing, 'The government should protect and uphold the rights of drug users' is too vague.





Acknowledgments – This is a chance to thank all the people who helped you to produce the report, including advisors, donors, volunteers, other NGOs, and the people you interviewed.

CASE STUDY | THAI DRUG USERS REPORT

Here is the outline that TTAG and HRW created for their report, *Deadly Denial*:

1. Executive Summary and Recommendations
 - a. Executive Summary
 - b. Recommendations
 - i. To the government of Thailand
 - ii. To the government of the United States
 - iii. To the United Nations and International Donors to Thailand
2. Methods
3. Background
 - a. Thailand as an HIV/AIDS “Success Story”
 - b. HIV/AIDS and Injection Drug Use in Thailand
 - c. Narcotic Drug Law and Policy in Thailand
 - d. Providing HIV Care and Treatment to People Who Use Drugs:
- General Principles
4. Findings
 - a. Drug Control Policy and Policing Practises Impeding Access to ART
 - i. Police Registration of Drug Users
 - ii. Interference with Harm Reduction Services
 - b. Obstacles to ART in Healthcare Settings
 - i. Denial of Antiretroviral Treatment to Drug Users
 - ii. Problematic Approaches to Methadone Patients
 - iii. Lack of Knowledge on Drug-Drug Interactions
 - iv. Inadequate Voluntary Counseling and Testing Services
 - v. Hepatitis C
 - c. Access to HIV-related Services in Custodial settings
 - i. Access to Antiretroviral Therapy
 - ii. Access to Medication-assisted Treatment for Opioid Dependence
 - iii. Continuity of Care in and between Custodial Settings
 - iv. Compulsory Drug Treatment Centers
5. International Rights Standards
 - a. The Right to Health
 - b. Rights of Detainees to Health Care
6. Conclusion
7. Acknowledgments





STEP 5: WRITE AND EDIT A REPORT

The final stage of the research project is, for many people, the hardest stage: writing and editing the report. This stage always takes longer than everyone thinks it should. Be prepared to write several drafts and edit the final draft several times. To save time, and create a strong report, here are some principles to keep in mind:

- Understand the difference between fact and opinion
- Never plagiarize
- Be careful and fair
- Use footnotes
- Define all the terms you use
- Get input from outside readers

UNDERSTAND THE DIFFERENCE BETWEEN FACT AND OPINION

One of the reasons researchers do research is to gather evidence to support our claims. In writing the report, it is essential to be precise about the facts you have gathered, and not to confuse those facts with opinions—either your opinions, or opinions of the people you interview.

What is a fact? A fact is something that can be tested and proven by any objective or fair person. An opinion is something that someone believes. If you believe that discrimination against people with HIV/AIDS is widespread, that may be a deeply-held belief. It's only a fact if you can use collect actual and clear-cut cases of discrimination to prove that it happens.

If someone you interview believes that they have experienced discrimination, that may or may not be a fact—it depends on the case. It's possible that that person had a misunderstanding, or that the interviewee is so used to being discriminated against all the time that they interpret things as being discrimination when they are not.

So for instance, if someone you interview says, "The doctor looked at me with a cold expression on his face as if he didn't like people who use drugs," that is not necessarily evidence of discrimination by the doctor—it is the interviewee's opinion. Maybe the doctor just doesn't have a good personality, or maybe he had a bad case of indigestion that day, or maybe he had just had a fight with his wife.





You can still include the testimony, saying, “According to interviewee A, ‘The doctor had a cold expression as if he didn’t like people who use drugs,’ or ‘This doctor reportedly had a cold expression.’” But unless you were there and saw the doctor’s face yourself at that specific moment, you cannot say as a fact that the doctor had a cold expression on his face. It’s just the interviewee’s opinion.

To avoid confusing fact and opinion in writing the report, researchers often use distancing phrases such as “according to the interviewee,” or “allegedly,” or “reportedly.” This makes it clear that the researcher knows the difference between fact and opinion.

In general, it’s best to avoid dramatic or emotional terms in your report. Stick to the facts and write in a factual, objective style, as if you were a lawyer writing a statement for the court. If you use ALL CAPITALS, exclamation points, or words like “pathetic,” “horrible,” or “terrible,” you will give the appearance of being emotional and biased. If you have done your research, the facts and testimony should speak for themselves. Adding drama to your report will make it sound less reliable than a straightforward, unemotional description of what happened.

Here are two examples:

This paragraph is a good example of objective and clear writing that is careful about its claims—it says children “may” face harassment, not that all of them do. It refers to an NGO staff person and uses her experience to give an example of discrimination. It also uses an excerpt from a journal, which is a form of first-hand testimony.

RIGHT:

“HIV-positive children may also face harassment or be refused access to school, violating their right to an education and heightening their isolation. A 2008 survey by the United Nations (UN) found that many people in China think that HIV-positive school-aged children should not be allowed attend school. Bao Ling, a Yunnan AIDS worker, described cases of teachers forcing HIV-positive children to sit across the classroom from other students. Xiao Liu, a child living with HIV/AIDS, wrote in a journal entry: ‘I can’t go to school. All the students in the school are afraid of me, and from the beginning they would not play with me. The teacher told me the school doesn’t want me to attend.’”

This paragraph is not as objective. It uses emotional words such as “cruel” and “horrible” and makes general statements without backing them up with evidence. It makes several exaggerated and vague statements, using words such as “everyone” and “always” and “a lot” that cannot be accurate. It also doesn’t include any first-hand accounts, only things that the researchers have heard second-hand.





WRONG:

“HIV-positive children are shunned by society and can’t even go to school. They have horrible health problems, and then don’t have any friends either. Children are very cruel and when they hear that so-and-so has HIV, they won’t play with them anymore. The UN said that everyone in China thinks that children with HIV/AIDS shouldn’t ever be allowed to go to school. Teachers always force HIV-positive children to leave school so that they don’t contaminate any other students. We’ve heard that a lot of children with HIV/AIDS are very unhappy.”

BE CAREFUL AND FAIR

When you write the report, be precise about the number of cases you have gathered to support a specific claim and avoid exaggerating even a little bit. Your precision enables the reader to make his or her own decision about whether or not you have proved that a rights abuse is part of a widespread pattern.

When you allege an abuse, try to be fair in the way you make allegations. It may be true that all the doctors in your town are cruel, heartless, and hate drug users. On the other hand, there may also be some good doctors who are just overworked and poorly trained. The same is true with the police—few police start out being corrupt, and some probably hope to do some good in the world. But if there isn’t enough money for the police department to pay officers a living wage, it may be very hard for even the best police to avoid taking bribes.

Is the issue you are documenting a problem with individuals who are cruel and heartless, or is the problem with a system that has failed to make and enforce good policies, that has failed to hold abusers accountable?

No one likes to be attacked. If you can be fair in your writing style and give credit where it is due, progressive officials and potential allies are more likely to seriously consider your recommendations.

Another question you should think about critically is when the abuse happened (remember: who, what, where, when, how and why? That when is important). If you have thirty cases of discrimination by one hospital, but 15 of those cases happened five years ago, then the hospital can say that this information is out of date and that they have addressed the problem. All your cases need to be recent—ideally, no more than a year old—in order to show that the pattern of abuse still exists.

NEVER PLAGIARIZE

Some people feel it is acceptable to copy something that was published by





someone else. But in fact, this is plagiarism, and it is the same as stealing someone else's intellectual property. Plagiarism can seriously undermine the credibility of your entire report.

If you copy something that was previously published into your report, you must:

- a. Put the section you copied in quotation marks, and
- b. Provide a footnote that gives the author, title, publisher and date of the publication.

USE FOOTNOTES

To publish a rights report that is taken seriously, it's a good idea to include a footnote for each fact. If you are really thorough, that could mean that you have a footnote after every sentence. It's slow and difficult work to write all those footnotes, but it adds tremendously to the reliability and professionalism of your report. Each footnote should include the author or individual who is the source of the information, the name of the article or report, the publisher or organization, and the date. This way, someone reading your report can check to see that you are quoting something accurately. They can also look up the original source in order to get more information.

Here are some examples of footnotes.

Here is an excerpt from a law. In this case, the report quotes the law to show what a government's obligations are. The quotation reads:

The state and the community shall show concern about and help patients with infectious diseases, pathogen carriers and patients suspected of having infectious diseases, and make it possible for them to receive timely medical treatment. No work units or individuals shall discriminate against patients with infectious diseases, pathogen carriers and patients suspected of having infectious diseases.¹

At the bottom of the page, the footnote reads:

1. Law of the People's Republic of China on Prevention and Treatment of Infectious Diseases [hereinafter, Law on Prevention and Treatment of Infectious Diseases], adopted at the 6th Meeting of the Standing Committee of the Seventh National People's Congress on February 21, 1989, revised at the 11th Meeting of the Standing Committee of the Tenth National People's Congress on August 28, 2004 and promulgated by Order No. 17 of the President of the People's Republic of China on August 28, 2004, Article 16.

Here is an example of a quote from an interview Asia Catalyst did with Xiao Fan (not his real name), an NGO staff person living with HIV/AIDS in China's Henan



Province:

ARV drugs are already ineffective, our CD4 counts have plummeted, and many people are already resistant to the first-line drug treatment. Second-line treatment is not free, so for many people the situation is not very optimistic.²

At the bottom of the page, the footnote reads:

2. Xiao Fan, Henan AIDS NGO Worker, Asia Catalyst interview, Beijing, China, August 2008.

The footnote includes the name of the person interviewed (in this case, it's a name he made up), the organization that interviewed him, where, and when.

Here is a footnote on a statement of fact in a report. The researcher didn't include all the testimony, because she didn't have enough space. However, she provided footnotes so that readers understand that the statement is based on her research:

None of the sex workers interviewed for this report had been informed by a doctor that she or he had contracted HIV. Two said they had learned by reading their own medical records.³

The footnote on the bottom of the page reads:

3. Mei Li, sex worker. Asia Catalyst interview, Yunnan Province, 2008; Yulan, sex worker. Asia Catalyst interview, Sichuan Province, 2008.

You can see more footnotes and how they are used in Appendix I.

TERMS

Some terms that you frequently use may not be equally familiar to other people. Write out a term the first time you use it in your text and put the abbreviation in parentheses right behind it. For example, you should first spell out terms such as "men who have sex with men" (MSM) or names such as the "United Nations Development Program" (UNDP). Make an index of any special terms that others may not know.

GET INPUT FROM OUTSIDE READERS

Your first draft will not be perfect. Discuss drafts with colleagues to see if you are all drawing the same conclusions from the material. It may be helpful to consult colleagues who are not working on the project with you, so you can have a fresh perspective. Looking at your analysis from different angles will make it stronger and inclusive of other arguments.





After your organization has agreed on a final draft, ask for input from others. If you have a group of trusted allies or advisors, ask them to review your draft and suggest changes. People who are not as involved in the research as you are will be able to tell you if anything is unclear or too repetitive. People with more experience in writing or the subject matter can help you find weaknesses in your arguments and develop strategies to respond to people that challenge your conclusions.

Give yourself time to review all comments. It could be that you need to do more research on some aspects or gather more supporting information. It's worth it if it makes the final report stronger.

CONCLUSION

In this chapter, you learned the importance of organizing, analyzing, processing, and protecting your data. Although it may seem tedious, all of these steps ensure that your organization produces the best report possible. An objective and accurate report will take you far in your advocacy efforts with experts, UN and government officials, as well as other persons of influence.

To review, you learned to do the following in this chapter:

- Organize your information
- Analyze and draw conclusions from your research
- Conduct follow-up interviews
- Create an outline
- Write a report

You now know all the steps to take in conducting research and writing a finished report. Good luck with your project!





APPENDIX I

Excerpt From a Finished Report

Here is an excerpt from a rights report by Asia Catalyst on barriers children face to accessing ARV treatment in China. The report uses testimony from children, interviews with experts, and reports from the UN and other agencies. The full report, "I Will Fight to My Last Breath: Barriers to AIDS Treatment for Children in China" is available in English and Chinese at www.asiacatalyst.org/news/. This excerpt is from a section on the high cost of ARV treatment.

• • •

Ken Legins from UNICEF reported that even when taking a free HIV test, patients were required to pay for the cotton balls, gloves, needles, and other small costs associated with the procedure.³

The average rural income in China in 2008 was US\$690.⁴ In Yunnan Province, the average rural income the same year was 3,102 RMB (about US\$453).⁵ For these families, a onetime trip to the doctor for an IV costing fifty RMB is a major expense. As Rui Na, the mother of an HIV-positive child, explains,

Some people are utterly unable to bring their children to the hospital [because of the cost]. They try to buy some of the medicines themselves, or do whatever they can on their own, and their children just die.⁶

Thus, some families face difficult choices. One parent said that he had been

3. Ken Legins interview, August 2008.

4. Shirong Chen, "China rural-urban wage gap widens," BBC News, January 16, 2009; <http://news.bbc.co.uk/2/hi/asia-pacific/7833779.stm>, retrieved March 15, 2009.

5. Yunnan average rural income exceeds 3,000 RMB, Xinhua news agency, February 1, 2009; http://www.yn.xinhuanet.com/newscenter/2009-02/01/content_15565752.htm, retrieved March 15, 2009.

6. Rui Na, HIV-positive mother of an untested child, Asia Catalyst interview, Yunnan, July 2008.





forced to discontinue treatment for his HIV-positive child because he could no longer afford the high hospital fees.⁷ Other families reported selling a home, a business, or a car in order to pay for a child's treatment.⁸ One boy wrote about how his older sister had to drop out of a coveted university position so that his parents' savings could be spent on his medical costs.⁹ Xing Lu explains the toll her medical costs have taken on her family,

Before I had this sickness, it wasn't that my family had a lot of money, but we were about middle class. Now we are in debt everywhere . . . [and] it's very bad and shameful to have to borrow money. We don't have anything except for a place to live.¹⁰

Recently, the Chinese government has announced plans to implement sweeping policy reforms that will expand the health insurance program to more Chinese citizens.¹¹ Zhejiang Province has also taken steps to include previously uncovered treatment costs for HIV/AIDS in the provincial health insurance program.¹² But for now, many aid workers and parents of children with HIV feel the frustration expressed by Li Yulan, the HIV-positive mother of an HIV-positive child:

The country says it will care for people living with HIV/AIDS, but talk is only talk. [Programs] exist, such as Four Free, One Care, but . . . the implementation still hasn't come through. It's only words on paper.¹³

7. Liu Fang interview, August 2008.

8. Xing Lu interview, June 2008; Liu Fang interview, August 2008.

9. Xiao Liu journal entry, August 2008.

10. Xing Lu interview, June 2008.

11. "Chinese Pin Hope on New Healthcare Reform Plan," Xinhua News Agency, January 22, 2009, http://news.xinhuanet.com/english/2009-01/22/content_10703561.htm.

12. "HIV Treatment Covered by Social Insurance," China Daily, March 4, 2004.

13. Li Yulan, HIV-positive mother of an HIV-positive child, Asia Catalyst interview, Yunnan, China, July 2008.





APPENDIX II

Know Your Rights

In order to write your report, you should be familiar with the relevant national laws and policies in your country, as well as international rights laws. This brief discussion gives a very general overview to international rights relating to HIV/AIDS. For a more detailed discussion, please see the first book in this series: Know It: The Rights Framework.

HIV/AIDS and Rights Under International Law

Every human being, regardless of gender, skin color, language, ethnicity, nationality, or any other factor, has certain basic rights and freedoms. These basic rights were first written into the Universal Declaration of Human Rights (UDHR) by member states (countries) of the United Nations (UN), after World War II. Since then, they have been contested many times by governments around the world, and continue to be contested even today. With the combined work of rights activists and experts, the UN has since written and passed several international human rights treaties that form the body of international human rights law.¹⁴

International human rights law does not have the same force as the national laws in your country. For the most part, you can't sue someone in your local court because they violate your human rights under international law. Some countries have ratified the rights laws, which means that their governments are obligated to incorporate these laws into national legislation so that they become enforceable. Other countries may not have ratified these laws, but they must still respect them.

While you generally can't sue governments for violating your human rights, you can use these international standards for advocacy. You can refer to these rights

14. Aside from the UDHR, other important rights laws include the International Covenant on Economic, Social and Cultural Rights (ICESCR), the International Covenant on Civil and Political Rights (ICCPR), the Convention on the Elimination of All Forms of Racial Discrimination (CERD), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT), the Convention on the Rights of the Child (CRC), the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (CMW), and the Convention on the Rights of Persons with Disabilities (CRPD).





laws when you write a report or meet a UN or government official, and it can lend your research extra power and authority.

Under certain circumstances, national governments have the right to derogate from these laws—that is, to temporarily suspend them during a major crisis—but otherwise, countries are required to not violate these basic rights.

Here is a short list of some basic human rights that may come up in the course of documenting AIDS-related abuses. Marginalized groups frequently encounter violations of these rights. Brief references are provided from the international bill of rights, which is made up of the UDHR, the ICCPR, and the ICESCR. Please take a moment to read each one and see if you can come up with an example from your community or people you know:

- 1. Right to life** – No one can be deprived of his or her life arbitrarily (ICCPR, Article 6).
- 2. Right to freedom from torture** – No one should be tortured or treated in a cruel, inhuman or degrading manner. Also, no one should be subjected without consent to medical or scientific experimentation (ICCPR, Article 7).
- 3. Right to equality and non-discrimination** – Discrimination means negative differential treatment based on gender, origin, opinion, or health status. All state services should be available to everyone equally (ICCPR, Article 26).
- 4. Right to liberty and security** – No one can be arrested or detained without cause. Detention and arrest must be done according to procedures that are established by law (ICCPR, Article 9).
- 5. Standards for treatment of prisoners** – Individuals who are in detention must be treated with dignity and respect (ICCPR, Article 10). Numerous other international laws detail the standards of detention, including the Standard Minimum Rules for the Treatment of Prisoners.
- 6. Right to work** – Everyone has the right to employment. This includes the right to have opportunities to earn one's living by work that one chooses or accepts (ICESCR, Article 6).
- 7. Right to an adequate standard of living** – Everyone has the right to an adequate standard of living for themselves and their families, including food, housing, clothing, water, and the right to be free from hunger (ICESCR, Article 11).
- 8. Right to health** – All people have the right to the highest attainable standard of physical and mental health. This includes the right to control your own body (sexual and reproductive freedom), and the right to be free from torture or any forced medical experimentation. It also includes the right to the highest attainable standard of health (any facilities or services) available in your country. In practical terms, this means that the state has a right to ensure that everyone in





the country can get access to the best health-related goods and services that are available in that country (ICESCR, Article 12).

9. Right to education – Everyone has the right to an education, and primary education should be required and free to all (ICESCR, Article 13).

10. Freedom of thought – Everyone has the right to freedom of thought, opinion and religion (ICCPR, Article 18).

11. Right to freedom of association and assembly – Everyone has the right to gather peacefully in public, and to form organizations, including trade unions. States (countries) can place restrictions on these rights to preserve public order, but these have to be reasonable restrictions that don't make it impossible to hold a march or organize a group (ICCPR, Article 21-22).

12. Right to marriage – Men and women have the right to marry (ICCPR, Article 23). International law does not state whether they only have the right to marry people of the opposite sex.

13. Right to freedom of expression—Everyone has the right to express an opinion without interference. This includes the right to seek and share information, including public health information. At the same time, everyone should exercise this right with respect for the reputation of others. States can restrict this right for the sake of protecting national security, public order, and public health, so some countries disagree about whether and how they can restrict this right (ICCPR, Article 19).

14. Rights of minorities – Members of ethnic, linguistic or religious minorities have the right to enjoy their own culture, follow their own religion, and use their own language (ICCPR, Article 27).

The Right to Health

Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) guarantees all people the right to the “highest available standard of physical and mental health.” This means that the government should ensure that everyone in their country can access the same high standard of health services, no matter who those people are or how much money they have. At the same time, the people who wrote the ICESCR understood that some countries are more economically developed than others. So, instead of requiring all countries everywhere to offer the same standard of health services immediately, the covenant requires states that ratify the covenant to “progressively realize” that right—or in other words, the country must have a plan to make progress towards offering everyone in the world the same high standard of health services.

The United Nations Committee on Economic, Social and Cultural Rights, which





is the group of people in charge of overseeing implementation of the Covenant, has also published General Comments, which explain in more detail what specific laws mean. General Comment 14 on the right to health requires States not only to provide health care in a timely and appropriate manner, but also to address the underlying factors that help people to stay healthy, such as access to health-related education and information, access to an adequate supply of safe food, nutrition and housing, and healthy environmental conditions.

The Committee has also identified core obligations that each state must uphold immediately. These include:

- ▶ Providing essential drugs identified in the WHO Action Program on Essential Drugs,
- ▶ Adopting a national health strategy and action plan, and
- ▶ Implementing the national health strategy and action plan.

The International Guidelines on HIV/AIDS and Human Rights

The “International Guidelines on HIV/AIDS and Human Rights” is another important document to help UN member states to develop programs and policies that protect and promote human rights in the context of the HIV/AIDS pandemic. They were adopted by the UN in 1996 to help “translate international human rights norms into practical observance in the context of HIV/AIDS,” ultimately to effectively reduce the transmission and impact of HIV/AIDS.¹⁵

These 12 guidelines cover the following areas: the national framework, community partnerships, public health laws, criminal law and correctional systems, anti-discrimination laws, the regulation of goods, services and information, legal support services, women, children and other vulnerable groups, changing discriminatory attitudes, public and private sector standards, state monitoring and enforcement of human rights, and international cooperation.

They provide important guidance, including on the right to health, and go further than the existing covenant articles in recognize that formal standards and laws are not always sufficient, for example, to change negative attitudes and develop a respect for human rights. Their specific recommendations, while not binding, may be useful to refer to when writing a human rights advocacy report.

15. HIV/AIDS and Human Rights International Guidelines, 2nd International Consultation on HIV/AIDS and Human Rights (United Nations, Geneva, 1998), p. 3.





CASE STUDY | THAI DRUG USERS REPORT

In *Deadly Denial*, TTAG/HRW concluded that Thailand's failure to ensure comprehensive HIV/AIDS services to drug users according to international standards violates its obligations to respect and fulfill the right to health.

One aspect of TTAG/HRW's *Deadly Denial* report focused on General Comment 14's requirement of States to guarantee certain core obligations as part of the right to health, in particular ensuring that marginalized groups have non-discriminatory access to health facilities. In Thailand, injecting drug users do not have that right.

In their report, TTAG and HRW reminded the Thai government that, having ratified the ICESCR, they are obliged to "move as expeditiously and effectively as possible towards the full realization of [the right]." The report recommendations included demands for time-bound and specific plans to fight discrimination toward IDU in the health care system.





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